

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh: A Qualitative Report

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# Summary of the report

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh

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This six month profile exercise was conducted with initial funding from Edinburgh Napier University and was a collaboration between NHS Lothian and Edinburgh Napier University, instigated by Patricia McIntosh.

#### BACKGROUND

Childhood immunisation is a complex area in the research literature with a number of contributing influences. Within Edinburgh Community Health Partnership (CHP), recent figures indicated that there was great geographical variety for immunisations and uptake rates. While initial primary immunisations were high, uptake of measles, mumps and rubella (MMR) did not always meet expected targets (e.g. Health Protection Newsletter, April, 2008).

#### AIMS OF EXERCISE

- To review the current literature on childhood immunisations.
- To explore the views and experiences of relevant stakeholders (parents, health staff and key management) for current childhood immunisation services across Edinburgh.
- To identify potential facilitators and barriers towards childhood immunisations that may affect uptake rates.

#### METHODS

The profile exercise was conducted in Edinburgh CHP across different local health partnerships (LHPs). Qualitative methodology was appropriate to address exploratory questions about stakeholder experiences and views with current services. A purposive sample was employed in order to sample a range of experiences. Four parents took part in semi-structured interviews, seven practice nurses took part in focus groups or interviews, seven health visitors and two staff nurses with the health visiting team took part in focus groups and interviews. Five interviews were held with key management staff. Interviews were audio-recorded following informed consent in order to facilitate analysis. Thematic analysis was used to extract the main themes.

#### FINDINGS

Thematic analysis highlighted three key themes in relation to the current immunisation services for both parents and health staff:

#### • Lay Beliefs about Immunisation

This theme related to lay beliefs and knowledge about childhood immunisations which could potentially facilitate or be a barrier towards childhood vaccination. Such beliefs included the importance of vaccination against harmful diseases

(i.e. the 'fear factor'); beliefs about the potential risks of vaccination (e.g. for autism) as well as additional lay beliefs about 'overloading the system' with the 'sheer number of injections'. Lay beliefs often rested on prior health experiences with health services and included aspects such as not experiencing any adverse reactions from the vaccinations, a family history of vaccination, or previous experiences with autism. These lay beliefs were evident amongst parents as well as amongst health staff.

#### Communication

Communication about immunisation related to the rapport and trust relationship between parents and health staff which was seen as beneficial particularly with the health visitor, but not exclusively. Such communication also extended to working relationships amongst health staff which could support immunisation services, as well as administrative support including reminder letters etc. Trust and rapport between parents and health staff were important in immunisation delivery. Previous experience of poor communication with health staff and a resulting lack of trust, in completely separate encounters with health staff, could affect parents' interpretation of the reassurances they were given about the safety of immunisation. Collaborative teamwork amongst different health staff was also clearly important and extended to administrative support which facilitated appointments. Good working relationships were reported amongst health staff but also poor relationships where debates about 'who' should be delivering the immunisation were 'left up in the air' and appeared as a stale mate between different staff members.

#### Organisational issues for Immunisation services

Organisational issues or wider structural and external issues also emerged as a theme amongst health staff. Within this theme, having available resources for delivery of services, such as relevant immunisation information was important. Staff knowledge and confidence for delivering childhood immunisation was also key, as were additional practical issues such as time constraints, staffing and space to carry vaccination. Wider government policy for immunisations and recent vaccine shortages were also relevant here in relation to the issue of increasing numbers of families from overseas with complex vaccination needs.

#### **Overall findings:**

Three key themes were highlighted from the analysis which impacted on current immunisation services. Lay health beliefs amongst parents and staff were significant. Beliefs about the importance of immunisation against diseases as well as previous experiences with vaccination appeared as facilitating influences for immunisation. In contrast, 'alternative' beliefs about the immune system as well as negative prior experiences with autism and vaccination scares appeared as potential barriers for immunisations. Good relationships built on confidence and trust with parents was likely to have a positive effect on parental decisions for immunisation whereas poor relationships did not. Similarly, teamwork and supportive working relationships with other staff for immunisation appeared as barriers. Practical and organisational issues for immunisations were also relevant: the availability of updated information; time, space and staffing issues as well as the impact of government polices and vaccine shortages which had the potential to impact negatively on immunisation service delivery.

#### **KEY MESSAGES AND RECOMMENDATIONS**

Based on these findings the following suggestions are made for current services:

- Lay beliefs about immunisation could be addressed (i.e. beliefs such as 'overloading the system' and the 'sheer number of injections'). Beliefs about autism could also be targeted amongst parents but also amongst health staff in order that professional and confident messages about immunisation are delivered by staff instead of contributing to ambiguity in this complex field.
- Communication and rapport for immunisation is important and was valued by parents. Clearly opportunities for discussion about immunisations with health staff were important for parents as opposed to a 'conveyor belt' experience. In addition, the finding that health staff considered time constraints to be a limitation for delivering services (i.e. 'pushing them out the door') clearly conflicts with the parental value for a quality of care service. This highlights a wider conflict between public health issues versus the financial model in current services (i.e. quantity versus quality of care).
- Increased parental choice about immunisation services delivery emerged as a key area amongst non-immunising parents. Due to the small number of parents included in the analysis, this area requires further study with a greater number of parents.
- For health staff the importance of developing confidence and skills for the delivery of childhood immunisations was highlighted and indicates further issues about staff training and education. This finding was in keeping with the parental value for professionalism. For practice nurses who may be increasingly required to deliver childhood immunisations, this needs further consideration in current services.
- Amongst health staff, **informed consent issues** were important and complex amongst parents with minority languages and adults with literacy difficulties. Staff requested that updated information and a greater variety of minority languages (e.g. Turkish) be available for downloading on the NHS Health Scotland website.
- Health staff considered that **greater public health campaigns** were needed in order to highlight the importance of vaccination against diseases.
- Greater support was requested by health staff for complex schedules for increasing number of families from overseas who had immunisations which were out of synchrony with the British schedule. Staff requested a timely system for support and confirmation about these complex needs.
- Government policies and vaccine shortages were unsatisfactory amongst health staff where the difficulties of physically giving three injections to preschoolers were highlighted. These policies were considered 'short-sighted' because negative experiences of immunisation influenced future decisions. These concerns appeared to be supported by parents and the wider literature which recognises the significance of past health services for future decisions.
- Further study is suggested which examines childhood immunisation experiences for later immunisation decisions (i.e. for Human Papillomavirus or HPV) in order to explore the impact of such early experiences on later decisions.
- From a local Edinburgh context, this work has wider relevance for the national immunisation campaigns.

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# Background to the report

Childhood Immunisation is a complex area in the literature with a range of influences affecting uptake of vaccines. Uptake of childhood immunisation is important to ensure herd immunity from infectious diseases such as measles, mumps or rubella. Since the Wakefield et al (1998) publication which linked the measles, mumps, rubella (MMR) vaccine with an increased risk of autism and bowel disease, public confidence in childhood immunisations was affected and remains a challenging public health issue. Recent figures within Scotland and specifically within Lothian/Edinburgh have indicated that while primary childhood immunisations remain high, that the MMR vaccination has not always reached its 95% target in Edinburgh (see Appendix 1 for the current childhood immunisation schedule). overall Furthermore, significant geographical variation existed within the different areas of Edinburgh (Health Protection Newsletter, April, 2008). This was in contrast to other areas in Edinburgh such as West, East and Mid Lothian. A recent study cited had examined uptake of the second MMR vaccine (i.e. MMR2) across Lothian and highlighted the following patterns (Health Protection Newsletter, 2008):

- A significant geographical variation existed for MMR1 and MMR2 and Edinburgh had the lowest rates
- South Central Edinburgh Local Health Partnership (LHP) was particularly low
- Children from both the most affluent and the most deprived areas in Edinburgh were significantly less likely to receive the MMR1 vaccine; they were also less likely to receive the MMR2 vaccine even once they had received MMR1
- Children from the most deprived areas were more likely to receive their vaccines at a later age
- Children receiving MMR1 late were then also significantly less likely to receive MMR2
- Children from affluent areas in South Central Edinburgh were significantly less likely to receive MMR2 than children from affluent areas elsewhere
- Uptake rates tended to vary by the appointment system that was used with highest uptake rates associated when the actual date and time was mailed out to parents
- Uptake tended to be lowest in smaller practices

While there were great variations indicated within the Edinburgh area for uptake rates, there is clearly a need to explore the reasons for such differences in greater detail. The research area of childhood immunisation and the factors that affect uptake is an area of importance both locally, in Edinburgh, and has national implications. In addition, with decreasing trends towards immunisation rates seen across developed countries where such serious diseases have been virtually eradicated, such work has relevance internationally. Further, in light of the national catch-up campaign for the human papillomavirus (HPV) virus for schoolgirls against cervical cancer, the significance and controversies about immunisations have again been placed in the public domain.

This work was initiated by Patricia McIntosh, Clinical Nurse Manager for Practice Nursing in Primary Care Development in NHS Lothian in order to undertake an initial investigation of user and health staff experiences of current services. Collaboration with Napier University was initiated in order to explore the experiences and views of current immunisation services by both users and health staff in an effort to inform further study and ultimately inform recommendations for immunisations.

#### A Literature review

#### Themes from the literature affecting Childhood Immunisations

A recent systematic review of the qualitative literature (Mills, Jadad, Ross and Wilson, 2005) examined the common barriers for parents for childhood immunisations and highlighted issues including harm, distrust and access issues as central. Common barriers across different studies indicated concerns with the risks involved in vaccines; concerns over causing the child pain; conspiracy beliefs; beliefs that the child should not be vaccinated when s/he had a minor illness; unpleasant staff or poor communication with staff; and being unaware of the vaccination schedule. In the meta-analysis by Roberts, Dixon-Woods, Fitzpatrick, Abrams and Jones (2002) of combined qualitative and quantitative research, two key factors were identified in affecting uptake of immunisation for parents. These included the child's health on the day of the appointment and lay health beliefs, which involved public understandings and beliefs about immunisations and risks. These factors were in keeping with the findings from the systematic review by Mills, Jadad, Ross and Wilson (2005). The literature review by Tickner, Leman and Woodcock (2006) aimed to identify factors associated with suboptimal childhood immunisations and identified

the following aspects from the literature as potential reasons: 'The MMR effect'; novelty; the perceived risks and benefits of combining vaccinations; the need for multiple doses; negative experiences with immunisations (i.e. autism); unintentionally missing vaccination and a dissatisfaction with immunisation services. The authors suggested that reminder and recall systems would improve uptake rates for immunisations, as would attempts to improve public understandings of childhood immunisations. Lastly, a recent systematic review of the factors underlying parental decisions for childhood immunisations by Brown et al (2008) indicated fairly consistent factors in the literature for uptake as related to the perceived vaccine safety, perceived vaccine efficacy and the perceived seriousness of the disease. The authors cited methodological limits with previous studies as limiting generalisability of these findings and that further empirical work is necessary.

Yarwood, Noakes, Kennedy, Campbell and Salisbury (2005) tracked mothers' attitudes from 1991-2001 in England using surveys in order to investigate attitudes towards childhood immunisations. The work highlighted that an awareness of the benefits of vaccination was important but so was sensitivity to the local environment. The risks and the safety of the vaccines were also important. While most parents reported being satisfied with their experiences of health services, there was a proportion who were not. Dissatisfaction with health services was related to a lack of opportunity to ask questions in consultations and the time allocated for discussion about immunisations.

#### Health Staff

In addition to work that has focused on parental attitudes, views and experiences, other research has indicated the key role of the health visitors in the provision and promotion of immunisation, particularly for counselling for this topic (Henderson, Oates, Macdonald and Smith, 2004). In addition, Henderson, Oates, Macdonald and Smith (2004) and Macdonald, Henderson and Oates (2004) indicated that a small but significant number of health professionals (i.e. practice nurses) had their own personal concerns over contraindications for MMR and a lack of confidence in discussing this with parents. Exploratory research by NHS Health Scotland (previously HEBS/Health Education Board 1999; 2001) was conducted in order to inform the developmental strategy for immunisation and similarly echoed these findings. This work appeared just after the MMR controversy. Health visitors expressed ambivalence in qualitative focus groups over their role as health

promoters of the MMR vaccine and advisers of potential adverse reactions. General practitioners tended to express greater confidence in promoting this vaccine. Amongst parents, while immunisation in general was supported, MMR appeared as the area of greatest concern which was not surprising given the timing of the NHS work in the midst of the controversy. In addition, parental perceptions of the seriousness of the disease appeared as a crucial determinant in decisions where measles, mumps and rubella were often not seen as serious diseases. Personal risk to the child was greater than any social duty to vaccinate. Harrington, Woodman and Shannon's (2000) qualitative study in Dublin indicated that the mass immunisation process there and low empathy was not satisfactory for mothers. Mothers preferred their own local general practitioners to carry out the immunisation rather than at the health centre for emotional reasons and empathy.

#### 'The MMR effect'

Clearly, from the above, Tickner, Leman and Woodcock's (2006) notion of the 'MMR effect' is an important area to consider in the literature on childhood immunisations. This vaccine in particular remains the most contentious since the Wakefield et al (1998) report. A number of studies have explored factors associated with this vaccine. For example, from a Scottish perspective, Gellatly, McVittie and Tiliopoulos (2005) used an Edinburgh sample and a mixed-method design to predict the factors influencing parental decisions for MMR. Uptake of the vaccine was predicted by the importance that the parents attached to the elimination of rubella as well as the importance that the parents attached to the value of the health information received. Barriers to uptake, however, were predicted by the risk of adverse reactions and the importance of the current research findings being reflected in health advice. The authors highlighted that further work was necessary to consider parental views over research findings as this factor had not been identified in immunisation research previously. Kaur's current PhD research at Stirling University also examined parental beliefs about risk related to MMR in Dundee and found that immunising parents held more positive views towards immunisation and regarded the risks associated with the vaccine to be minimal. Non-immunising parents, however, held more negative views over the vaccine and tended to regard the risks of the vaccine as being equivalent to the vulnerability for the disease itself. Recently, a mixed-method study by Challenor, Fox and Lido (2008), investigated parental decision making for MMR and highlighted four factors as significant for MMR: having an immunised sibling; a perceived severity of the diseases; experience with autism and a high powerful other health locus of control (i.e. the tendency to regard health as being controllable by powerful others' rather than being under their own control). From the qualitative analysis, a distrust of the government and medical professionals, concern over safety and a belief in the susceptibility of boys to autism were relevant amongst this affluent population. A survey by Lunts and Cowper (2002) in an inner city population indicated the main reasons for non-uptake as due to 'alternative views' on immunisation, fears of autism, fear of acute reactions, difficulties with attending for vaccination and medical reasons. Health visitors and general practitioners were also surveyed about the reasons for non-uptake by parents and health visitors found to have a greater understanding for parental reasons compared with general practitioners. The authors recommended greater communication between parents and health professionals about this issue. Another survey by Flynn and Ogden (2004) examined parental beliefs about MMR and predictors of uptake by age two years. Uptake of MMR was related to previous uptake of vaccination and positive beliefs such as an increased faith in the medical profession and the media, and a lower belief about the harmful effects of vaccination. Most parents considered the severity of the diseases as key and many were ambivalent about trust.

Trust issues were also highlighted in the survey by Casiday, Cresswell, Wilson and Panter-Brick (2006) amongst both immunising and non-immunising parents. An ethnographic study by Poltorak, Leach, Fairhead and Cassell (2005) highlighted that mothers' narratives about MMR occurred within broader contextual discussions about personal histories, birth experiences, previous medical experiences, social interactions with peers, families and friends and medical professionals. The study was significant because it highlighted that decisions about MMR did not occur in a vacuum but were inseparable from the wider contextual interactions with the medical professionals over safety and issues of a lack of informed choice. McMurray et al (2004) used a qualitative approach to investigate parents' accounts of decision making for MMR. The authors highlighted that parental decisions were informed by personal experiences (i.e. either with autism or with measles, mumps and rubella) as opposed to scientific evidence and similarly raised issues around informed consent for parents.

# Summary

Thus, the influences affecting childhood immunisation in the literature indicate a complex interplay of influences including parental views, attitudes and previous experiences, as well as the influence of health professionals, access and delivery of services. Parental personal experiences (i.e. for autism and adverse reactions or for measles, mumps, rubella) and past medical experiences are relevant. Clearly the 'MMR effect' occurs within the broader context of childhood immunisations and implicates issues of trust as well as shapes future interactions for immunisations.

# Aims of the project

The aims of the project were broadly to conduct a profiling exercise of current childhood immunisation services in Edinburgh. Specific aims included:

- A review of the literature examining uptake for childhood immunisation
- A profiling exercise in Edinburgh in order to identify the potential factors that affected immunisation uptake in this area
- An exploration of parents and health professionals views and experiences with current health services for childhood immunisation
- The identification of potential factors that were likely barriers and facilitators for childhood immunisation uptake rates
- To inform further study and ultimately inform recommendations for childhood immunisation service delivery

The following research questions were addressed:

- What does the research literature on childhood immunisation indicate about the influences affecting uptake and about barriers?
- From the literature, what influences are relevant locally in Edinburgh for immunisation uptake?
- What are the facilitators/barriers to childhood immunisation that parents experience?
- Who should deliver immunisations in order for them to be most effective and how/where should they occur?

- How do parents experience the health services in Edinburgh for immunisation?
- What are the views of relevant stakeholders towards the facilitators/barriers towards childhood immunisation?

# Methodology

While disparate figures were indicated across Edinburgh for childhood immunisation rates, as indicated above, the reasons for such disparities are not clear. Qualitative methodology is valuable for addressing exploratory questions about parental and health staff views and for addressing experiences of current health services and is appropriate for a profile exercise which aims to explore current services across Edinburgh by examining the views and experiences of relevant stakeholders including parents, health staff, and management.

## Ethical procedures and access

The study protocol was reviewed by Lothian Research Ethics Board and was deemed to be service evaluation which did not require ethical application. The work was registered with the NHS Research and Development Office in keeping with requirements for work involving NHS staff and an honorary contract was obtained for the research fellow with NHS Lothian in order to carry out the work. A favourable ethical application was obtained from Napier University Ethics Committee. In accordance with this approval, informed consent rested on information sheets about the study and written consent being provided (see Appendices 2, 3, 4, 5 for the information sheets and consent forms). Verbal information about the study was also given. Finally, access to potential NHS staff was facilitated by the primary grant holders in order to advertise the study to practice nurses, health visitors and managers for possible participation in the study.

## Participants and sampling used

Participants were parents, practice nurses, health visitors and staff nurses with the health visiting team, as well as key management staff. Participation was anonymous

and confidential. A description of the participants is provided in the appendix (see Appendix 5). A purposive sample was selected for the data collection in order to reflect a representative sample from the different LHP areas in Edinburgh, as well as from different medical practices in order to encapsulate a range of experiences. This was important in view of the wide variation in practices for childhood immunisations.

#### Data Collection

Data collection consisted of individual face-to-face interviews and focus group interviews, in keeping with a qualitative methodology. The individual interview and focus group is a widely used means of data collection in qualitative research and is appropriate for investigating participants' views and experiences about a topic. Topic guides were developed in order to facilitate discussions in the interviews about experiences for current childhood immunisation services as well as potential facilitators and barriers (see Appendices 6 and 7 for the topic guides). Data collection consisted of four phases which are outlined below:

#### **Parent Interviews**

Individual interviews were held with four parents from two local health partnership areas. Individual face-to-face interviews are appropriate for allowing an in-depth exploration of participants' views and experiences about a particular topic. Interviews were conducted in parent's homes. Two interviews were held with parents who were up-to-date with current immunisations; one interview was held with a parent who had refused all immunisations and one interview was held with a parent who had opted for the single MMR vaccine. One of the parents was Polish and all parents were mothers with one or more preschool children.

#### Focus Groups and Interviews with Practice Nurses

Seven practice nurses took part in two focus groups and two interviews about their experiences of health service delivery and involvement with childhood immunisations. The practice nurses were invited to take part by advertising the study with the local practice nurse team leads, which was facilitated by Patricia McIntosh. Practice nurses came from four different LHP areas and included five different

medical practices. Both affluent and deprived areas were represented by the sample, as well as the inclusion of a range of involvement for immunisation delivery. Such involvement ranged from not being routinely involved in childhood immunisations except for catch-up campaigns, to immunising preschoolers only, to those who were responsible for childhood immunisations as part of their current role.

#### Focus Groups and Interviews with Health Visitors

Seven health visiting staff and two staff nurses associated with the health visiting team took part in two focus groups and two interviews about their experiences with health service delivery for childhood immunisations. The health visiting staff were recruited by advertising the study with local community team leads and was facilitated by Rhona Hogg. Health visitors came from two different LHPs and reflected a range of medical practices with some staff working across multiple practices. Affluent, middle class and deprived areas were represented by the sample. Health visitors had a range of involvement with childhood immunisation ranging from administrative only, to shared immunisations with the practice nurses or general practices.

#### Interviews with Key Management Staff in Immunisation Work

Key management staff for childhood immunisations were identified and invited to take part in the study in order to provide their own views on this topic and to contribute their experiences of current childhood immunisation services. Five individual interviews were held with management which included: the Chief Nurse, the General Manager for Primary Care Contracts, the Public Health Consultant, a Clinical Nurse Manager from one of the LHPs and the Clinical Nurse Manager for Practice Nursing in Primary Care Development.

## Analysis

All interviews were audio-recorded following informed consent procedures to facilitate analysis. Initial interviews were transcribed fully and notes were taken from later interviews. Thematic analysis (e.g. Marks and Yardley, 2004; Boyzatis, 1998) was

used as a means of extracting the main themes relating to the research questions. Thematic analysis is appropriate for considering the key themes in relation to a particular topic under study. The constant comparative method from grounded theory was also useful in the thematic analysis in order to consider the similarities and differences across interviews. Analysis, in keeping with a qualitative methodology, was an iterative process which took place during the literature reviewing, data collection, transcription/playing the audio-recordings and during the process of writing the report. Analysis consisted of listening to the recordings, reading transcripts or notes from the interviews and extracting the main themes relating to potential barriers and facilitators towards childhood immunisation. Once individual interviews were explored in this manner, a process of extraction took place whereby the main themes across interviews were compared in order to reflect higher order themes. These are presented below.

# **Findings**

The findings from the analysis are organised around three central but overlapping themes which occurred across the different stakeholder views' including: the parent interviews and the health staff interviews and focus groups. Views of key managers are presented separately. The three key themes are presented along with extracts from the data to illustrate the themes. Analysis, in keeping with the aims of the study, was concerned primarily with parental and health staff experiences with the current health services and with identifying potential facilitators and barriers towards childhood immunisations. It should be noted that these themes are organised in this manner for analytic clarity but should not be considered mutually exclusive from each other.

# 1. Lay Beliefs about Immunisation

Lay beliefs and knowledge about childhood immunisations was a key theme which appeared to have an influence on immunisations. Such beliefs included the importance of the vaccinations in the face of very harmful diseases (i.e. 'the fear factor'). On the other hand, beliefs about the potential risks of the actual vaccinations (e.g. for autism) was also significant. There were a number of other commonly held 'lay' beliefs which appeared to contradict health advice such as 'overloading the system' and the 'sheer number of injections'. Lay beliefs amongst parents tended to rest from prior health experiences with the health services and included such aspects as not experiencing any adverse reactions with vaccinations; prior family history and past experiences of vaccinations or conversely, immediate knowledge and experience about autism as associated with immunisations. Such lay beliefs were not exclusive to parents but were found across parental views and health staff views.

## The Importance of the Vaccinations

## The 'fear factor'

Protecting the child from potential harmful diseases was discussed by parents as a reason to have the child immunised. For example:

P:...I think it's just the fear factor that makes you have the injections
I: the fear factor?
P: yeah you wouldn't want your child to have any of these problems and I think that's more or less why my children get them (laughs)
I: is that fear of the diseases?
P: exactly, even though you know in this day and age, well you, hopefully, that they won't get them but you never know – I think I don't know what the percentages are actually of people actually getting these problems anymore – but obviously it must be quite high if the injections are still there...so that's why I got it I felt like I just went with the flow to be honest with you but that's it – fear factor I think (I: is the main thing?) exactly, and of course you would feel guilty if something did happen and you didn't have the child immunised...(Parent, Interview 3).

Amongst health staff, disease outbreaks were seen as paradoxically reinforcing the need for immunisation and meant that the importance of vaccination remained in the public eye. Particular diseases such as meningitis, for example, were seen as a scary disease which put the 'fear of death' into parents (Health Visitor/Team Lead Interview 2).

#### Lack of Public Awareness about Diseases

Conversely, amongst some health staff, there was a general perception that the public and present parental generation were not aware of the severity of these

diseases due to the success of immunisations programmes, as seen from this comment:

*PN: ...people do not see disease anymore...they don't see measles, mumps, you hardly see these things because they've been virtually eradicated by immunisation programmes so you don't see – you don't see the after effects of these diseases you know you don't see the children that've got horrendous encephalitis following measles and are now sort of you know permanently brain damaged so people – the general public and that don't realise the severity of these illnesses...(Practice Nurse, Interview 2)* 

# Risks and other 'lay' beliefs about Vaccinations

## The MMR Controversy

Perhaps unsurprisingly, the MMR controversy emerged from all parental interviews in discussion about the risks associated with childhood vaccinations. The following examples are highlighted:

*P: ...but after I had my son and then it did -all the negative things came out and I did kind of have second thoughts about it all...(Parent, Interview 1)* 

*P*: ...it was also a case of would we feel worse if they got the illness and were very ill with it or if we had actually knowingly given them something that then made them ill um and personally I think it would felt worse that way round... (Parent, Interview 2)

*P:* I think just because of the MMR was so cos obviously it's the one injection you're getting everything at once so because of that there's a slight chance that it could develop into a – my son could develop autism that's really why we got them done singularly and took the single vaccine...(Parent, Interview 3)

*P: ...I* can tell about my husband who read smart papers somewhere and he said some immunisation er are not as safe as good as they should be...it was a time in – I think UK- where they were giving one immunisation and they – I can't remember exactly what it was exactly but there was a problem with some immunisation... (Parent, Interview 4)

Clearly the risks associated with the MMR were articulated by all parents. (This was alluded to in interview 4). However, there were also differences amongst parents associated with these risks. For example consider the extended extract from the above:

*P: ...but after I had my son and then it did -all the negative things came out and I did kind of have second thoughts about it all () but then I thought well* 

[son]'s fine so I thought I know they're different people but luckily they have all been fine...(Parent, Interview 1)

This can be contrasted with the following where personal risk to the child was considered to be the most important aspect for the MMR vaccine and where even the slightest risk was a risk too great to take:

*P: ...they're now saying there's no side-effects – that the MMR doesn't have any bearing on the autism but there's still that risk factor if you couldn't say for 100% sure that it didn't cause autism so but it was just mainly that little bit of doubt...(Parent, Interview 3)* 

Practice nurse staff also discussed how vaccination scares impacted on parental decisions for immunisations and appreciated that 'it's very hard for them [parents] because there's always been controversy about vaccination' (Practice Nurse, Interview 2). Also, MMR was generally the still the most problematic vaccine: 'MMR is still the one that people want to stop' (Practice Nurse, Interview 1). Such ideas about MMR were seen as difficult to challenge, for example:

*PN1: ...and there's one parent recently that would not under any circumstances get it done [MMR] – very fixed views and you have to wonder what's the point really...(Practice Nurse, Focus Group 2)* 

Vaccine scares such as MMR were considered by some staff as being less of an issue today than previously with less parents turning to the single MMR vaccine option (Health Visitor/Team Manager, Interview 2); however, anxieties about vaccinations were still present.

Lay health beliefs about MMR were not solely present amongst parents, however. Health staff ambiguity over MMR was also expressed in two of the health staff interviews which related to the tendency to advise parents to delay giving the immunisations for MMR in order to wait for development for autism or for the child to develop in size. This was an issue which did emerge from previous literature in immunisations relating to health staff beliefs and concerns over adverse reactions, particularly for MMR. An example is given below:

PN:..I'm not saying I'll put it off [MMR] but I mean I have said to a mother in the past when the child was quite small just to wait maybe another month or so – not put it off drastically – just give it another month and I don't have any scientific basis for that apart from talking to another medical person who's child had autism um after the MMR and again she doesn't necessarily believe that but she did say you know the child was much smaller and was small for weight and things again it's not a scientific thing if a child was very very small I would just want to know that they were developing properly – because it's a live vaccine doing damage but you know...(Practice Nurse Interview 1)

## 'Lots of needles' and other lay beliefs

Parents discussed the numbers of injections that the child was expected to receive in negative terms. This was expressed as follows:

*P*:...the sheer number of things that they're given at one time you know they get...they get at two months old they get the diphtheria, polio and tetanus one um they also get – oh I can't remember what else they get at the same time - I think these days they also get meningitis as well um there are just about 5 or 6 that should be given all at one time when she was so tiny and we just felt we wanted to give firstly her immune system a chance to mature before we bombard it like that um an also she was completely breast fed and I continued feeding her for 12, 13 months um so I knew she was getting some protection that way and really I would have preferred it had there been anyone around that she would have got some of these illnesses when she was little because I did therefore I have lifelong immunity to most of them... (Parent, Interview 2).

*I: ...so do you think something like the number of injections would influence you?* 

*P*: er it possibly might – I mean if they didn't do – I'm not too keen on getting them () I tend to get nervous when they get the injections but as I say I think they should get them but I think if they bring out lots of needles like say 3 or 4 needles I'd be a bit 'ah she's not getting all a' them today' but it's all combined in the one injection now I think that the tetanus and the polio and rubella is all one injection now (whereas) I think it was tetanus, rubella was in one injection and the polio was drops in the mouth () but she got all that at four months and she got her meningitis as well so that was two but that's the most she's had but aye if there was lots of needles I think I would have – I don't think I'd be too keen...cos it's traumatic for them as well so you kind of tend to put them through as less as possible...(Parent, Interview 1).

Along with the above discussions about the negative aspects of having so many injections at once, there were also a number of lay beliefs discussed as important in immunisation decisions. As seen from the above these included: not bombarding the immune system with immunisations while the child was small, the protection from breast feeding against diseases, catching the diseases while young in order to have lifelong immunity (i.e. for mumps). In addition, the emotional aspects with immunisation was discussed and the belief that fewer injections were better in terms of inflicting trauma on the child and parents. This was reinforced by health staff, for example:

*PN: ...there's this kind of notion that if you give three injections if you give you know a combined immunisation that it's bombarding a very young child's immune system and it can't cope and all this sort of thing (I: oh yes) well of course the minute you're born your immune system is bombarded with hundreds of different things...(Practice Nurse, Interview 2)* 

#### 'Compliant Parents' versus 'Alternative' and 'Chaotic' Parents

There was a clear indication that staff viewed parents that did not question vaccination as being more compliant and so easier to vaccinate. This was in comparison to 'difficult' parents who were more informed, well-read and questioned the vaccine with staff. Such parents were seen as more educated or 'intelligent' and coming from more affluent areas whereas 'compliant' parents tended to be seen as 'working-class' or from deprived areas. Other compliant parents were parents coming from outside Britain and included increasing numbers of Eastern Europeans, Africans or Asians, for example. These parents were viewed as 'taking anything for free' more 'matter or fact' or 'appreciate what they're getting' for immunisations compared with parents from the UK who tended to be more critical and so less content to receive the vaccinations. This is illustrated below:

I: and how are the parents?

PN3: the parents are fine yeah they don't ask too many questions to be honest (which I don't know about other practices) PN1: you see it's easy for us in a practice like this-PN3: cos we don't get much objection to MMR or anything like that PN (no) PN3: very very rarely

PN1: they don't come because they're fazed about about coming, they don't come because they forget to come, very few refuse MMR I: right

PN1: whereas perhaps in another area they're () where the parents are a bit more informed or a bit more into pre-reading more, take more interest then they probably have more questions but ours tend to be quite take what you get

(Practice Nurses, Focus group 1)

PN2: I had a chat with [Health visitor] on Wednesday (we had a lot of) and from what I can gather is that we really don't have any issues to do with uptake of vaccines

*I: in your practice?* 

*PN2:* no I think notoriously just our parents are compliant – and that's not to do with childhood immunisations that's to do with the whole lot they seem to be quite happy to just – they don't have any issues – health visitor's got one family in the whole x amount that don't take up. So I think that's predominantly the area...

*I:* so what do you think it is about this population that makes them more compliant?

PN2: well working class probably and they don't have any issues over the bigger picture and I'm sure the whole MMR scandal probably went over their head from an intellectual point of view- which is a terrible thing to say but that's the way it works...

(Practice Nurses, Focus Group 2)

I: and just coming back to this practice, how is uptake here?

PN: it's pretty good I mean I couldn't tell you exactly what it was I: no I'm not looking for figures PN: but it's pretty good because of where the practice is [central] and there's a lot of sort of [affluent] people in the practice and we do have a pretty good uptake of immunisation (Practice Nurse, Interview 2)

In contrast, two types of families were singled out by the health visitors as being harder to engage in vaccination programmes, which supports the above practice nurse data. The one type of family was called an 'alternative family' and tended to be more affluent, educated parents who were more likely to choose 'organic foods' and more likely to be concerned about 'chemicals' in the body. They were more likely to ask detailed questions from health staff which was challenging at times as 'sometimes we don't have that information to give' (Staff Nurse, Focus Group 2). In addition, the 'chaotic' family was also difficult to engage and this was a family from more deprived circumstances who tended to be 'forgetful' about appointments, and often needed several reminders in order to attend for immunisation. This type of family often came out of schedule but were seen as a family that was not likely to hold reservations about immunisation per se, but as a family that were too busy and concerned with other issues.

#### The Internet: A 'thorn in our side'

Tied to the above parental group called 'alternative' by health staff, were parents that were educated, middle class or from affluent areas, who were well-read and informed about debates in immunisations. Such parents were likely to be influenced by arguments over the risks associated with vaccines and made greater use of the internet in order to do so. This was seen by health staff as an 'information overload' whereby parents appeared unable to 'sift the good from the bad' in order to make an informed choice over immunisation. The internet in particular was therefore seen as a 'thorn in our side' (Health Visitor, Focus Group 1) for delivery of services.

#### **Previous Parental Health Experiences**

'No Problems'

Having previously not experienced any adverse reactions from particular vaccinations appeared to mean that parents were more willing to proceed with further vaccinations for their child and for additional children, as seen below:

*P:* they've actually been quite good here cos we've recently just moved here X years ago so they've really only dealt with my youngest and the second one but aye the health visitors have been great and the doctors have been great as well so I've not really had any problems to be quite honest... (Parent, Interview 1)

*P: ...but luckily we've not had any bad reactions to any of the injections at this point...(Parent, Interview 3)* 

*P:* to be honest so far I'm quite happy with the all the health services especially for immunisations because I've never had bad experience – any problem – with my child so probably that's why... (Parent, Interview 4)

#### Just 'something natural to me'

The way in which immunisation was discussed by some parents (immunising parents particularly) meant that a belief that the vaccination was important, necessary and was considered as something that was not questioned. This often came from a personal family history of such immunisation (i.e. where the parent themselves had also been immunised as a child). Such personal family history of immunisation was also associated with the above about not experiencing any adverse reactions from vaccinations. This is illustrated by the following:

*P*: ...I never really thought about not getting them done to be quite honest er I've always had the attitude that I would get them done and my three have been great at getting it done so I think if the first een kind a had a reaction to it but he was fine so I think I just carried on and they've all been great...my mum's said we've all been done as well so we were all fine as well so I think that was all part of the reason as well we decided to get them done as well... (Parent, Interview 1)

*P: ..in my country, as you know I'm from Poland, I was immunisation – I was immunised and all my family was immunised so that was something natural to me, that wasn't something new that I would think 'oh what's that why are they doing what are they trying to, you know, do' so something natural – I never thought about it as something strange or something – just natural I think so every child should get it... (Parent, Interview 4)* 

While a personal family history of immunisation and a belief in its importance appeared to influence decisions about immunisation, this was not necessarily always the case. For example in explaining a decision about opting for the single MMR a parent responded that: '...we've got a big family and they've all had the single – sorry

the MMR – luckily nothing's happened but we didn't want to take the chance' (Parent, Interview 3). [This theme is discussed more fully below].

#### **Issues of Trust and Previous Health Experiences**

*P*:...and that [previous health experiences with health service during pregnancy] just left me thinking well maybe they're not always that truthful, maybe they just tell you what they think you need to hear... I think if the information that we got from that information leaflet [NHS Information sheet] had felt more honest, it - the leaflet- didn't feel honest which was as I say a big part of the problem, when you really look at it the lack of any real safety test available other than by the people who sell the vaccine um you know they're doing it- they're purely in it for the money so why would you put your children's health in their hands really...(Parent, Interview 2)

The above illustration highlights that immunisation decisions do not occur in a vacuum but within the context of everyday encounters with health services. Negative experiences therefore impacted on parental decisions for immunisation where a lack of trust with health messages became an important consideration in the decision against childhood immunisations.

In addition, when describing the decision for opting for the single MMR over the combined MMR, having personal experience or acquaintances with autism were cited as the main reason for the decisions, for example:

*P:...but my husband – he knows a couple of children () friends of his and they have two little boys and they actually developed autism () and one of the mums actually – she's a nurse and she feels that it has happened after the MMR injection...(Parent, Interview 3)* 

## 'Chinese whispers'

The notion of 'Chinese whispers' was discussed by one health visitor to refer to a parent's indirect experience of someone that had experienced an adverse reaction to the vaccine or who had developed autism following MMR. These may have been only through very indirect or distant links but were seen by staff as affecting an undue influence on parents.

# 2. Communication issues for Immunisation

Communication about immunisations was an important influence on such decisions. The rapport and trust relationship, particularly with the health visitor, was commonly cited as beneficial for immunisation behaviour. Such rapport, however, was not exclusive to the health visitor, but was also relevant to other health staff such as practice nurses. Communication across health staff was also relevant whereby health staff could promote and support immunisation. This also included administrative and systems support such as reminder letters and recall etc. Trust was an important issue between parents and health staff. Previous experiences of poor communication with health staff and a lack of trust, in separate encounters with health staff could affect parents' interpretations of the reassurances they were given about the safety of immunisations. Collaborative teamwork amongst different health staff was important and extended to administrative support to facilitate appointments. There were examples of good working relationships but also poor relationships where debates about 'who' should be delivering the immunisations appeared as a stalemate situation which could negatively impact services.

## Parent-Health Staff Rapport

#### 'The health visitor was very good'

Interactions with health staff were discussed in relation to the process of childhood immunisation. The health visitor was often cited as key in terms of the way in which the immunisation occurred within a wider context of the relationship of rapport and which influenced the quality of the experience. Here the skills of the health visitor for immunisation were discussed in terms of interactions with the child to distract them with toys and the rapport with the parent. The following examples are relevant:

*I: ...and was there anything that you found particularly helpful about the services that you received?...* 

*P*: aye wie my middle child when she was four she got a preschool booster and they really relaxed her and spoke to her and whereas with my son they didn't really do that...

I: ...oh I see so the way they dealt with her before?

*P*: aye and afterwards like after they done the injection they gave her like a toothbrush and a book or something so she was fine she had no bother at all... (Parent, Interview 1)

*P*:...and maybe things to distract them  $\cos I$  thought that was very good the health visitor was very good at that actually distracting them and then giving them something noisy to play with ...once they'd had the injection it just takes their mind off it – I know they're only little and sometimes that's what doctors forget they just get on with their jobs and they've very busy, they all are

actually, but I think the health visitors just have that little care... (Parent, Interview 3)

While the relationship with the health visitor was often singled out in particular, it was not the only interaction discussed for immunisation with interactions with the practice nurse and the general practitioner also discussed in favourable terms: 'I think the nurse actually had toys as well' and '...the practice nurse who is very nice and the doctor is very nice...' (Parent, Interview 3). The influence of the health visitor was also singled out by practice nursing staff as providing information about the importance of attending immunisations due to their contact with families and for prompting non-attenders, as well as support for new arrivals.

PN2: I think the health visitors do prompt the ones that they know are a bit more chaotic and not very good attenders in making sure that their children are immunised but I think it's a bit of a battle with some that don't actually realise that it's important that they come... (Practice Nurse, Focus Group 1)

*I:* what kinds of things encourage parents to ... PN: well I think the fact that they come – the health visitors do explain to them when they take over the care of the baby about immunisations so I think that helps...(Practice Nurse, Interview 2)

I: what do you think works well or anything needing improvement [in your interactions with other health staff for childhood immunisations]? PN: em certainly there were two health visitors here and one of them I worked with more closely and she was very good when we got new families in she would get a copy of the imms record for me that was a big help because the health visitors are the first point of call and before they would have done it themselves but now because they're not involved in immunisations they don't necessarily so that to me was a big help em especially foreign families getting a copy ...(Practice Nurse, Interview 1)

The influence of the general practitioner was also discussed in one focus group for promoting vaccine attendance with families, as seen by the following:

*I:* what do you think works well in your practice at the moment for promotion uptake? PN1: I think probably the GPs are quite good at going through with the parents a bit clearer and making it more – I don't know – I think they listen to their GP a bit more and the GPs here are quite convincing at telling people that they should attend for vaccines and that's worked I think (Practice Nurse, Focus Group 2)

Health visiting staff discussed the significance of knowing the families in order to tailor a particular approach for immunisation. Knowledge of particular families meant that staff could determine the reason for non-attendance and tailor their response accordingly. Such practices included, for example, discovering that Tuesday morning

appointments were not suitable for the family and so arranging a different time for the appointment or a change of address whereby the parents had not received letters to attend for immunisation. In addition, immunisation was seen as taking place within the wider context of the relationship whereby parents responded to staff prompts to attend for immunisation because of the more general trust in the health visitor or medical profession in general. While MMR controversies had 'put a dent' in the trust, it was still seen as largely present in the population.

## Professionalism

While the above themes indicated positive interactions with health staff and additional themes as being conducive to a quality care experience, there was also an indication that professionalism was singled out as the most important aspect for immunisation by this Polish parent where, a preference for the doctor was expressed and for professionalism:

*P: …Probably doctor's knowledge is better than a nurse knowledge and if the doctor would have better experience than nurse in giving immunisation I would prefer doctor to give it to [my] child … so probably doctor would be best person but I didn't mind really…I know it's something my child needs as long as it was done professional I was happy with it… (Parent, Interview 4)* 

## 'White coat syndrome'

Against the above, in two different interviews, a concern was expressed by staff over being 'blasé' towards those families that did not question vaccination and that did not appear to be concerned or require further discussion about immunisations. Families from abroad, particularly Eastern European families were considered to have a 'white coat syndrome' where they did not tend to question the authority of the staff member in delivering immunisations. While this tendency promoted uptake of the vaccine, it was discussed by the staff as a concern which professionals needed to strive towards in order that they made sure of informed consent with such populations and did not assume compliance. As well as parents from abroad, this also extended to parents from deprived areas who tended to question less, and other vulnerable populations such as parents with literacy issues.

#### Being on a 'conveyor belt'

The process of the immunisations were also discussed with one parent contrasting her positive interactions with the health visitor with the negative aspects of feeling as though it was a 'conveyor belt' experience with a lack of personal contact:

P:...-before you feel - with my previous health visitors we've had to, before you were in the door and you had to be out kind of thing - you felt that you were on a conveyor belt sometimes they didnae take the time to really know your children whereas here they do...(Parent, Interview 1)

#### Lack of Communication about Immunisation Practices

P: [explaining experiences with immunisations services for different children]...and it was all the health visitors that actually done all the injections the immunisations then but when - since I've had my second child it's now - the actual doctor did the first one – which I didn't realise I thought the doctor would then do all the injections but it's not it then goes to the practice nurse which I find very strange because obviously the child builds up confidence with the health visitor so I don't understand- I don't know why it's been taken away from the health visitor so I think that was slightly different. And also we decided to get the single vaccine for MMR and the first time round – cos obviously my daughter's not at the age to get that yet () but we didn't get much support from our doctors... I would have thought they would have been a bit more supportive... I would have preferred to have been able to talk to my doctor to find out why they are so against it and why they weren't – they didn't take on my point of view I don't think...cos I did feel a bit guilty about that getting them single vaccinated I felt that it made me doubt why they weren't being supportive and um we never got any feedback why they weren't being supportive so I think that was the only thing I had a problem with my own GPs... (Parent, Interview 3)

From the above extract it is clear that there was a lack of communication about immunisation services as experienced by the above parent. Firstly, in relation to the perceived different practices for immunisation from one child to another whereby the health visitor had administered all the immunisations to the general practitioner doing the first immunisation and then the practice nurse doing subsequent immunisations. The lack of communication about this process was reacted to negatively here with: 'it would have been great if during the transition from the health visitors doing it to the doctors to the practice nurses, it would have been nice to have advised parents...'. In addition, the parental decision for the single MMR vaccine was also experienced in negative terms such as: 'they didn't take on my point of view', feeling 'guilty' about the decision for the single MMR was considered to be the only blemish in the parental relationship with their local surgery where 'apart from that they've been

absolutely fantastic'. However, clearly there was a lack of communication for immunisation practices here.

# Health Staff Communication and Practices

## Good Relationships with other Health Staff

Establishing good working relationships with other health staff for immunisations was discussed as important as seen below:

*HV: ...I* do immunisation clinics once a week and have a good working relationship with our practice nurse colleague so if I'm on holiday or as I mentioned some of my management responsibilities, so if I'm not available em on the afternoon, they're very good at filling in so we do it between us but I would probably say I do 80% of them and they do the rest...they will also accommodate parents who can't come on a Thursday afternoon...the practice nurses will see [working parents] at other times and we have a very good relationship with the that but that's just been developed over time, good luck, good will of the personalities...(Health Visitor/Team Manager, Interview 2)

## Immunisations left 'up in the air'

This picture of good team working was contrasted by the following which illustrates the current dilemmas about childhood immunisations and over which professional should be administering the immunisations:

I: what about your own interactions with other health staff for this issue...? PN: well it's a bit of a contentious issue because the health visitor's line manager had wanted the practice to start doing immunisations because of course the practices get paid for the immunisations and the health visitors they don't so to speak cos the GPs obviously get the money for it so they felt it was our responsibility to do it and the GPs argued that it was the health visitors area of expertise and they should be doing it and we came to a bit of stance where we said no we won't be doing it we just will not be doing anymore until this is sorted out and so the health visitors are doing it and then they wanted me to help with the preschool vaccinations and I said no I didn't want to and so it's just been kind of left up in the air in the minute.. (Practice Nurse, Interview 2)

# Practice Issues: opportunistic vaccinations, reminders and administration

Practice nurse staff involved in delivering immunisations discussed the value of doing opportunistic vaccinations, particularly in relation to families from deprived areas where attendance was inconsistent. This is illustrated below:

PN3: ...we like to get as many jags into the kids when they come as we can because there's no guarantee that they'll come back or to complete PN2: particularly when we do have so many non-attenders that maybe come months and months after they should have been (Practice Nurses, Focus Group 1)

*P:I think the system they're doing [for preschoolers] at the minute is perfect – I think you should combine them – two in one day – I think that's perfect, there's no need for them to come back and that's another thing or issue is parents who demand to come back... (Practice Nurse, Focus Group 2)* 

Clearly the idea that getting in more injections was preferable to single injections was apparent because it meant fewer appointments for parents.

Reminder letters were also considered useful for children's vaccination as seen by the following:

*I: ...anything that you liked when you took your child to be immunised? P: yeah now I'm thinking what I liked was they remind- they sent me letters with exact day, exact time, exact day so that was quite handy...(Parent, Interview 4)* 

While reminder letters with the exact day and time were considered useful for the child's immunisations by parents, administrative issues involved with moving practices where the surgery had 'lost some records' (Parent, Interview 4) meant that the reminder was not sent out. Here the parent discussed having the Redbook and so was aware of an approaching immunisation despite the lack of the reminder.

*I:* and what do you think works for promoting uptake in your practice? *PN:* hmm I think mostly the information's been sent our by SIRS or the health board, most of the mums I would say we have a very small amount that don't that don't pick up ...(Practice Nurse, Interview 1)

The SIRS system of sending immunisation information for appointments was also considered important in such attendance for vaccinations. Such systems were discussed along with the Redbooks which kept parents informed and up-to-date for their child's vaccinations.

## Lack of Parental Choices

In relation to the above, a lack of parental choice in relation to immunisations services was discussed in various ways, particularly by non-immunising parents. For example:

*P*: ...I just find that – I mean the price of them and I think people that can't afford it are then left forced into having the MMR because they can't afford the single vaccine. So I think for some parent's it's being taken away from them because of the price of it... even just a matter of choice – parent choice – I think it should be your own choice [for the single MMR vaccine] but em they were trying to say the MMR would be best and so on but I think [the health visitor] was saying it's your choice and she supported me in whatever you decide to do but obviously I didn't feel that I got that support from the GPs at all that was the down side really (Parent, Interview 3)

*P: ...I think having some choice [for location and professional] might be useful for people who don't necessarily have a good relationship with their health visitors like I did I do have friends who didn't have such a good relationship with their health visitors (laughs) um so maybe some element of choice would help...(Parent, Interview 2).* 

From the above, although the single MMR option was considered to be a parental choice, it was only accessible to those families that could afford to pay for it privately and so limited to affluent parents. Lack of support from the general practitioners, as highlighted in the above, was also discussed here in relation to not respecting parental choice about the single MMR and the clear need by the parent for support from the local surgery. Finally, from interview 4, the idea that parents should have some choice in terms of location for the immunisation and the professional administering the injection was considered as a possibility by this non-immunising parent for those that had not developed a good relationship with their health visitor.

In discussing decisions that were contravening current health recommendations (i.e. against immunisations in general or opting for the single MMR vaccine), mothers tended to discuss these decisions as consciously made and deliberate choices made with the father, for example:

*P*: ...and it was a joint decision I mean my husband looked at it was well and if he'd been very strongly for immunising them you know we'd have discussed it more or at least probably done some of them... (Parent, Interview 4)

# 3. Organisational issues for Immunisations Services

Organisational issues or wider structural and external issues were also relevant from the data analysis, particularly amongst health staff. The availability of resources in order to deliver services was significant such as the availability of up-to-date immunisation information for dissemination amongst parents. Staff knowledge and confidence was also important in order to effectively deliver the immunisations. A number of external barriers were also cited here as impacting on immunisation services including: time constraints in which to do the actual vaccinations; staffing issues and space issues. Wider government policy for immunisation more generally, as well as the recent vaccine shortages were seen to negatively impact on the service delivery. Another important development was the increasing numbers of families from overseas with complex vaccination needs and the challenges in delivering immunisations safely and effectively to this client group.

# **Child Friendly Practices**

The atmosphere and context of the immunisation was also expanded by one parent when asked about the location of immunisations, as seen below:

I: and in terms of location – where should it be done - any ideas on that one? P: again when the health visitor does it – I think the nurse actually had toys as well – it's quite nice to have a friendly atmosphere, nice and colourful and there's lots of things to play with as well so that was quite important as well (I: oh yes) whereas when the doctor done it, the doctor didn't have anything like that to play with – I don't think anyway – like a colourful pen or something like that to try and distract them with whereas the health visitor had all these toys and so did the nurse actually toys as well to try and distract them – a nice colourful atmosphere as well – when they've got that many injections rather than the dull doctor's room (laughs) I think it's the atmosphere, colourful and things to play with... (Parent, Interview 3)

Clearly a child-friendly environment was discussed as important for putting the child at ease, and distracting them with toys. While this was achieved by the health visitor and the practice nurse, it was seen as absent from the doctor's consulting room.

Particular practices were considered by health staff to be child-friendly for immunisations services and included practices where two professionals delivered immunisations simultaneously so that the child had minimal discomfort. A further technique was for general practitioners to have a double appointment with the health

visitor and for the child to be taken in to the consulting room only once the injection had been drawn. While these practices were considered successful for reducing the trauma inflicted on the child, the expense of having two professionals involved and the difficulties achieving double appointments were seen as impractical for other medical practices but was seen as something that every child should receive.

## Health Staff Knowledge and Confidence

Some practice nurses who were currently working in immunisation services discussed growing confidence in the area of childhood immunisations and the opportunity to develop skills in this area. Here rapport with the health visiting staff was important. For example:

*I: and just speaking generally about childhood immunisations, who do you think should be the one to deliver it? ...* 

PN: I mean it has always been the role of the health visitor in the past, I personally don't have a problem with it because it's my baby in that sense in that when I came the other nurses had their thing so this is my thing so I'm quite happy with that em and I think that I have still good support initially with the health visitor who's still here and we have the GPs and I work quite closely with the health visitor and we check up and if there's somebody who's not been turning up if they see them they try to get them to come so there's a good relationship there em it doesn't bother me as long as it's getting done I don't mind who's doing it I know that there are other practice nurses who feel very strongly that it's the health visitor role but I also know having worked with health visitors that they are under a lot of stress (a) there's not enough of them and (b) they're so full of families at risk that that takes up so much time that I can appreciate that it's not on their agenda...(Practice Nurse, Interview 1)

Against the above, practice nurse staff also tended to discuss the contrary theme of a *lack* of confidence for childhood immunisations, as well as child development issues specifically. This is seen below:

PN: ...I think that where it does fall down is where if people want to ask me questions about the child, child development and I did my Sick Kids but it was you know a long time ago so I don't feel qualified to deal with that or if they want to get the baby weighed I mean I can do the weighing of the baby but if they had queries about the baby's development that's where I feel it falls short but then you know to me that's the health visitor's remit of the doctor's and that's where they should be going so I'm not dealing with that as such but I think in terms of health visitor numbers we don't have the numbers to do it...(Practice Nurse, Interview 1)

*PN: ...and we're asking questions about the baby and young children and that's not my area of expertise you know, I could say what I thought I would* 

have done with my own kids but that was quite awhile ago so you know I would have to refer them back to the health visitor...it's not something I feel completely comfortable doing I mean I've (been) on a course I've been on an immunisation study day and upgrade ...I still feel it's not my area of expertise and I don't feel entirely happy – it's not that I don't feel happy because I can easily give an injections, it's confidence...I just feel that I'm not knowledgeable and confident enough to be doing it and I don't enjoy doing it as I say when I do it I just feel uugh I look on the computer and see that someone's coming in for a vaccine and I go 'uugh' you know there's a sinking feeling... (Practice Nurse, Interview 2)

Against this lack of confidence for child development issues was the appreciation that the health visitor or doctor was more appropriate for such specialist queries and also an appreciation for limited numbers of health visiting staff. In addition, the complexity of the vaccination schedule was discussed as a challenge, particularly for staff who did not administer vaccinations on a regular basis, or for increasing numbers of families seen coming from overseas. (This is discussed below further).

# Resources: Having available time, staffing, appointments, space and information.

Along with issues of knowledge and confidence for childhood immunisations, practice nursing staff also discussed how time constraints impacted on such work and impacted on the quality of the experience for parents. This is seen below:

*PN: ...it's the time element as well I always feel really rushed and I've only got a 10 minute appointment so you can't give them enough time as you feel they might want I feel as if I'm rushing them through...(Practice Nurse, Interview 2)* 

PN1: they get a ten minute appointments and to get everything in ten minutes you're always in a (rush)...I mean we can get a kid in for the preschool year () it's a fast appointment and there really isn't much time and to do their height and weight fifteen minutes and you're really pushing them out the door by that time because you're got another ten patients...(Practice Nurse, Focus Group 2)

PN1:... I can't speak for other practices but as the health visitors here have less to do with it they're being deskilled therefore they're [parents] not being counselled when they come so that has implications for us too so you don't really have time to counsel at the baby clinic PN2: ...some of the health visitors are actually saying [to parents]...'oh no that's not us you know I don't deal with that you'll have to ask the practice nurses'...(Practice Nurses, Focus Group 1)

The appointment system used was discussed in relation to promoting vaccination uptake. An 'open clinic' or flexible appointment system was considered important in order to accommodate parents. Working parents in particular were difficult to accommodate where they may have to take time off work in order to attend the practice. However, in view of other constraints for health staff (i.e. such as time, staffing and available consulting rooms) such appointments had to be negotiated to suit both parents and staff.

Having immunisation information readily available to give to parents about immunisation was considered important. Such information included the NHS explanation folder for MMR, Green book; and information about immunisations in other languages such as Polish which was available on the NHS website. Another key area that emerged here from health visiting staff was the lack of available information and access to relevant, up-to-date information about immunisations in other languages. While the HEBs/NHS Health Scotland website was used in order to disseminate relevant information, there was a need for information in more languages (e.g. Turkish and other minority languages) to be reflected on the website which was relevant and up-to-date so that it could be downloaded and given to families for informed consent. This was relevant in view of the increasing number of families seen coming from abroad.

Health visitors spoke about practical issues that impeded the delivery of immunisations and which related to having an allocated room available for the immunisations which was flexible to allow working parents to attend. Immunisation was also seen as time-consuming from an administrative point of view and takes 'our precious resource' (Health Visitor, Focus Group 2). Here the dilemmas and tensions over the health visiting role was discussed as to whether childhood immunisations were appropriate for health visitors to be physically administering in view of staffing issues and changing roles or whether such resources were more suited for work with vulnerable families. There were mixed views over this issue with some health visitors seeing the contact with families as 'more than a jag' but which allowed discussion about other issues for the child and others saw the skills and expertise of the health visitor as requiring targeting for those most in need.

#### Wider government and management policies

Present preschool vaccine shortages were discussed in many interviews with health staff as impacting negativity on the immunisation process due to difficulties associated with physically delivering three injections to preschoolers who anticipated the injections and reacted against them. Staff appeared critical of management planning of the vaccine. For example:

*PN: they've run out of pedicel so we now have to give three injections which I have to say is a big bug bear – three injections at once or they have to come back for the third one because the child won't take it but I mean that's ghastly it's bad enough doing three when they're four months old but doing three at four is ghastly and I feel quite cross that the situation wasn't addressed beforehand...(Practice Nurse, Interview 1)* 

In some interviews there was a clear sense that there was nothing more that practice nurse staff could be doing to improve immunisations, that there was no problems with uptake rates in their area and that any improvements should come from management. The idea that 'there was nothing we can do' (Practice Nurses, Focus Group 1) meant that attention was paid in these discussions to outside factors rather than to individual personal responsibility such as public health and national campaigns to improve public awareness of disease or by health visitors delivering health promotion.

I: ...is there anything that you think needs improvement in your own practice for immunisations for children – for promoting uptake rates? PN: um well there's a lot of information about it around the practice and posters around in the waiting room – out in the hall there – I don't know that we could do any more about it – the doctors talk to people about it when they bring their babies in for the 6 week check and the health visitors talk about it – it's not something that anybody asks me about to be honest I can't remember the last time somebody was in asking me about childhood immunisations cos they don't see it as part of my role... (Practice Nurse Interview 2)

Government decisions relating to immunisation delivery were criticised by health staff and considered 'short-sighted'. In particular, the decision taken to give preschoolers three injections was seen as 'short-sighted' and 'traumatic'. Health visitors reflected that the preschool age was an important phase for the child and that the child's early experiences with immunisations at this stage would affect future decisions for immunisations in later life because a period of 'sensitization' was recognised to occur at this stage of life. Thus, these early negative experiences associated with immunisation at this age would mean that future vaccines requiring consent by the child, may be more likely to be refused. In addition, the government was criticised for not admitting that some children had been damaged by the vaccines and for not accepting liability for such damages which meant that public confidence was affected. Health staff also discussed how the differences in immunisations delivery across different medical practices, meant that it was confusing for parents 'as neighbours talk' (Staff Nurse, Focus Group 2). Such disparities also meant that it was challenging to work across different practices for covering a service.

### Complicated Schedules and Potential for Mistakes with Families from Abroad

Health visiting and practice nursing staff discussed the complexity of the immunisation schedule and how it was important to be doing immunisations 'often and regularly'. The challenges of the schedule in relation to parents that came 'out of step' to the British schedule also emerged as an aspect whereby it was easy to make mistakes and time-consuming to 'decipher' (Health Visitor/Team Manager, Interview 2). This was an area in particular that required further support in view of the numbers of families from abroad and the challenges of working out their immunisation requirements. Health staff appeared anxious to avoid make mistakes on schedules in these instances and requested further support and reassurance. The previous system whereby staff could phone health protection for a query and then be called back promptly for advice or confirmation of a vaccine was seen as a particularly good system. The present system of emailing the query, however, was seen as less timely and more likely to result in delays for immunisation.

# **Discussion from the Parent and Health Staff Findings**

The above findings arose from the profile exercise which was based on a small sample of parents and staff. The qualitative analysis was considered amongst parents and health staff in order to capture key themes across the data as a whole. The findings here suggest that parents who tended to contravene health advice for immunisations tended to make joint decisions as a conscious and deliberate choice. This appears against the notion that such decisions were based purely on 'ignorance' or a lack of knowledge. Such parents had considered their choice and weighed up the risks and benefits of such decisions as well as consulted information online. These choices appeared against immunising parents who generally appeared more accepting of vaccination and who generally valued the immunisation programmes. All parents in the analysis, as well as health staff, alluded to the MMR controversy, indicating pervasive concerns and worries about risks. Such controversy was still

apparent ten years after the Wakefield et al (1998) report and indicates issues around trust. Previous wider health experiences also tended to inform later decisions about immunisations which indicates how trust in health messages are shaped by, and occur in, a wider context of experiences. There were also issues about parental informed consent and parental choices for immunisations, from this analysis.

Parental suggestions for potential improvements of current services centred on improved parental choices for immunisations. These suggestions came primarily from the non-immunising parent and the parent who opted for the single vaccine instead of the combined MMR. Parental choices about when the child should be vaccinated (i.e. when the child was strong and healthy) and by whom were also suggested as ways of improving the communication process. Provisions for a separate measles vaccine and/or the single MMR at local surgeries were also discussed, as well as general practitioners being open to such choices for a single MMR. Fewer vaccines and fewer vaccines so early were also discussed as well as greater communication about changes of staff administering immunisations (i.e. from the health visitor to the general practitioner to the practice nurse).

From the data with practice nurse staff, the idea about 'getting in as many jags at once' emerged as a potential conflict with parental expectations for immunisations where a preference for fewer injections at once was expressed. Clearly this strategy by health staff may be effective in terms of cutting the number of appointments, particularly for parents that are perceived by such staff as 'chaotic' and 'forgetful'. However, analysis from the parent interviews indicated that such experiences affect future interactions with health services. The theme about 'time constraints' and ideas of 'rushing' parents is also an area of concern if the negative experiences of a 'conveyor belt' by parents are to be avoided. The analysis from parent interviews and staff data, showed how parents valued a guality interaction with the health staff. Practice nurse discussions about a lack of confidence and knowledge are perhaps unsurprising when considering that they may have been required to take on this role from the health visitor. Clearly the area of childhood immunisations, from a positive perspective, does remain as an area where such staff can potentially gain skills and confidence (as seen from the above data extracts). However, there are particular challenges in terms of practice nurse staff beliefs that this was not their 'area of expertise'. Practice nursing staff did indicate an awareness of the need to refer on to other staff such as health visitors or general practitioners for child development queries. From the parent analysis, professionalism in immunisations was valued and so this remains an area where such professionalism should be developed for staff required to deliver immunisations. Broadly, practice

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nurse staff had a good overall understanding of parental reasons for a lack of attendance for immunisations but appeared uncertain about specific reasons for non-attendance. From the literature, health staff beliefs about autism and delays for the MMR, tended to contravene current health recommendations and also indicates staff ambiguities in this area. The theme that some practice nurses felt that there was 'nothing we could do' for improving immunisation services indicates a sense of powerlessness and points to the challenges of delivery of the immunisations within the wider context. In summary, while challenges to the practice nurse role for childhood immunisations that through time, and with support from the health visitor and the wider context, that such confidence could be facilitated.

Finally, ideas about deprived populations and families from overseas as 'compliant populations' may be useful descriptions of particular populations but should not be take at face-value or accepted uncritically. More work is required amongst such populations in order to explore their particular experiences of immunisation services in more depth. Talk about such populations, it is argued, tends to obscure the complexities involved in parental decision-making for immunisations and may also implicate issues about informed consent for such groups.

Suggestions from practice nurses to improve current childhood immunisation services implicated greater public health campaigns in order to emphasise the significance of the vaccinations and the severity of the diseases. Other suggestions included governmental and senior management responsibility for vaccine-planning as well as tackling families early about immunisations (e.g. before peer influence) through the health visitor and for maximising opportunistic vaccinations. There were mixed views as to the role of the practice nurse role in delivering immunisations with some staff seeing this as an opportunity to be involved in immunisations and develop skills, and other staff considering this as the remit of the health visiting staff and not wanting to be involved.

From the health visiting staff interviews, particular local issues that emerged for immunisation related to: issues to do with the complexities of the schedule for families from abroad and the need for up-to-date, relevant information on immunisation in various languages. In addition, vaccine shortages also emerged as a problematic issue as it did amongst the practice nurse staff, with both groups of staff being critical of this service failure locally. Health visiting staff also appeared to reflect on the potential early trauma inflicted by having three preschool injections and how it may shape future immunisation decisions amongst this group. Health visiting staff were also insightful about the dilemmas associated with informed consent for relatively 'compliant' populations and about the dangers of being 'blasé'. Hence, suggested improvements by health visiting staff included information in other minority languages such as Turkish and increased public health support for the increasing numbers of families from overseas with complex immunisation needs. There was a mixed response to the role of the health visitor in immunisation services. For example, one health visitor considered the health visitor's role as requiring 'targeting our scarce resources to vulnerable families' and that staff had other skills so that it was 'not a good use of our time just a whole clinic of sticking needles into babies' (Health Visitor, Interview 1). On the other hand, others considered the giving of immunisations as 'more than just a jag' and as a means of contact in which to discuss other issues relating to the child with families.

Hence, from the health staff data, potential facilitators to childhood immunisations included a good working relationship with other health staff; parental awareness of the need for immunisation and confidence in the safety of the vaccines. Potential barriers for immunisation delivery included vaccine shortages for preschoolers which were attributed to poor management/government planning; lay parent beliefs and experiences for immunisation; time constraints; vaccination scares and trust issues; as well as the complexities and challenges associated with delivering immunisations to families from overseas.

# **Key Management Input**

Interviews with key management in the area of childhood immunisations were held in order to contribute views and input to this topic. Such interviews were held in NHS Lothian and included: the General Manager Primary Care Contracts, the Chief Nurse, the Public Health Consultant, one of the Clinical Nurse Managers and the Clinical Nurse Manager for Practice Nursing in Primary Care Development, to discuss this topic. A number of key areas emerged from these interviews in relation to the parent and health staff analysis. These are outlined here in relation to some areas of overlap and issues highlighted by the managers:

- The need to identify a model of good practice within Edinburgh in view of the 'mixed-economy' of practices across Edinburgh CHP which were based on historical reasons as opposed to best practice.
- Integrated nursing care and general practice vocational liability versus professional disputes over payment and over which professional should be immunising.

- The need for patient-centred care over professional disputes about payment for immunisations which had the potential to negatively impact on service delivery.
- Concerns about sustainability of the current services and about safety issues. Issues about resourcing from the health staff analysis were echoed here. The current staffing was not seen as sustainable over the long term and debates about the distribution of funding for immunisation services and over the distribution and volume of work required immediate resolution. For example, recent figures for immunisation (e.g. June) were improved and had indicated that NHS Lothian had reached its target for MMR1. This was seen as due to the results of hard work by practitioners on the ground. However, health staff calling Health Protection for advice on the vaccination requirements for families from abroad was not seen as a viable option given the current staffing. One option suggested a dedicated service set up for this whereby health staff were able to call up and get advice and reassurance for such vaccinations requirements.
- Health staff knowledge and training for immunisations. This area supports findings from the health staff analysis. While this had received emphasis (e.g. Elearning training), the initial feedback from this was that staff preferred faceto-face training.
- Supporting Parental Confidence in Immunisations
- Government Policies for Immunisation needed greater attention. Shortages of vaccines had had negative implications both for the practitioners who were required to deliver the vaccines but also for the experiences of preschoolers and parents.

# **Overall Findings**

Three key themes were highlighted from the parent and health staff analysis and which was supported from input from management views about current immunisation services. Lay health beliefs amongst parents but also health staff was a significant influence on vaccination decisions. Central to this theme was: a belief in the importance of the vaccinations ('the fear factor'); undermining this belief were ideas about risks (i.e. for MMR) and other commonly held 'lay' beliefs which contravened health messages; and previous wider health experiences also appeared instrumental in shaping future decisions about immunisations. Communication was also a

significant theme which occurred between: the health staff member and parent, particularly, but not exclusively, the health visitor; and amongst different health staff members and within the health care system. Teamwork or integrated working was important for effective practice, with support from administration. Conversely, where a lack of such teamwork occurred in a context of professional disputes over which professional should be immunising, immunisation services were likely to be negatively affected. Wider organisational and external influences on immunisation services were also an important theme in the analysis. Here child-friendly practices were seen as important as were health staff knowledge and confidence, particularly amongst practice nurses. External barriers to immunisation services appeared related to resources including: staffing, time constraints, flexible appointments and available and relevant immunisation information to disseminate to parents. Government and senior management policies in relation to vaccine planning were seen as negatively impacting on immunisations for health staff delivery as well as inflicting unnecessary trauma on preschoolers. Finally, safety issues relating to complicated schedules for increasing families from abroad emerged as a local issue.

## Recommendations

The report supports the Chief Nurse's suggestion for a dedicated specialist service which provides reassurance, advice and information for health staff in relation to the vaccination requirements of newly arrived families from abroad, in view of the increasing number of families from abroad and in view of health staff concerns about safety. In relation to this, education and training of staff to promote confidence and knowledge is also significant. While Elearning is important, ongoing face-to-face learning may also be relevant.

In the wider scheme of professional disputes about who should be immunising and considerations about payments, it would appear that parents and children are likely to be the ones that are on the receiving end of such negative effects. It is important that such disputes are resolved at senior management level in order that current services are not jeopardised and in order to deliver a patient-centred service. This is important because early experiences and interactions with the health services are influential in shaping future decisions.

This report has not identified a model of service which could be considered as a 'gold standard' of service but has highlighted key areas which require attention for the current services: the importance of targeting and addressing lay health beliefs in both parents and health staff in order that ambiguity is resolved and in order that parents receive a clear message about the benefits as well as risks for vaccines; the importance of communication for this area both between health staff and parents but also across different staff members; and finally wider organisational issues within NHS Lothian which have impacted on service delivery and which could be addressed at senior management level. In summary, the following suggestions are made from the work:

- Lay beliefs about immunisation could be addressed (i.e. beliefs such as 'overloading the system' and the 'sheer number of injections'). Beliefs about autism could also be targeted amongst parents but also amongst health staff in order that professional and confident messages about immunisation are delivered by staff instead of contributing to ambiguity in this complex field.
- Communication and rapport for immunisation is important and was valued by parents. Clearly opportunities for discussion about immunisations with health staff were important for parents as opposed to a 'conveyor belt' experience. In addition, the finding that health staff considered time constraints to be a limitation for delivering services (i.e. 'pushing them out the door') clearly conflicts with the parental value for a quality of care service. This highlights a wider conflict between public health issues versus the financial model in current services (i.e. quantity versus quality of care).
- Increased parental choice about immunisation services delivery emerged as a key area amongst non-immunising parents. Due to the small number of parents included in the analysis, this area requires further study with a greater number of parents.
- For health staff the importance of developing confidence and skills for the delivery of childhood immunisations was highlighted and indicates further issues about staff training and education. This finding was in keeping with the parental value for professionalism. For practice nurses who may be increasingly required to deliver childhood immunisations, this needs further consideration in current services.
- Amongst health staff, **informed consent issues** were important and complex amongst parents with minority languages and adults with literacy

difficulties. Staff requested that updated information and a greater variety of minority languages (e.g. Turkish) be available for downloading on the NHS Health Scotland website.

- Health staff considered that **greater public health campaigns** were needed in order to highlight the importance of vaccination against diseases.
- Greater support was requested by health staff for complex schedules for increasing number of families from overseas who had immunisations which were out of synchrony with the British schedule. Staff requested a timely system for support and confirmation about these complex needs.
- Government policies and vaccine shortages were unsatisfactory amongst health staff where the difficulties of physically giving three injections to preschoolers were highlighted. These policies were considered 'short-sighted' because negative experiences of immunisation influenced future decisions. These concerns appeared to be supported by parents and the wider literature which recognises the significance of past health services for future decisions.
- Further study is suggested which examines childhood immunisation experiences for later immunisation decisions (i.e. for Human Papillomavirus or HPV) in order to explore the impact of such early experiences on later decisions.
- From a local Edinburgh context, this work has wider relevance for the national immunisation campaigns.

# Strengths and Limits of the Exercise

This work utilised a purposive sample in order to gauge the experiences and views of a variety of stakeholders including parents and health staff for current immunisation services in Edinburgh as well as key management. A small sample of participants were interviewed from a range of different areas across Edinburgh about their experiences and so further work is necessary in order to examine this area in-depth. As an initial exploratory exercise, this work will be further supplemented by in-depth qualitative study with a greater number of parents.

# **Future Directions**

This initial profile exercise of the views and experiences of different stakeholders' across Edinburgh has highlighted particular avenues for further study. Further funding has been secured from the Health Services Research Programme in order to conduct further in-depth qualitative study, which builds on this initial profile. The research aims to conduct an in-depth exploration of wider stakeholder experiences and decisions for controversial vaccines, by focusing on the MMR and HPV vaccines, in order to explore the findings of the exercise in a wider sample. This research is due to commence in July 2009.

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# Appendices

Appendix 1	Childhood	immunisation	schedule 2008
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Age	Diseases Protected Against	Vaccine
2 months old	Diptheria, tetanus, pertussis (whooping cough), polio and <i>Haemophilus</i> <i>influenzae</i> type b (Hib)	DTaP/IPV/Hib
	Pneumococcal infection	
		Pneumococcal conjugate vaccine (PCV)
3 months old	Diptheria, tetanus, pertussis, polio and <i>Haemophilus influenzae</i> type b (Hib)	DTaP/IPV/Hib
	Meningitis C	MenC
4 months old	Diptheria, tetanus, pertussis, polio and <i>Haemophilus influenzae</i> type b (Hib)	DTaP/IPV/Hib
	Meningitis C	
		MenC
	Pneumococcal infection	
		PCV
Around 12 months old	Haemophilus influenzae type b (Hib)	Hib
	Meningitis C	MenC
Around 13 months old	Measles, mumps and rubella	MMR
	Pneumoccocal infection	PCV
3 years 4 months to 5 years old	Diptheria, tetanus, pertussis and polio	DTaP/IPV or dTaP/IPV
<b>,</b>	Measles, mumps and rubella	MMR
13 to 18 years	Tetanus, diphtheria and polio	Td/IPV

Other:

Hepatitis B (Hep B) to babies born to mothers who are Hep B positive Tuberculosis (BCG) to babies more likely to come into contact with TB/selected need HPV catch up from September 2008

Downloaded from Department of Health: <u>http://www.immunisation.nhs.uk/Immunisation\_Schedule</u> 24 September 2008



#### PARENT PARTICIPANT INFORMATION SHEET

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh

My name is Carol Gray and I'm a researcher in the School of Nursing, Midwifery and Social Care at Napier University in Edinburgh. I'm working on a team-led project about Childhood Immunisation in Edinburgh.

This study aims to find out more about parents' experiences and views about immunisation services for their child in Edinburgh. The study also explores the views and experiences of health professionals such as general practitioners, health visitors, practice nurses and managers. This is an initial study which will hopefully lead to further research in this area.

#### Why have I been chosen?

You have been chosen because you are a parent of child who may or may not have been immunised in Edinburgh. For this study we are hoping to talk to parents from all five local health partnerships in Edinburgh – two parents from each area will be chosen for the study. You were chosen because you met the criteria for inclusion in this study.

#### Why is this important?

The findings of this research are valuable because they will provide greater understandings about parents' experiences and views of services for immunisation for their children in Edinburgh. It will also provide greater understandings of health professionals' views of this topic. This research is funded by Napier University.

#### What does the study involve?

If you agree to take part in the study then you would be contacted by me to arrange a time to be interviewed about your views and experiences. Interviews would last about one hour and would be audio recorded to help with the analysis. You would be asked questions about your experiences with services for immunisation and your views about immunisation. Interviews would be conducted at a time and place most suitable for you (e.g. at home or over the telephone). You would be free to withdraw from the study at any stage and you would not have to give a reason for doing so. You would also be free to refuse to answer any specific questions at any time. The researcher is not aware of any risks that are associated with this study.

#### Is this study confidential?

Yes. Your participation in this study would be anonymous and confidential. You may be identifiable from tape recordings of your voice, but only the researcher and research team would have access to this recording. Your name would be replaced by a pseudonym (a false name) so that it would not be possible for you to be identified in any reporting of the data gathered. All data collected would be kept in a secure place within locked premises and password protected on computer. Data would be stored for 7 years after which it would be destroyed.

#### What will happen to the findings of the study?

The results of this work may be published in a journal or presented at conferences.

#### What happens next?

The researcher would ask your permission to contact you again after 48 hours after receiving this information sheet and consent form. If you would like to participate in the study then please indicate this when the researcher contacts you then. The researcher would then arrange a date for your interview and you would be asked to sign a consent form. Alternatively, if you refuse to participate or if you would prefer not to be contacted at all by the researcher then please indicate this.

If you refuse to participate in the study, or if you withdraw from the study at any stage, your decision would not affect any future interaction with Napier University or with your healthcare from NHS Lothian.

#### Where can I get more information?

You can contact me for more information: *Carol Gray, Research Fellow, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh, EH9 2TB. Tel: 0131-455 5677 or 07810332801 or email:* <u>c.gray2@napier.ac.uk</u>

Or, if you would like to talk to someone who knows about this study but is not directly involved, you could contact: *Dr Dorothy Horsburgh, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh, EH9 2TB. Tel: 0131-455 5628 or email: d.horsburgh@napier.ac.uk* 

#### Thank you for taking the time to read this information. Parent Information Sheet June/2/2008





#### HEALTH PROFESSIONAL PARTICIPANT INFORMATION SHEET

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh

My name is Carol Gray and I'm a researcher in the School of Nursing, Midwifery and Social Care at Napier University in Edinburgh. I'm working on a team-led project exploring Childhood Immunisation in Edinburgh.

The study aims to find out more about the views and experiences of health professionals such as general practitioners, health visitors, practice nurses and managers about immunisation. This study will also examine parents' experiences and views about immunisation services for their child in Edinburgh. This is an initial study which will hopefully lead to further research in this area.

#### Why have I been chosen?

You have been chosen because of your role as a health professional involved in childhood immunisation. For this study we are hoping to include the views of parents and professionals from all five local health partnerships in Edinburgh. Focus groups will be held from different partnerships consisting of health visitors and practice nurses. GPs and management staff will also be interviewed about their experiences with providing services for immunisation. Two parents from each partnership will also be interviewed about their experiences.

#### Why is this study important?

The findings of this research are valuable because they will provide greater understandings about parents' and professionals' experiences and views of services for childhood immunisation in Edinburgh.

#### What does the study involve?

If you agree to take part in the study then you would be contacted by the researcher to arrange a time either to take part in a focus group interview (for health visitors or practice nurses) or a face-to-face interview or telephone interview (for general practitioners, clinical leads and management staff). You would be asked questions about your views and experiences with service provision. Focus group interviews would consist of 4-6 participants and would last approximately one hour. Individual interviews would also last no longer than one hour. All interviews would be audio recorded to facilitate analysis. Focus group interviews would be scheduled for a time and location convenient for you. Individual interviews, likewise, would be conducted at your convenience and may take place at your place of work or over the telephone. You would be free to withdraw from the study at any stage and you would not have to give a reason for doing so. You may also refuse to answer any specific question at any time. The researcher is not aware of any risks that are associated with this study.

#### Is the study confidential?

Yes. Your participation in this study would be anonymous and confidential. You may be identifiable from tape recordings of your voice, but only the researcher and research team would have access to this recording. Your name would be replaced by a pseudonym (false name) so that it would not be possible for you to be identified in any reporting of the data gathered. All data collected would be kept in a secure place within locked premises and password protected on computer. Data would be retained for 7 years after which it would be destroyed.

#### What will happen to the findings of the study?

The results of this work may be published in a journal or presented at conferences.

#### What happens next?

On receipt of this information sheet, the researcher would ask your permission to contact you again after 48 hours. Should you wish to participate in the study then please indicate this when the researcher contacts you then. The researcher would then arrange a date for your interview and you would be asked to sign a consent form. Alternatively, if you refuse to participate or if you would prefer not to be contacted at all by the researcher then please indicate this.

If you refuse to participate in the study or withdraw at any stage, your decision would not affect your interaction with Napier University or your employment with NHS Lothian.

#### **Further information?**

If you would like to discuss the study further with the researcher than please contact: Carol Gray, Research Fellow, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh EH9 2TB. Tel: 0131-455 5677/ 07810332801 or email <u>c.gray2@napier.ac.uk</u>

If you would prefer to discuss this study with an independent advisor, please contact: *Dr Dorothy Horsburgh, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh EH9 2TB. Tel: 0131-455 5628 or email:* <u>*d.horsburgh@napier.ac.uk*</u>

#### Thank you for taking the time to read this information.

Health Professional Information Sheet June/2/2008





#### PARENT CONSENT FORM

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh

Name of Researcher: Carol Gr	ау	Please tick box	
I confirm that I have read and u Information Sheet for the above opportunity to consider the info had these answered satisfactor	e research study. I hav rmation, ask questions	e had the	
I understand that my participation withdraw at any time without give my decision impacting in any we Napier University or with my he	ving any reason and w ay on my future intera	rithout ctions with	
I agree to interviews being audi understand that I will not be ide		ribed and	
I agree to take part in the above	e research study.		
Name of Participant	Date	Signature	
Name of Person taking consent	Date	Signature	

Participant Pseudonym:

P Consent Form May 2008

Appendix 5: Consent form for health professionals





#### HEALTH PROFESSIONAL CONSENT FORM

#### A Profiling Exercise of Childhood Immunisation Services in Edinburgh

Name of Researcher: Car	ol Gray	Please tick box	
Information Sheet for the	and understand the Participant above research study. I have had t e information, ask questions and ha factorily.		
withdraw at any time with my decision impacting in a	cipation is voluntary and that I am to out giving any reason and without any way on my future interactions w mployment with NHS Lothian.		
•	erviews/interviews being audio and understand that I will not be		
I agree to take part in the	above research study.		
Name of Participant	Date	Signature	
Name of Person taking consent	Date	Signature	

Participant Pseudonym:

HP Consent Form May 2008

## Appendix 6: Description of the participants

## **Description of the Participants**

Date	Туре	Description
15 July 2008	Focus Group Interview	Practice Nurses:
		3 From NW LHP
		Deprived Area Currently all immunising
22 July 2008	Semi-structured Interview	Parent:
		Mother of 3 preschool children SC LHP
		Up-to-date with immunisations
23 July 2008	Semi-structured Interview	Parent:
		Mother of 2 preschool children
		Non-immuniser
30 July 2008	Semi-structured Interview	Practice Nurse:
2000		1 From SE LHP
		Affluent area
		Currently Immunising (GPs 1 <sup>st</sup> )
8 August 2008	Focus Group Interview	Practice Nurses:
		2 From SC LHP
		Affluent area & deprived area Preschool immunisations & not
		routinely involved except for
		catchup - HVs
12 August 2008	Semi-structured	Parent:
2000		Mother of 2 preschool children
		Single MMR vaccine option
13 August 2008	Semi-structured Interview	Practice Nurse:
		1 From NE LHP Affluent area
		Not routinely involved except for catchups - HVs

Date	Туре	Description
15 August 2008	Focus group interview	Health Visitors:
		1 HV & 1 Staff Nurse From SC LHP Work across different practices Currently Immunising
	Semi-structured interview	1 HV From SC LHP Not routinely involved in administering immunisations
20 August 2008	Focus Group Interview	Health Visitors:
2000		4 HVs & 1 Staff nurse from NW LHP Come from 4 different practices
		Deprived area & affluent area Currently involved in immunising & not routinely involved in administering immunising
29 August 2008	Semi-structured interview	Health Visitor/Team Manager:
2000		NW LHP
19 September	Semi-structured interview	Parent:
2008		Mother of 1 preschool child SE LHP
		Currently up-to-date with immunisations
1 October 2008	Semi-structured	Management:
		General Manager Primary Care Contracts, NHS Lothian
15 October 2008	Semi-structured interview	Management:
		Clinical Nurse Manager for Practice Nursing in Primary Care Development Service, NHS Lothian
20 October 2008	Semi-structured interview	Management:
		Clinical Nurse Manager, NHS Lothian

Date	Туре	Description
14 November 2008	Semi-structured interview	Management: Public Health Consultant, NHS Lothian
20 November 2008	Semi-structured interview	Management: Chief Nurse, NHS Lothian

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#### Topic Guide for Parent Participant Interviews:

- Experiences with health services for childhood immunisation
- Views on childhood immunisations
- Was there anything/What was helpful about the services received
- What needs improvement for immunisation services
- How could these services be delivered to meet your needs
- Who should deliver immunisations/how should it be done/
- Interactions with health staff: health visitors/ practice nurses/general practitioners/other staff for immunisation
- What made you decide to immunise/not immunise
- · What was likely to influence you to immunise child
- What was likely to prevent you from immunising child
- Comments about this topic

# NAPIER UNIVERSITY

#### Topic Guide for Health Professional Focus Groups Interviews/Telephone Interviews/Face-to-face Interviews:

- Experiences with delivering childhood immunisations
- How does childhood immunisation occur in your practice/caseload
- Views about childhood immunisation
- What works for promoting uptake in your practice
- What is less successful/needs improvement in your practice for immunisation
- What promotes/facilitates immunisation uptake generally
- What inhibits/prevents uptake generally
- Who should deliver childhood immunisation/how should it occur to be effective
- What are parents' experiences and views about childhood immunisations/why don't parents get their children immunised/why are there differences between practices
- Interactions with other health staff: health visitors/practice nurses/general practitioners/clinical management for immunisation
- Comments about this topic

HP Topic Guide July 2008