

Southern Health Board
Bord Sláinte An Deiscirt



IMMUNISATION: The views of parents and health professionals



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Many thanks.

Foreword

Disease prevention is the key to public health. It is always better to prevent a disease than to treat it. Vaccines help prevent infectious diseases and save lives. Vaccines are responsible for the control of many infectious diseases that were once common in Ireland. The current national recommendation in Ireland is that children are vaccinated against ten infectious diseases: diphtheria, pertussis (whooping cough), tetanus, polio, *Haemophilus influenzae* type b, meningococcal group C, measles, mumps, rubella (German measles) and tuberculosis. The national target for vaccine uptake is 95%, the level needed to prevent outbreaks of disease. At present the uptake of childhood vaccinations falls far short of this target, especially for the measles, mumps and rubella (MMR) vaccine.

It is vital that health professionals and health service managers have an understanding of the factors influencing parents' decision on whether or not to have their child vaccinated. This decision was perhaps never simple, but in recent times has become increasingly difficult and stressful due to the confusing and conflicting information parents are receiving regarding immunisation. Within the health services there is need for an understanding of parents' concerns and of the factors, both positive and negative, which influence them. Only then can these concerns be addressed and parents be assisted in their decisions.

Dr Elizabeth Keane
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Executive Summary



Executive Summary

This study endeavoured to improve understanding of factors influencing vaccination rates in the Southern Health Board area using both quantitative and qualitative methodologies. The study looked at both parents' and health professionals' perceptions and knowledge of vaccines and their experiences with the vaccination system. It sought to identify how and why parents make their decisions about vaccinating their children.

This study was done in three stages – each of which complements the findings in the other components.

The first step was to identify what the main issues were – for this, selected GPs' opinions were sought. They articulated the extent and type of parental concerns concerning childhood vaccination that confront GPs routinely. The need to effectively address these concerns was also highlighted.

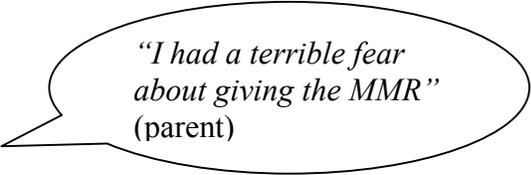
The second part of the study used focus groups to explore the issues raised by GPs among parents and nurses. The parents came from diverse backgrounds and represented a wide range of socio-economic groups in the region. The nurses – public health nurses, midwives, and practice nurses – all had extensive dealings with, and provided health information to, parents. These groups were considered key providers of vaccine and child health related information for parents in the region and their input was considered essential. The views expressed by both parents and health professionals confirmed what GPs had highlighted and provided greater insight into the determinants of decisions to vaccinate or not vaccinate children.

For the final part of the study, we carried out a survey of GPs to determine if our findings were representative of the experiences of GPs in the region. The results of the survey confirmed that the issues are widespread and similar throughout Cork and Kerry.

In essence this study gives a voice to the views and concerns of both parents and health professionals on vaccination. It is only with a greater understanding of these concerns that we can begin to address them.

Summary of main findings

The decision of parents on whether or not to vaccinate their children is influenced very strongly by **fear**; fear if they do and fear if they don't.



*"I had a terrible fear
about giving the MMR"*
(parent)

Parents expressed considerable **mistrust** of the health services and intimated a fear of issues being covered up.



*"I don't trust
the health
board"* (parent)

Health professionals recognise this parental **mistrust**.

“The whole polio scare... the vCJD concerns...it undermines trust” (health professional)

Parents expressed concern that the ‘population approach’ to vaccination appears to disregard their **child’s individuality**. Their desire for the health services to regard each child as an individual was highlighted.

“...your thing is the population...that’s your job..you don’t see us as flesh and blood” (parent)

Many parents feel **guilty** if they choose not to vaccinate their child – their child might become seriously ill and then they would be considered bad parents.

“you feel guilty...he gets it [illness] and ends up in hospital ... it’s your fault” (parent)

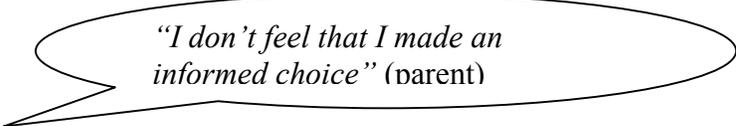
“you could cause other children to get ill if your child spread it to them...” (parent)

Parents feel under considerable **pressure** to have their children vaccinated, with pressure coming from society and the health services.

“there’s a choice but at the same time you’re told this is the time... it’s not actually your own choice” (parent)

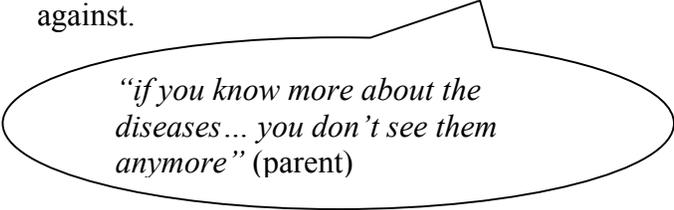
Parents are receiving **confused messages** from a variety of sources, including the health services, for example, the frequent changes in vaccination schedules. The reasons for which are unclear to parents and to many health professionals.

Parents feel that they are given **insufficient information** about vaccination.



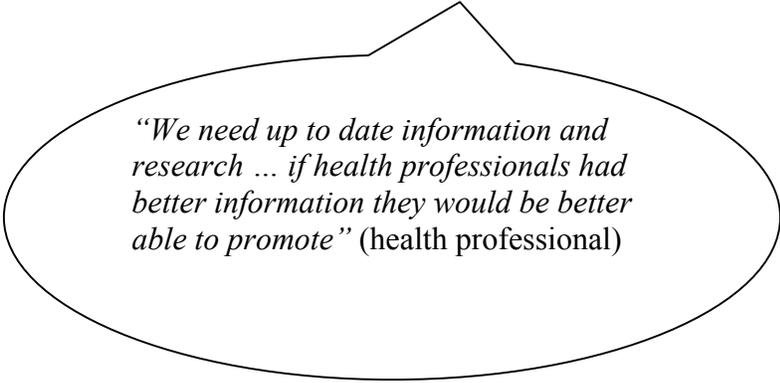
“I don’t feel that I made an informed choice” (parent)

Many parents are **poorly informed about the diseases** that their children are being vaccinated against.



“if you know more about the diseases... you don’t see them anymore” (parent)

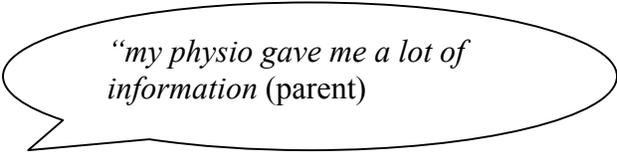
Many health professionals themselves feel poorly equipped to answer the concerns of parents.



“We need up to date information and research ... if health professionals had better information they would be better able to promote” (health professional)

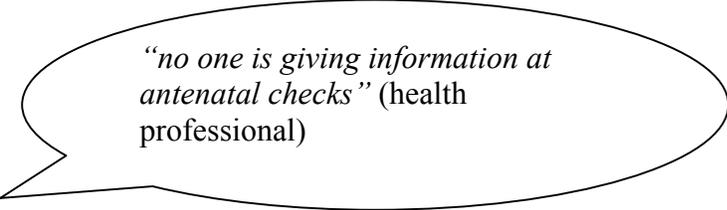
Those health professionals who are most involved in immunisation demonstrate most knowledge.

Parents seek and expect information from many health professionals, even those not directly involved in immunisation services.



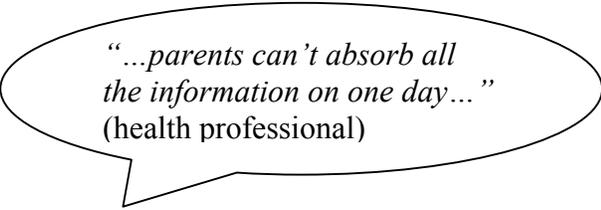
“my physio gave me a lot of information (parent)

Midwives were identified, by those delivering the service, as having a key information role. However, midwives themselves considered that their role was unclear and that they lacked adequate information.



“no one is giving information at antenatal checks” (health professional)

Parents need time to assimilate information provided on vaccines and related issues.



"...parents can't absorb all the information on one day..."
(health professional)

Health professionals consider '**negative media**' to be the most important factor affecting uptake. This is not only by means of a direct influence on the parents but also indirectly through family and friends, who also influence parents' decisions.



"biggest problem is adverse publicity in press" (health professional)

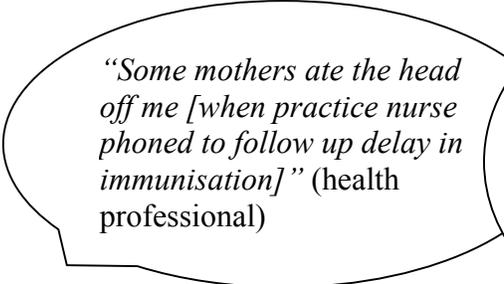


"Headlines scare" (health professional)

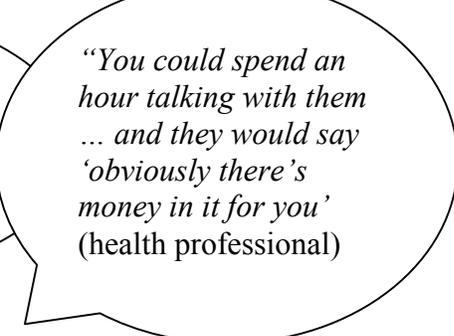
Parents have more mixed views on information from the media but consider that it is a useful source of facts on vaccines.

Health professionals consider that there was insufficient response from authoritative national bodies and the health boards to negative, often inaccurate, information in the media.

The health professionals involved in immunisation services show great commitment to attaining high uptake levels, often at personal cost. ~~Parents do not~~ always appreciate their efforts.

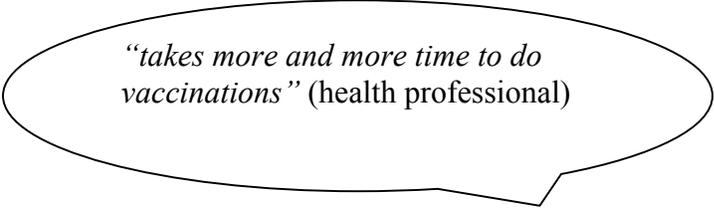


"Some mothers ate the head off me [when practice nurse phoned to follow up delay in immunisation]" (health professional)



"You could spend an hour talking with them ... and they would say 'obviously there's money in it for you'" (health professional)

The immunisation process is taking more and more time to inform and reassure parents about vaccines.

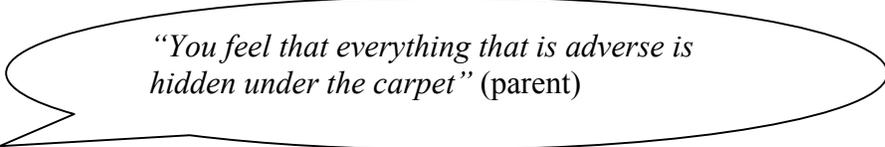


"takes more and more time to do vaccinations" (health professional)

The vaccines, other than MMR, routinely administered to children are generally of less concern to parents.

The health professionals' experience is that parents who do not have their children vaccinated are not a uniform group and come from all socio-economic groups and levels of education.

Parents commented that many health professionals did not take seriously their reports of **adverse events** occurring in their children after vaccination.



“You feel that everything that is adverse is hidden under the carpet” (parent)

Health professionals involved in this study identified several **logistical problems** in the primary childhood immunisation system, which need to be addressed to improve uptake.

Conclusions

On the whole, the levels of knowledge and information of many parents on vaccines is poor and confused. This is not acceptable. Communication of information that is unambiguous and honest is vitally important. Parents are unclear on the concept of population immunisation and the diseases their children are being vaccinated against.

Parents are concerned about the side effects of vaccines. Parents expressed fear and mistrust about vaccines and about those advocating them. This level of fear and mistrust will not be overcome lightly. The decision to have their children vaccinated is as much emotion based as science based; the hesitation and the ultimate decision whether or not to vaccinate is decided by fear of the consequences of this action.

Health professionals feel that they are ill-equipped to properly inform parents about vaccine related issues. They consistently expressed a need for timely and accurate information to help them address parental concerns.

It must be recognised that we are living in an information era and an increasingly questioning era. If media campaigns for example, are to be used, then messages from studies such as this must be taken on board. Otherwise, it has been a waste of time asking parents for their views. We must be ready to respond and to use this same information era to adequately inform parents of the facts in a balanced and clearly transparent manner.

Recommendations

Information – general

- **Information is key** to both parents and health professionals. Information on immunisation and vaccines needs to be produced and disseminated nationally to ensure a consistent message.
- **Information needs to be balanced and complete.** Data on both the risks of disease as well as the risks of vaccinations needs to be provided.
- Attention must be given to the **format and presentation** of information provided to the various groups. Adequate resources must be made available for this.
- **Misinformation needs to be addressed** rapidly by authoritative, scientific and trusted bodies.
- **Regular and timely updates** on vaccine related issues are required for health professionals and parents.
- **Increase access to information** – both parents and health professionals should be well informed about where further, accurate, relevant information may be sourced.

Information – for parents

Different formats are required

- Parents require information to address their issues and concerns. Information will need to be in different formats to suit different needs and different education levels.
- Clear and simple leaflets, addressing the main issues, are essential. These should include information regarding the following: the vaccines themselves and potential side effects; the diseases they are protecting against; the concept of ‘population protection’; risk from vaccine versus risk from disease; the use of single or multiple vaccine preparations and the child’s response to multiple vaccines.
- Information videos on immunisation for use in health facilities used by parents of young children should be considered.
- Information material produced for the public should be tested with the relevant target group before publication.
- **Increased accessibility of information.** Traditional venues for accessing information (doctors and nurses in hospitals, clinics, practices) may need to be augmented and innovative methods for widely disseminating information explored.
- **Detailed complex information for parents.** More detailed information is required for those who wish to research the issue further. Parents now access the Internet for

information on health issues and balanced, evidence based information must be provided on Irish health service sites.

Information – for health professionals

- Health professionals on the front line of immunisation services need to be provided with **detailed, up to date and evidence based information** so that they can assist parents in making their decisions.
- A **rapid cascade system** needs to be put in place to ensure that health professionals receive adequate and timely information in emergency situations or controversies.
- Health professionals not directly involved in immunisation services also require information.
- The priority issue for provision of information is MMR (measles, mumps and rubella) vaccine.

Health professionals and parents –working together

- Health professionals need to acknowledge and address parental fears.
- Methods of improving communication skills and channels among health professionals, health boards and national bodies need to be identified and developed
- Parents' feelings of guilt and pressure need to be allayed by supporting and reassuring them about vaccinations.

Education

- Immunisation is a crucial health issue of our time and this needs to be reflected in undergraduate and continuing medical and nursing education.

Media

- Clear, evidence based information will need to be made available to the media on an ongoing basis to ensure an informed public.

Increasing trust and confidence in vaccination and monitoring systems

- Any changes to the immunisation schedule should be preceded by an information campaign for health professionals and parents, fully explaining the rationale for the proposed change.
- The availability of clear, evidence based information addressing the current immunisation issues for both health professionals and parents will go some way to addressing the mistrust felt by parents of the health services and those who deliver these services.

- Accuracy and efficiency of record keeping is seen by many parents and professionals to be a reflection of the quality of the system. Methods to improve record keeping need to be identified
- Widespread use of parent held child health records should be considered to assist both parents and health professionals in documenting vaccinations received
- The Irish Medicines Board (IMB) Adverse Reactions and Quality Defects Yellow Card System (monitoring adverse events) needs to be strengthened and the information regularly analysed, interpreted and disseminated both to professionals and the general public.
- Consideration should be given to a national no-fault compensation scheme for vaccine adverse reactions.

Vaccination programme issues

- Logistical problems in the delivery of the primary childhood immunisation programme need to be addressed to assist those delivering the service. The issues identified include: vaccine supply and delivery, health board's computer system, accuracy of uptake statistics and payment issues.
- Methods of optimising vaccination delivery in GP practices should be encouraged including reminder systems, follow-up of defaulters, flagging of charts and minimisation of missed opportunities for vaccination.
- Current difficulties encountered by parents and health professionals in obtaining accurate records of vaccinations should be addressed. Efforts should be made to increase efficiency and user-friendliness of vaccination record keeping to authorised individuals. The provision and use of unique individual identification numbers and development of appropriate information systems is essential.

Introduction



Introduction

Protecting our children against disease and ill health is of prime importance to parents and health professionals. Vaccines are widely regarded as being one of the most effective ways to ensure protection against many of the most common childhood illnesses. Diseases that up until the last century caused substantial illness in our population are declining. However, in recent years vaccination rates have fallen – giving rise to fears that these previously common and now preventable diseases will once again affect our children.

This study sought to understand why vaccination rates are falling in Cork and Kerry and to identify how the problem might be addressed.

The report is in five sections

Part one - Have similar studies been done before – how was this study done?

In the **background and methodology** section we present information on similar international studies that have looked at factors influencing vaccination rates and provide some backdrop to the on-going debate about vaccine safety. The different methodologies used in this study (qualitative and quantitative) are described.

Part two – What are the issues surrounding falling vaccination rates?

The **telephone interviews** with **general practitioners** in Cork and Kerry highlight and describe the views of GPs in Cork and Kerry about what they consider to be the major issues influencing vaccination uptake in their communities. This part of the study identified important vaccine related issues that were further explored in focus groups with parents and nurses and in a survey of GPs.

Part three – Trying to understand vaccine issues

For this part of the study we held **focus groups** with **parents and health professionals** from different areas in Cork and Kerry. We listened to their views, knowledge and experiences about vaccines, vaccine-preventable diseases and the vaccination process. These in-depth discussions helped us to understand the factors that influence parents' decisions regarding vaccination.

Part four – How widespread are vaccine concerns?

For the final part of the report, the results of a **postal survey** among **GPs** in Cork and Kerry highlight and confirm the earlier reports of parents and health professionals regarding the extent, nature and similarity of vaccine concerns among parents throughout the region. Information is seen as key to vaccination decision-making and the perceived deficits in information provision are identified.

Part five – Conclusions and Recommendations

This section draws together the findings from the various groups of parents and health professionals, identifies those areas that need to be addressed and makes specific recommendations.

Part 1

Background and Methodology



Background

Vaccines have been widely used in the developed world since the mid 1900s. During that time, incidence of vaccine preventable diseases has declined markedly – to such an extent that it is now common for many parents and doctors to be unfamiliar with the vaccine preventable diseases. At the same time that vaccine preventable disease incidence is decreasing there has been an increase in public anxiety related to vaccine administration. This is leading to an increase again in vaccine preventable disease.

Factors influencing vaccination rates are multiple and complex and include belief and trust in vaccines among the public and medical communities; public and medical perception of the importance of vaccination to protect against disease; efficiency and effectiveness of vaccine delivery systems; access to health care and costs associated with vaccination.

Since the late 1990s there has been much public debate about the supposed link between MMR vaccine (Measles-Mumps-Rubella vaccine) and development of autism and/or inflammatory bowel disease (e.g. Crohn's disease)¹. Although such debate has predominantly fuelled concerns amongst parents it has also generated confusion among health professionals, resulting in the provision of information to parents that is often lacking in clarity and detail.

The impact of this uncertainty among health professionals and parental concern is evidenced by falling vaccination rates for MMR vaccine in both Ireland and the UK. National data relating to MMR vaccination coverage, available from the National Disease Surveillance Centre (NDSC), indicates that MMR uptake among two-year old children is currently 70% (third quarter of 2001)². MMR coverage among the same age group in the SHB region was 74% for the same time period. Low vaccination rates have obvious public health implications for many sections of society, children as well as adults, and outbreaks are likely to occur. In 2000, a measles outbreak in Ireland in which more than 1600 cases of measles and three deaths were reported was directly attributable to low MMR vaccination uptake^{3,4}.

Although during outbreak situations the immediate concern is the care of those affected, the prevention of further cases is also important. Outbreaks related to vaccine preventable disease still occur in the developed world particularly in areas where the memory and fear of the disease no longer exists. In recent years outbreaks have been reported in populations where vaccination levels are low, resulting in substantial morbidity and occasional mortality⁵⁻⁹. Such outbreaks typically involve both abstainers from vaccination as well as those not vaccinated for specific reasons (e.g. children too young for vaccination).

Recent reports suggesting a link between MMR and autism and inflammatory bowel disease proposed by Wakefield *et al* (1998)¹⁰ have been carefully reviewed by national and international expert groups (the Irish Department of Health and Children¹¹, the Medical Research Council¹², the American Medical Association¹³, the Institute of Medicine, USA¹⁴, the World Health Organisation¹⁵, the American Academy of Pediatrics¹⁶, and the Population and Public Health Branch of Health Canada¹⁷) to determine whether such an association has been demonstrated. Although this hypothesis has not been substantiated it continues to be articulated in the press and among the public.

Public concern has been partly fuelled by reports of increasing incidence rates of autism in western countries in recent years. However, retrospective reviews have identified that autism incidence rates had already begun to increase in the UK prior to the introduction of MMR vaccine in 1988^{18, 19}. Whether this increase is real or artefactual (influenced by changes in reporting methods and/or improved identification) is unclear. Other studies in both Sweden²⁰ and Finland^{21, 22} have similarly failed to demonstrate an association between MMR and the subsequent development of autism or inflammatory bowel disease.

Many studies have looked at how parents perceive childhood vaccination and what influences them to decide to vaccinate or not vaccinate their children²³⁻²⁵. Additional studies have looked at other factors influencing vaccination rates such as vaccination systems and physicians' attitudes and practices to childhood vaccinations²⁶⁻³³. One such study undertaken in the UK, similar to the study presented here, specifically looked at parental perception of MMR vaccine. The findings of their study were that parents found the MMR vaccine decision-making process stressful, and many felt pressurised by health professionals to take vaccinations and expressed doubt about vaccine safety despite UK Department of Health reassurances of vaccine safety³⁴.

Other studies among health professionals have identified that personal or perceived parental objections to multiple injections negatively influence vaccination uptake²⁵. However, the reasons for such concerns are often diverse and disparate; concerns may be related to perceptions of immune overload to children, the number of needles at one visit, or difficulty in identifying adverse vaccine reactions when multiple vaccines are administered simultaneously. Infant immune systems have been demonstrated to adequately respond to the majority of thousands of antigens* with which they are confronted in the first year of life (including those found in vaccines) and their health is not compromised during this process. Contrary to popular opinion, the stimulation to children's immune systems as a result of vaccination is far less today than that found in vaccines administered 20 years ago. In the past, childhood vaccines contained far more antigens than today's vaccines³⁵.

Medicolegal concerns about vaccine-associated liability risk have also been found to negatively influence GPs administering vaccines^{32,33}. Inappropriate deferral of vaccination and missed opportunities for vaccination have also been reported in the literature²⁶⁻²⁸.

Lack of accurate, up to date vaccine information, which can generate confusion among health professionals and diminish their support for vaccines has also been identified as a potential negative influence on vaccinations. A recent UK study, specifically looking at health care provider attitudes to MMR vaccine, identified that a substantial minority of health professionals, especially practice nurses, were lacking in knowledge about established side-effects of MMR vaccine, disliked administering multiple injections at one visit and some also considered that there might be a link with autism despite the lack of evidence³⁶.

The role of the World Wide Web (Internet) as an important source of health information for both the medical and lay community is increasing and is anticipated to increase further. However,

* Antigens are proteins or carbohydrates capable of stimulating an immune response.

with a myriad of available information of variable quality it can be difficult for the public to decipher accurate, scientific, evidence-based information. It is important that accurate, easily accessible vaccine related information is made available to parents seeking it so that they can be well informed, thus allowing the decision making process to be facilitated^{37,38}.

It is widely acknowledged that parental knowledge and attitudes, are major influencing factors on vaccination rates. With this in mind the following study provides insight into parents knowledge and attitudes towards vaccinations, vaccine delivery and information needs in the Southern Health Board region in 2001.

Methodology

Aim

The aim of the study was to determine factors influencing vaccination rates in the Southern Health Board region.

Objectives

There were five main objectives of the study:

1. To determine parental attitudes that influence vaccination uptake rates
2. To identify influences on parents' attitudes to vaccinations
3. To ascertain the level of knowledge amongst parents about vaccines and vaccine preventable disease
4. To determine GP practice issues that might impact on vaccination programmes
5. To identify the information needs of health professionals advising on immunisations

The study also sought to explore communication channels that might contribute to increasing parental awareness of vaccine preventable illness, vaccines and vaccine schedules.

Initial semi-structured interviews with GPs

All available GP tutors for the Irish College of General Practitioners (ICGP) and GP trainers were interviewed by telephone using a semi-structured interview schedule seeking information on the main factors perceived to be negatively influencing vaccination rates in their practice. Each interview lasted about twenty minutes.

The objective of these preliminary interviews was to identify themes and issues relating to vaccine uptake for later and more detailed exploration. Themes identified from these interviews informed the development of the GP questionnaire (discussed in the next section) and the questions used in the parent and nurse focus groups.

Postal questionnaire of GPs

GPs were then surveyed using a two-paged postal questionnaire to determine whether, and to what extent, those factors already identified during exploratory interviews were applicable to a representative sample of GPs in the SHB area. For the survey, GPs were systematically sampled using list of all GPs on the childhood vaccination programme kept by the Primary Care Unit, SHB area. The sample represented 50% of GPs providing routine vaccinations in the SHB area. The survey was sent out in July 2001 with a follow-up of non-responders in August 2001.

Focus groups with parents and nurses

Fifteen focus groups were held to gain an understanding of why vaccination uptake rates are so low in the Southern Health Board region. Eight of the focus groups were held with parents from throughout the region: Kerry,

West Cork, North Cork and Cork City. A further seven focus groups were held with service providers: practice nurses, midwives and public health nurses, again from throughout the region.

Parent focus groups were identified through Family Resource Centres or Mother and Toddler groups supported by the SHB in Cork and Kerry, or local branches of national parent organisations (La Lèche League or Cuidiú). Parents from different backgrounds (urban/rural, and different socio-economic groups) were specifically included and efforts were made to recruit from different areas in the SHB region. Local co-coordinators of these groups were contacted by the researchers, the study was explained to them and they were asked to inform and invite parents to participate.

Different nurse groups were recruited for the study based on their known, or perceived, role in providing parents with vaccination advice and/or administering vaccines to children. They included senior public health nurses for immunisation, area public health nurses, midwives/nurses working in all the public maternity hospitals and GP practice nurses.

Midwives for the study were nominated by senior nurse management in the health board maternity hospitals in the region (Erinville/St. Finbarr's and Tralee General Hospital). The representative midwives from each ward/department in regular contact with mothers were included (e.g. antenatal, postnatal, labour wards and out-patients department). Selection was based on scheduling, availability and in some cases, interest in the issue.

One focus group was held with senior public health nurses for immunisation (one for each Community Care Area) and two with area public health nurses. Area public health nurses were selected by the senior public health nurse for immunisation in three Community Care Areas (North and South Lee and West Cork). The selection of Community Care Areas (three out of five in SHB) was based on the desire to include as many areas as realistically possible and to ensure that public health nurses covering both urban and rural areas were included. All public health nurses selected were active either in administering vaccines or in providing advice and were interested in participating in focus groups.

Practice nurses were self-selected. Practice nurse coordinators of the Irish Practice Nurse Association recruited participants in their organisation. Focus groups for practice nurses were held in Cork and Kerry.

No incentives were provided for participation. Focus groups were held in the Family Resource Centres, SHB premises or in hotels and lasted between 1 and 1½ hours.

The fieldwork for the study was conducted between May and July 2001.

Detailed Methodology – GP telephone interview

Potential key informants for this part of the study were identified as GP trainers (Cork/Kerry training Programme) or Continuing Medical Education (CME) tutors of the Irish College of

General Practitioners (ICGP) who were associated with training or ongoing medical education in the Southern Health Board area.

All potential interviewees were initially contacted and informed of the study by letter. A follow-up phone call was used to arrange a telephone interview at a convenient time. Three attempts were made to contact each GP. A semi-structured interview schedule was used. Interviews lasted between 20-30 minutes. The questions sought information on their experience of the vaccination programme in their practices (coverage, national and regional immunisation programme system, practice vaccination systems), expressed parental concern to vaccines, and how they thought these concerns could be addressed; factors influencing vaccination uptake; profile of defaulters in their practice and perceived reasons for defaulting; and sources of vaccine information for parents and GPs. They were asked to identify areas where they felt action was needed to increase vaccination uptake. If selected GPs could not be interviewed after three attempts then no further attempt was made to contact them.

Notes from the interviews were read through repeatedly to identify key themes and issues.

Detailed Methodology – GP postal survey

The objectives of the GP survey were to determine factors considered to be most important by the GPs as influencing vaccination rates in the SHB area. The design and content of the questionnaire was developed following the exploratory telephone interviews with a number of key informant GPs (mentioned above).

A systematic sample of SHB GPs was taken from a list of all GPs in the SHB region contracted to provide routine childhood vaccinations (described earlier). A cover letter explaining the purpose of the survey, questionnaire and a return stamped addressed envelope was sent to each selected GP in July 2001. Non-responders were identified (tracking numbers were used in first mail out) and follow-up was undertaken in August 2001.

The two-paged questionnaire consisted of predominantly closed questions. For the majority of questions a Likert scale of 1 to 5 (strongly agree to strongly disagree) was used. The questionnaire sought information on parental attitudes to vaccines, perceived reasons for vaccination defaulting, adequacy of available vaccine related information, and issues related to vaccination in the practice.

Epi Info 6.04 was used for data entry and analysis.

Detailed Methodology – Focus Groups

Eight focus groups were held with parents (47 mothers), 3 focus groups were held with public health nurses (23 participants), two focus groups were held with midwives (14 participants), and two focus groups were held with practice nurses (12 participants).

Focus groups were attended by the same facilitator and a scribe who noted the comments of the participants (with the exception of one focus group attended by the one person who acted as both

facilitator and scribe). The analysis and write up was conducted by another, independent researcher. The focus group data were analysed in accordance with recognised qualitative research techniques. The notes from the focus groups were transcribed and these were analysed by content³⁹. The transcripts were read through repeatedly to identify emergent key themes and issues, which were then coded. The focus groups with each discipline (parents, practice nurses etc.) were all read through and analysed separately. Care was taken to consider minority opinions as well as the majority viewpoint⁴⁰. This was done in consultation with the group facilitator. Clarification was sought with the facilitator on points in the transcripts where the context was not clearly understood. Emergent themes and main issues were later compared with those identified independently and separately by the group facilitator.

Part 2

Exploratory Telephone Interviews with General Practitioners



Exploratory Interviews with General Practitioners – Results

Exploratory telephone interviews were undertaken with 19 GPs; 14 of 24 GP trainers, three of five CME tutors (an additional CME tutor was also one of the GP trainers interviewed). Additionally, two GPs who had recently completed training were interviewed.

Attitudes, practices and experiences of vaccinations

GPs interviewed were all in favour of routine childhood vaccination, although one GP expressed concern that some GPs appeared to be ambivalent about vaccination. A number of GPs referred to the lack of co-ordination between the different groups providing health care to mothers and their children

“not team players...no one is giving information at antenatal checks...if we could organise who does what...sometimes I think the health boards and GPs are in competition...I sometimes get a letter stating that this patient has been vaccinated by the health board...”

The topic of administering multiple injections at one visit was raised and met with mixed reactions - some GPs suggested that more combined vaccines would be better while another reported that he felt single vaccine antigens should be available to those who were averse to the combination vaccines. Different vaccine administration approaches were adopted by GPs – some would stagger the shots if requested by parents whereas others would suggest splitting them to the parents.

“usually we give all shots together...sometimes give separately after the Men C vaccine started... a flexible approach... if after talking to them [parents] and if they are unsure about shots altogether I offer to stagger them [vaccinations]”

“most don't like all injections together... [but] 99% take all vaccines together...if premature baby they might prefer to take separately”

“I hate giving the babies the three injections...it is tough on the mothers and the doctors...it is difficult to find three places on babies...”

“there's a problem with all vaccinations together...there is objection...parents don't want three needles at one time...we need vaccines as 'four in one' or 'five in one'...if they [parents] are motivated enough they don't split them up”

Estimated vaccination rates reported by those interviewed varied – with coverage rates as low as 80% to “nearly 100%” reported. Most GPs appeared to be dependent on the reports from the immunisation programme for these estimates although some reported having this data on their own immunisation computer databases. There was a broad consensus that recorded immunisation uptake rates by the health board were underestimated. Estimated MMR vaccination coverage was substantially lower in most practices (10-20% lower in many instances) than that for other routine childhood vaccinations.

“MMR uptake...uptake not great”.

Reasons for the lower rate of uptake for MMR were attributed to a parental perception that MMR had more side-effects and that measles was a lesser threat to child health than some of the other vaccine preventable diseases such as meningitis or polio.

“when look at possibility of autism and Crohn's...don't see measles in same light as meningitis...don't see it as a threat, they see polio and pertussis more [as a threat] whereas with measles... [they] know [that there is] only a 99% chance of not dying”

Most of them agreed that uptake had been affected following negative publicity to vaccinations such as the polio vaccine scare (vCJD donor and out of date vaccines) and particularly to controversy surrounding MMR vaccine.

"[MMR uptake] ...different kettle of fish...they ask straight out about MMR"

A number of GPs expressed dissatisfaction and frustration with the national programme in terms of administrative difficulties relating to the programme. Frustration was expressed regarding the amount of paperwork and delays in payment for vaccines administered.

"form filling needs to be easier...all these forms are a real pain...so tedious...when they switched to the new vaccines we still had the old forms and had to fill in different ones for different vaccines...it takes so much time"

"vaccine system is creating more hassle than it is worth...also financial issues"

"the amount of paperwork...why should we have to fill out the form... filling out our returns...then not paid until three visits [completed] and then wait 7-8 months for payment and if one thing wrong it is sent back..."

Logistical issues relating to vaccine delivery were also a source of frustration to GPs and compared with faster delivery provided by some of the pharmaceutical companies.

"have other things to do than queuing up to collect vaccines.... it is not a minor convenience to pick-up...X [name of pharmaceutical company] can deliver within 24 hours of calling them..."

"the health board ran out of polio vaccines..."[and GP had to cancel appointments]

Perceived parental attitudes to vaccines

The majority of GPs felt that parents were supportive of vaccines, regarded them as routine, and a minority (less than 10%) were reported to have serious concerns, although this varied by practice. Although some parental concern was common they were usually able to deal with them effectively.

"they don't really seem concerned.... sometimes both parents will come in, especially for the first vaccinations...most parents have their children vaccinated...some are lax...it might not be a high priority..."

Some GPs reported that there was a general apathy and ambivalence to vaccination.

"parents are quite apathetic...there is a lack of motivation- people leave it too late"

There had been an increase in the number and type of questions and concerns relating to vaccines, with some parents being less accepting of messages from the health boards and Department of Health and Children (DOH&C).

"there's a mistrust of national bodies...a perception is that health boards are less than honest with parents"

"the whole polio scare...the vCJD concerns...it undermines trust..."

"they don't rely on the information from the official sources...some would suspect plots...they suspect the expertise of the health board"

Regarding specific vaccines of concern, the MMR was mentioned by all GPs with a few reporting concerns with Diphtheria-Tetanus-Pertussis vaccine (DTP). Among some parents vaccine fears were often deeply entrenched.

“one family- no matter how much information you give them, won’t believe it...”
“often it’s an emotional problem...you can’t counteract with logic...”

There was no easily identifiable “type” of parent who was likely to default. However some GPs had within their own practices identified certain characteristics of those parents who had defaulted, but there was no consensus among them that parents who did not bring their children for vaccination were likely to have certain levels of education or belong to a specific socio-economic group. Many identified parents that were particularly busy, either at work or with other activities, forgetful or disorganised, and some GPs reported that some of the ‘alternative lifestyle’ parents were more likely to default. The variation and lack of consensus in profile of defaulters is demonstrated by the comments -

“they refuse out of fear...”
“middle class- semi-well educated...get a lot of information on the internet...”
homeopathic...well educated, well researched...”
“most who default are just careless...”
“[it’s the]... suggestible, inclined to listen to everyone [parents]...”
“they forget...need reminders”
“...so busy they never get around to it...”

All of the GPs identified media as playing a large role in generating parental anxiety about vaccines. The consensus of the group was that most of the coverage was scare mongering, non-factual and sensational.

“biggest problem is adverse publicity in press...the X [name of newspaper] is the greatest [at fault]”
“balance is currently ...against vaccines...”

Recent adverse vaccination publicity relating to other vaccines was also perceived to have affected uptake.

“parents were very concerned after the polio scare...some definite refuses”

Concern was expressed that newspapers often had reports with misleading sensational headlines and factual information in the smaller print that was often not read by parents-

“they don’t really go beyond the headlines and certainly don’t read it [the rest of the article]”

The majority of expressed vaccination concerns from parents were related to MMR. There was widespread public perception that MMR vaccine might cause long-term side effects such as Crohn’s disease and autism. This concern had negatively impacted on MMR uptake. The decline in MMR coverage was attributed to concerns generated predominantly by negative media. The possibility of defaulting being associated with the time lag was also mentioned by one GP.

“MMR vaccine is harder to sell because of concerns about autism and Crohn’s [disease]”
“MMR particularly... all are aware of the big question mark...”
“[regarding] fear of side-effects... most people mention autism and inflammatory bowel disease [and cite local newspapers]”

As a result of increased concerns many GPs referred to the need to talk parents through vaccination, and allay their fears.

“some generally will feel uneasy (about vaccinations)... many people will discuss with GPs...”

“takes more and more time to do vaccinations”

Many GPs reported that authorities on vaccinations (national or health boards) were slow in notifying them about vaccine scares and expressed frustration with the lack of timely information provided by the national bodies or health board about vaccine related issues. The need for a standard and accurate response from all parties was stressed.

*“biggest thing is communication problem...there’s no support...GPs are left in the lurch...”
“...like left naked...back-up has to be there...”[GP referring to how they were not prepared to answer parents questions and had not been warned about the problems with the polio vaccine]*

A number of GPs referred to the positive impact on vaccine uptake caused by media coverage of deaths and serious morbidity associated with meningococcal meningitis (both national news and fictitious television dramas e.g. ER)

*“ a 20 minute programme talking with a 14 year old girl who had meningitis...[it was] good news...it showed side-effects of illness and helped increase uptake”
“single greatest uptake was after Gay Byrne [show] had a mentally handicapped child on” [who had been damaged by a vaccine preventable disease]
“ on ER they showed a child with meningitis who died.... got across message that kids do die”*

TV advertisements were considered to have huge impact, especially those about influenza and meningitis -

“huge improvement in coverage”

During the measles outbreak of 2000 one GP reported that parents were flocking to have their children vaccinated with MMR. Reports of vaccine preventable disease occurring in the community instilled fear in parents, which made them seek vaccination.

*“during the outbreak parents were running scared...”
“parents vaccinate out of fear”
“if there is a local case of meningitis it brings them in droves...”
“sometimes disease (occurrence) makes them change their mind [referring to anti-vaccine parents]”
“I spend a lot of time and effort in discussions... occasionally they change their mind-it takes something dramatic to happen...[e.g. outbreaks]”*

Many GPs reported on the positive impact of a practice nurse on vaccination administration, information for parents and vaccine uptake rates– the nurse was often considered to have more time to communicate with parents and to follow-up on defaulters.

*“practice nurse speaks to them first when she is taking the temperature and talks about vaccination... then I come in ...I don’t really tell them that much about vaccines...the nurse does it all...she goes through the diseases...”
“practice nurse follows-up on defaulters”
“our practice nurse does most of the vaccines...she has time to talk.... parents often raise issues with her” [that they do not raise with GP]
“after we got our nurse it became more structured...it is more relaxed coming into nurses- it takes a lot of time taking off clothes...it’s the ideal thing for practice nurses...”*

“have had a practice nurse for one and a half years and have noticed an increase in uptake...she has time to listen...does a more thorough check-up and instills confidence...”

Recommendations to increase uptake relating to media

GPs considered that information needed to be available to respond to negative, often inaccurate, information in the media. They considered that there was insufficient rebuttal from authoritative figures and bodies.

“Need to confront media”

“Need more public awareness and advertising...many issues in newspapers are not challenged...”

“There should be some reply to major stories when they occur...some way of dealing with them...”

“high profile in press is important...to keep hearing about the importance of vaccines...”

“it is at the public relations level.... layers and layers of education are needed, followed up by direct approaches...”

“leaflets with risk of vaccines versus disease are very helpful... to give to young parents ...just statistical stuff...it’s helpful for public and doctors...people need to put figures into perspective”

“need to have ICGP, Department of Health put scientific view across...people tend to go to Internet...we need to sell ourselves”

On their part they often felt ill prepared to deal with the questions coming from parents regarding the newest controversy.

“it makes doctor look silly if he doesn’t have the immediate information to respond to questions from parents...need good rebuttals to have to counteract negative messages...”

“we GPs do not get regular updates on information on new topics...do not get structured information, get information haphazardly, do not get feedback system”

The follow-up of defaulters was identified by nearly all of the GPs interviewed as being important. How this was done differed by practice and often entailed telephone calls, letters or making a note in the chart.

The GPs interviewed reported high vaccination rates for most vaccines except MMR. Some of this success was attributed to both a good relationship and communication between parent and doctor as well as follow-up of defaulters- others pointed out the importance of vaccinating opportunistically. Identification of defaulters was done either by staff (manually looking through records or by using the computer). Many commented on the improvements since a practice nurse was employed or the practice was computerised. The role of the public health nurse in supporting GPs in this activity was also referred to by a number of GPs.

“our one to one relationship...can easily follow-up defaulters”

“keep reminding people...keep referring back to the records...”

“send out letters and ask them to call up for an appointment...otherwise will have defaulters...if they turn up at another time [not vaccination time]...we’ll vaccinate”

A number also referred to giving parents more responsibility for keeping appointments such as with handheld vaccination cards

“parents should have responsibility...give responsibility back to parents...most parents love it (vaccine cards)”

The need for user-friendly information and resource materials was highlighted by the GPs. Some of them already have materials for the parents to study in their practice clinics. One of them reported that he had a folder with all the information, press cuttings, and articles so that parents could read them in the waiting room. Many also mentioned the need for regular updating, which could take a number of formats – newsletters, sessions etc. It was evident that the recent changes had also caused some confusion among GPs.

“need more forums and multiple small group sessions to discuss and learn about vaccines...”

“need an immunisation file for ‘iffy parents’ [unsure about vaccinations]...they can look at it themselves and read it and then decide”

“vaccinations are very difficult...should have a folder with just vaccination data in each GP surgery from different sources...[I] know it makes it sound like we need to be spoon-fed...”[but he suggested that GPs do]

“There’s a lot of confusion...changing MMR to 12 months...not sure if it is back to 15 months now...changing protocols needs rationale (explained)...” [this GP expressed uncertainty for rationale for DTP boosters]

There was a general consensus that parents needed information about the role of vaccinations from early on. A number of them suggested that discussions about vaccinations should begin routinely during the antenatal period as most first time mothers will attend antenatal care. Many also expressed a belief that if the first child was vaccinated this set the tone for the rest of the children.

“no one is giving information at antenatal checks” [referring to maternity hospitals]

“the first child is very important for setting the tone for mother...identify the mothers at antenatal clinics...at that time they are most interested in the health of the baby...”

“my gut reaction is that most 1st time mothers go to antenatal classes- they are a willing and co-operative target [for information]”

“if have rapport antenatally there would be better uptake...”[mothers don’t usually meet the public health nurses until after the baby is born]

“[in our practice we have] active education antenatally and postnatally and if parents have questions then their chart is flagged...[so that questions can be dealt with at each visit and special attention given to these parents]...there’s a lack of concise information...why not have vaccine information pack to give to parents before the baby is born?”

Nearly all felt that talking about vaccines when a child comes in for its first vaccines was too late.

“Even if the mother brings the child in for vaccination...they are so tense...it is not the time to give information (this GP reported that they provide vaccination information on date prior to vaccination day)...so that all the questions are dealt with...parents can’t absorb all the information on one day....”

One GP suggested that discussion on vaccinations should just be one part of the overall life skills training for young mothers.

“...we want to talk about lifestyle...include this topic with another”

Some GPs have come across a resistance and mistrust from parents relating to vaccination and the need to repeatedly defend and justify vaccination is wearing for many GPs. One GP reported that some parents see a conspiracy among doctors to make money.

“you could spend have an hour with them [talking and then still not get the vaccine] ...and they would say ‘obviously there’s money in it for you’ ...some want confirmation of what they suspect”

Some GPs considered that when discussions and information was not successful there was often no point in pursuing it. Such non-productive discussions were “wearing” and the discussions often difficult. Fear of potential litigation makes some GPs hesitant to pursue vaccination with some parents.

“it's easier not to battle...and fear of litigation...many GPs are genuinely afraid ...ultimately the choice is theirs [parents].”

There was general consensus that parents should have ultimate responsibility for vaccination – but that GPs need to be able to provide up to date information that parents need.

“what we [GPs] need is information pack ...would make it easier to sell...need factual information, we are here to guide them [parents]”

“ultimately the choice is theirs...I say to them...look you make the choice...in most cases you can appropriately reassure them, telling them the side-effects and the benefits”

“I have pushed the responsibility on to parents...they want to push it back to the GP...” [one GP who has met a lot of resistance from some parents and been accused that he is only doing it for the money] ...it wears me down...”

Discussion

This part of the study identified frustrations on the side of the GPs with regard to both logistical and administrative issues of the vaccination programme. Feedback on immunisation rates was considered to be often inaccurate which added to frustration.

Overall routine childhood vaccination coverage was reported to be more than 90% in most practices with the exception of MMR, which was highlighted as being substantially lower. The lower levels of MMR coverage reported by GPs had already been identified by the SHB childhood immunisation computer system. Negative media coverage was perceived to be a major detrimental factor in immunisation rates by these GPs.

It was reassuring that each GP reported a minority group of parents with serious concerns about vaccinations. However, if it is only minorities who have serious concerns why are our official uptake rates generally so low? It could be that this group of GPs interviewed has a higher than average vaccination coverage than other practices. This finding may be a reflection of their role as trainers, a group that might be expected to be more informed, organised, proactive than many of their peers. It is also possible that vaccination rates are over-estimated - previous studies have demonstrated over-estimates of vaccination rates when self-reported.

The perception expressed by GPs that parents' confidence had been shaken in the system has been voiced in other studies³⁴. Much of this loss in confidence was attributed to recent national vaccine headlines (out of date polio vaccine, vCJD donor) and negative media surrounding MMR vaccination and the alleged association with autism and Crohn's disease.

The role of information as a tool to defend and promote vaccination was a recurring theme among GPs. They reported that they were often unprepared to deal with media allegations about vaccine safety issues because they did not have ready access to scientific reports and evidence that could be used to allay parental fears immediately following media releases. When prepared

and informed however, most GPs reported that the communication of factual information was sufficient for parents to decide in favour of vaccination.

This need for accurate, timely information was highlighted by all GPs - both for themselves and for parents. GPs need to be kept abreast of all-new vaccine related information and controversies so that they can appropriately answer parents' questions. Resource materials, which could be used by parents, with additional detail for GPs to support them in their discussions, should be developed. New technology methods such as email distribution networks could be developed to provide a rapid source of information to GPs and parent networks. Use of accredited Internet sites for vaccine information should be encouraged. Methods of improving communications from authoritative bodies to GPs need to be explored as information from such channels has been shown to have particular impact on increasing adherence to vaccine recommendations³¹.

The area of information for parents was also addressed in depth. GPs were aware of parents concerns and suggested that early education on vaccination was needed. Parents concerns need to be identified and appropriately addressed before vaccinations are due if vaccination rates are to increase. Other studies have reported on the effectiveness of such measures to increase rates⁴¹. The timing of providing such information is crucial. Many of the GPs felt that such information could be provided during antenatal and post-natal periods, a period when parents are especially open to information relating to their child's health.

Some suggestions for informing GPs included regular newsletters, alerts, organising their information in folders so that everything was easily available. In one area of the Southern Health Board there was reference to the potential for videos to be used in practices (where such facilities were available).

Strengthening vaccination systems was also identified as having a major role in achieving high vaccination uptake. Flagging charts or medical records of children due vaccines, sending out vaccination reminders and actively following-up defaulters have all been acknowledged as playing an important part in successful vaccination programmes^{42, 43}

The importance of a united and uniform approach to vaccination was evident. Some GPs referred to a sense of competition and at times adversarial relationships between GPs and health board or national bodies. As one person mentioned "*we need to sing from the same hymn sheet*". The provision of consistent information to GPs from a number of authoritative professional bodies has been widely shown to assist in improving vaccination coverage⁴⁴.

It was evident that GPs have different levels of knowledge about vaccines, some being very up to date and others less so. Some GPs also expressed doubt about some of the vaccine schedules and one GP expressed concern that some GPs known to him were quite ambivalent about vaccination. Such ambivalence has been shown to decrease vaccination uptake³¹.

Different approaches to administration of vaccination were also evident. Some GPs indicated that they would never vaccinate if the child had any sort of viral illness although evidence has shown that that is not an absolute contra-indication for vaccination. Another indicated that too often mild temperatures were used as a reason not to bring a child for vaccination.

In summary, amongst GPs, the most frequently cited reasons for decreased vaccination coverage related to parental concerns generated by conflicting messages concerning vaccine safety and lack of information with which to counteract such beliefs. This study's findings are similar to findings of other similar studies internationally.

Part 3

Focus Groups – Parents, Practice Nurses, Midwives and Public Health Nurses



Parents

The issues and themes, which emanate from this study, clearly illustrate the perspectives and roles of the parents and the service providers. The service providers play a role in influencing parents' decisions whether or not to vaccinate their children but they are also influenced by medical issues concerning the vaccines as well as by the dictates of society as a whole.

Eight focus groups with parents were conducted. Parents' attitudes towards vaccinations and factors influencing their decision to vaccinate centre largely around four main themes emanating from the research: (i) uncertainty about giving the vaccine, what it is made of and what it might do, (ii) lack of full knowledge and information about the vaccine and its side effects and benefits, (iii) logistical experiences of having their children vaccinated, (iv) feeling under pressure to vaccinate.

Uncertainty about giving the vaccine

The theme of uncertainty about vaccination was prominent in the study. Most of the uncertainty related to parental fears about the effects the vaccine may have on their children.

[the meningitis vaccine] "has only been around for a short period of time, not sure of side-effects"
"I am very concerned about MMR...my girl had it and had a serious side-effect after it...10 days after it she started going blue...they put it down to rotavirus...but I worry about giving it to my other boy [due his booster]"

One parent expressed 'terrible fear about giving the MMR'.

"I had terrible fear about giving the MMR...the doctor said there's no scientific proof...but people are still saying it..."

With similar frequency, parents expressed concern that administering the vaccines mean that a lot of chemicals are being injected into bodies that are very small to have the ability to cope.

"don't like idea of giving many vaccines...amount of chemicals going into little bodies, couldn't cope"
"too much when too young"
"I am more aware of the issues surrounding the vaccines [now]...babies are being bombarded with these vaccines"

Parents repeatedly suggested that it might be better if the vaccines that are currently given in a combined dose were to be administered separately.

"as long as any question of doubt at all why just plough ahead with MMR, why not separate out the vaccines?...if there's doubt out there..."
"separately the vaccines are OK...but the interaction when they are all given..."
"too many vaccines are together...it would help vaccination if they were broken up"
"I feel happier getting my child vaccinated...the MMR would be the big one that I worry about...but if people could split it...maybe give the mumps to boys who might get infertile and rubella for girls...but you don't have a choice...the whole idea is to protect them..."

On a related point a few parents expressed the opinion that the vaccine should be administered with greater regard for the individual, they felt that policy was a population policy and that parents and their children were not seen as having individual concerns.

"we want you to treat us with as much care as if we were your family..."

“the impression you get from the health board...willing to have one autistic child rather than an outbreak...but when it is your child...”

They also expressed concern that vaccines are administered when children are very young and in one case a parent commented that the lack of consistency regarding when to vaccinate is worrying.

“I would have some concerns about getting vaccinated so young...”

“...I waited until they were 1½ years...I wanted a break between them [vaccines]”

“the lack of consistency is worrying...the only explanation [for the early vaccination schedule] was that you’re in the loop...”

Parents in two groups were concerned that giving the vaccines to the children might lead to more aggressive forms of the diseases.

“pumped with medicines and resistance now developed”

“a little bit concerned about antibiotics...they are stronger...bacteria are stronger...if a lot of children are vaccinated are these illnesses going to become stronger?”

Knowledge and information

In the focus groups the main sources of information were cited as: the GP, media, other people, public health nurses, leaflets given out by the hospital at the time of birth and baby books and magazines. However, parents felt that they do not always know where to look.

*“I get my information from my GP, the library or other mothers”**

*“we need to be able to access more specific information...but you wouldn’t know where to look...”**

Several major issues were raised under the emergent theme of knowledge and information about the vaccinations recommended. In essence, the most dominant issue was the need for more complete information. Parents want more factual information to be made available and information that will allow them to hear both sides of the story.

“I don’t feel that I made an informed choice...”

“What we need is risks of not vaccinating versus risks of vaccinating...”

“...need to know the risks ...they tell you it’s better to give than not...but they don’t tell you why...”

“you have to know both sides of the story...”

“...say factually, for instance - ‘measles can be a benign disease, but some may have severe side-effects’...more factually...”

This need for information has a very medical dimension. Parents are concerned about the possible long-term side effects of giving the vaccines to their children. In particular, the reported link with autism was cited. Many parents are very worried about this perceived risk.

“you hear about autism...you’re praying before you go in and when you come out”

“quite iffy about MMR, doubtful about it really...afraid of autistic reaction...so much bad publicity recently...”

A recurrent issue throughout the research was the point that the health services themselves do not know the full long term effects of receiving the vaccines. Parents repeatedly made the point that

* This mark denotes that the comments were made in the same focus group; with reference to the topic immediately preceding the quotation(s) in normal font.

the health services do not know the possible repercussions of the vaccines ten years from now and cited previous cases and mistakes from the past.

“health board don’t have full knowledge of what is going to happen 10 years down the road”

“but in 10 years what will they be saying about what we are giving now?”

“don’t really know when the side-effects might come to the surface”

One issue of concern to arise in the research process was that the parents mistrust the health services, are suspicious of their intent and express considerable misgivings. They have cited several reasons to support their mistrust. These reasons range broadly from vaccine batches being out of date, to changes in policies regarding when they should be administered with each child in the family, different levels of information available, not feeling they are being given the full facts, no discussion or choice, perception of it being pushed on them, as well as past history such as the thalidomide cases in the 1970s. Some parents directed their concern at particular groups or sectors but others expressed suspicion over the entire service.

“I just don’t trust the health board, the office of health gain...your thing is the population...that’s your job...you don’t see us as flesh and blood”

“vaccines out of date...no explanation for that...why should they take the risk with something out of date. It’s such bad press from the health board’s point of view. It has to effect how people feel...the fact that this is such sloppiness?” This point was continued by another participant *“if all these things coming out...it makes you wonder what is not coming out?...How long would they have waited to tell you?”*

One mother reported that she told the GP she would have her child vaccinated at the same time that the GP was vaccinating his own children...with the same batch... *“we [herself and her husband] made the decision that we were going to take the risk to vaccinate”*

“I have huge distrust of pharmaceutical industry, I do often feel that there is money behind it”

“I made the decision...there is a lot of talk, the more people are pressurised...[it makes her wonder] why are you pushing it so much?”

In addition the parents felt that adverse effects that they notice should be notified and centrally collated. They feel that the health system is not listening to them and that their concerns are not being taken seriously.

*“you feel that everything that is adverse is hidden under the carpet”**

“side-effects should be recorded...GPs need to be encouraged to listen and need to be on the side of the parents and not of the health board”

*“adverse events information should be available to people who want to know [referring to a kind of database kept on all adverse events]...small reactions are not considered”**

Parents are confused over the information they are receiving and observe that standards and guidelines vary not only from country to country but between counties in Ireland.

“You get different instructions about the vaccinations in different places...BCG isn’t given in Cork...why is that?”

“if there is something banned in the United States why isn’t it banned here? Other countries are giving us the information but why aren’t we doing anything about it?”

Some parents felt the Irish system did not compare favourably with systems they had experience of in Germany and the UK. They observed that health professionals in those countries had more specialised roles. In addition, the fact that GPs administering the vaccines did not question the child’s or the parent’s medical histories in any detail was expressed as a concern in a number of cases. Parents perceived this negatively.

*"[mother] trusted him much more because he only did children and he knew so much about it"
"I would have liked to have been quizzed in and out [about family medical history and adverse events to vaccines]"*

Throughout the study parents related incidences or experiences they had or were aware of that influenced their decision whether or not to have their child vaccinated. In these cases, the decisions made were quite arbitrary and had little bearing on actual information or knowledge they may have had.

*"...it was only when I talked with a nurse who had seen meningitis and told me about the side-effects after the illness that I felt really scared [and got the children vaccinated]"
"When I heard about the meningitis outbreak in (name of town) I was terrified...I went and got the children vaccinated...everyone is terrified of meningitis...it happens so quickly"*

Information was a hugely dominant issue to emerge from the research, particularly the quality of information available. Different groups identified the desire that the information given should be more personally or individually targeted and that there should be someone that parents could speak to about it and their concerns. Parents are not happy that the personnel they have contact with are adequately equipped or informed to provide them with the information they need.

"Need more personal information...the health nurse does not really have the information...isn't really helpful...if your child is healthy you want more information where you could personally talk about it..." However another mother continued the conversation by adding, *"I don't know if it would work [having the public health nurses giving more information]...usually they tell you things, they don't listen to you telling them things"*

*"you need someone you can talk to about it [about what is in the leaflets...a big issue seemed to be able to understand the information]...the pharmacists, GP, people dealing with children..."
"when I asked the doctor about the statistics on adverse reactions the doctor was not able to give it..."*

One mother commented that the information she received, although excellent, came from a totally unexpected and 'haphazard' source.

"Pure haphazard word of mouth...my physio gave me a lot of information and it was relevant at the time [she had physiotherapy for a sore neck after the baby was born and saw the physiotherapist who spoke about vaccines...gave her very useful information]"

Parents also commented that they feel that their concerns were not being listened to or taken seriously.

"I had made an informed decision [not to vaccinate] but it was not respected...no one ever rang me about the vaccines I accepted to ask me was I sure.... prior to that I was pro-vaccine...I would have weighed up the pros and cons and made the decision...it made me determined not to have my child vaccinated..."

Although some parents feel that they are being given too much information, or do not want any more, others feel that they are not given enough, that they have to find out too much for themselves. They relate this in particular to information on the diseases their children are being vaccinated against.

*"I don't think I want more information..."
"you have to go and find out [about the vaccine and the illness] they don't give you the information"
"If you know more about the diseases...you don't see them anymore...but I read about them...but I had to find the information myself...it should be more obvious...available"*

Parents in one focus group mentioned that the timing of the information is more relevant if given at certain times.

“Need a leaflet of information on the vaccines when you get the letter from the SHB about bringing your child for vaccinations...it is more relevant then...”

One parent commented that she was quickly told about the vaccines and given a form to sign which she did not have time to read.

“don’t get a chance to read it”

Logistical experience

There are three broad issues, which arose consistently: the actual experience of acquiring alternative vaccines, the administration of vaccines and the relationship of the parent with the GP.

Acquiring alternative vaccines

Parents expressed difficulty and dissatisfaction with trying to get alternative vaccines for their children whom, they believe, have allergies to some of the ingredients in the regular vaccine. This included cost and lack of co-operation with the health service.

“I’ve got conflicting information about meningitis and vaccine...asking about egg in vaccine and some people tell me that it is there and others that it is not...I have to know every single thing about the vaccine [before she could give it to her child with allergies]...sometimes I get very conflicting information...I go by my allergist...my GP is very supportive and understands...he would not give her any vaccines in the surgery...I would have to go to the hospital...to the paediatrician in the (name of hospital) and I can’t afford it...”

“I would be very pro-vaccine but I have two problems...my child has an egg allergy...I tried to get the egg free MMR...they wanted to bring me into hospital and give it there just in case there was an allergic reaction...it was so difficult to get the egg free vaccine...I got it eventually...I felt I was being fobbed off...I wasn’t getting the information...the health nurse should be more aware of it”

Administration of the vaccines

Some parents expressed dissatisfaction with the way the vaccines were administered, citing long waiting times in particular. Dissatisfaction was more often expressed with the clinics but did also include GP surgeries in some cases. Waiting causes problems for parents and children.

“I hate it with the doctors...the waiting 2-3 hours in the GP’s...it’s much better with the nurse...you just go in...”

“having all babies here once a month is not the way to do it...all the children are there and there is a long wait and children and mothers get upset...and the older children get upset seeing the other children come out crying...”

Parents were equally split in their comments about getting their children vaccinated at the health centres. Some felt that it was very good while others felt the experience was bad.

“my son got his 3 in 1 in the health centre...[she thought it was better].... none of this big push...[the nurses had more time and seemed to see the child as an individual rather than not]”

“too many babies lined up...it stresses them [the doctors]...and all the babies crying...it upsets them [the older children for the MMR]”

In general, parents who had vaccination cards recording the vaccines their child had received were very pleased with them. The system, however, is not uniform throughout the region and in some cases it is the parents themselves who complete the cards.

"vaccination books help...you can remember what he's got...and look it up...it's like a wee passport...I just gave it to my GP"

"really good, brilliant...I had a record of everything...I knew what vaccines were given...and then when I came to my new GP I gave it to him to fill in after the vaccinations".

One parent commented that she felt that the vaccines should be given in areas where there are already cases of the disease first, that parents should be made aware that there were cases in the area. She feels that the vaccination programme should be more localised.

Relationship with GP

Parents expressed satisfaction with the vaccination experience when their GPs took the time to listen to their concerns and advised them on expected reactions, or checked back with the parent that the child was alright. In these cases the experience of having their child vaccinated was positive. It was also felt, however, that not all parents would have had this experience, that it very much depends on the GP.

"with my GP, I asked her all the questions...he [son] got a very strong reaction, she said 'we'll wait a month longer' and she staggered the doses [vaccines]...I wonder how much is related to the GPs [manner and way of dealing with vaccines]...maybe the GPs aren't informed as well...the way she talked me through it and we vaccinated in the morning and then I came back in the afternoon and he was checked...it was very good"

"my GP told me that if the leg became more swollen than my forearm then I should call him...but if not then it was a normal amount...then when my baby had swelling I was able to tell my husband that it was within normal...he wanted me to phone the GP...but I knew what to expect because my GP told me...if he hadn't told me I would have been calling him...it's just having the information, what to expect" In this conversation another mother commented

"if everybody got the same advice it would be much better....it all depends on the doctor"

"My GP says... 'no need to worry' [very off hand]... 'the statistics are there'..."[saying that it is proven how important and safe the vaccines are]

Parents felt that the public health nurses do not give them as much help or information as they would have liked.

"but the public health nurses only tell you if you ask them...the information is there but only if you ask..."

Pressure and guilt

Parents feel under considerable pressure to have their children vaccinated for a variety of reasons. They feel that it is what they expect of themselves, that it is what society expects of them and what the health services expect. The bearing on this issue is almost wholly societal.

Self-expectation

Parents feel that they should get their children vaccinated, that they would blame themselves if anything awful were to happen to them because they had not done so. It gives the parents peace of mind. This arose in every group except one.

"Feel you're doing the right thing"

"I was all for it at first and then heard about the side-effects...I was very worried then...but my father said better safer than sorry..."[and she had it done]

" you feel guilty...he gets it [the illness] and ends up in hospital...it's your fault..."

Societal-expectation

In addition, parents are under pressure from the larger society. This issue arose in most of the focus groups. They feel disapproval from other parents if they choose not to have their child vaccinated, that their children are being protected because every other child has received the vaccines. Pressure is overt where parents are asked to explain why they made the decision not to have their child vaccinated and when they are advised that they may not be offered a place in pre-schools without being vaccinated.

“[one mother said that if she did not vaccinate her child she would not tell others about it]...fear of disapproval because it is the norm to vaccinate and that my child was being protected because of all the other children being protected”

“that you could cause other children to get ill if your child spread it to them”

*“it was probably ticking boxes...I had to sign that she wasn't getting it...[school vaccinations] within the hour I was called...I couldn't believe it...it was an accusing 'why?'”**

*“you may be refused a place in preschool [if child not vaccinated]...my child can't be vaccinated”**

In some cases parents felt that they were put under extreme pressure to have their child vaccinated and frightened into agreeing to it.

“the hospital say they have to inform the disease control in the Southern Health Board, when his tests came back, they came back negative...they told us he could have died in the next 24 hours” [mother disliked the way they frightened her so much about the presumed diagnosis of meningococcal meningitis...]

“vested interests are telling us it's totally safe...and the people who are anti-vaccine quite often are portrayed as cranks, extremists... I was very disturbed when I had vaccinated all my children except for meningitis...[and was contacted by the school vaccinating doctor] 'did we know what we were doing...were we quite happy with our decision?'...it was very intimidating, two phone calls and two letters... 'it won't cost you anything'...”

Some parents expressed dissatisfaction with their GP. They felt that the GP put them under unnecessary pressure and felt intimidated.

“but I changed my GP over vaccinations...[she related how she called up her GP one weekend when he was not on call to ask for medical advice about her child]...his voice was cold, and he asked me about her vaccinations...I was devastated...If my children or myself got sick we didn't have a GP... 'you know if you don't get your child vaccinated we'll have to report you to the health board as a defaulter'...it was very intimidating”

Some parents commented, that they are not really given a choice. In some cases they are made to feel that there is not a decision to be made, that their children must be protected.

“there's a choice but at the same time you're told this is the time...it's not actually your own choice...”

“not information, it was instructions...you get a list of instructions”

One parent commented that she admired the way another mother opted not to have her child vaccinated, she admired her ability to make that decision.

“I really admire you not getting your child vaccinated at 8 weeks...before they even congratulated me about my baby they talked about vaccination. My GP believes he is doing the best for me...I got the whole shebang”

It is ironic that it is exactly because of the pressure being exerted on parents that some are choosing not to have their children vaccinated.

“so we carried on then...and I dug in my heels [against vaccines] partially because I don't like being taken for a fool”

Parents also argue that their children do not need the vaccines and cite the fact that they had most of the vaccine preventable diseases themselves as children. Other parents, however, cite personal experience as to why they feel they should have their children vaccinated.

“from the MMR campaign it said these are desperate diseases...but we all got through them...to me they overstate the issues”

“what kind of illnesses have been in the family...my sister had polio and knowing about the disease made me very aware of the need to vaccinate against it”

Parents also commented on the role of the media but there was no overall consensus. It was generally felt that it is a good communications medium but that it often ‘hypes up’ an issue. It was commented in one group that the newspapers give a balanced view. Parents are interested in media that gives different perspectives of the topic.

“not negative information but facts”

The pressure put on parents to vaccinate their children has also had an effect on the children of those parents who have decided against vaccination. These children are afraid of getting sick.

“my boy didn’t get a lollypop because he was the only boy in the school who did not get the vaccine... I really had a problem with him not getting a lollypop ... [son] thought he was going to die [because he did not get the vaccine]”

Discussion

Parents’ knowledge of the vaccines being administered, the preventable diseases they target and the accuracy of this knowledge have a huge impact on the attitudes of parents towards getting their children vaccinated. Many parents are afraid to give the vaccines to their children because they fear the vaccines themselves will do them harm. These views, however unsubstantiated by science, are commonly held and deep-rooted. The fear of parents, that babies are unable to cope with the numerous vaccines and ‘chemicals’ they are being given, lacks scientific evidence³⁵. Parents also expressed concern that vaccinating their children might encourage the emergence of more aggressive forms of the diseases. This concern may have arisen following media releases about ‘superbugs’.

Misinformation too, often both exacerbates and is exacerbated by, parents’ mistrust of the health services in general. Parents often feel that they are not being given the ‘whole story’. They feel that they are not in a position to make an informed decision. They are suspicious of what they are not being told and why they are not being told. Their awareness that there are different policies in different countries and even different counties within Ireland compound this suspicion. They are anxious to hear all sides of the story, to be informed if there is a risk and what this risk is so that they can make an informed decision. Without this perceived ‘balanced’ information some of the parents resist the pressure to vaccinate their children for no other reason than they feel they are not being given a proper choice. In part, it is a reaction to societal pressure put on parents to have their children vaccinated. Although aware of the oftentimes sensationalist approach of the media, parents see the media as offering the other side of the story in a way that the health services do not.

There have been concerns raised about the administration of MMR vaccine to children perceived to have egg allergies. Review of the evidence has found that severe allergic reactions are rare

and when they do occur they are more likely to be related to allergies to other vaccine components (neomycin or gelatin) than egg protein. The recommendation for a child with a definite anaphylactic reaction to eggs is to be vaccinated under controlled circumstances in a hospital setting⁴⁵. Ironically, this recommendation has sometimes meant that parents perceive the health services as being uncooperative in providing special vaccines. Such a perception has led to some parents becoming more determined to procure alternative vaccines (sometimes at great cost to themselves).

In addition, parents repeatedly questioned why they cannot have the MMR vaccine administered in single doses as they feel that it is the combined version of the vaccines that is the greatest risk in the long-term to their children. There is also a perception, expressed in one of the groups that it is the boys who suffer from mumps and girls from rubella and to vaccinate accordingly. Information prepared for parents and messages through the media should take these types of issues into account

Parents want information that addresses their concerns. This information needs to include the expected reactions that are possible in their children in the short term after receiving the vaccination. The information should also include up to date details on any perceived associated risks of having the vaccination as well as risks of not having the vaccination.

However, knowledge acquired is affected by not being given adequate time to read the documentation and the timeliness of the material being presented. It is also affected by them feeling that their concerns are not listened to by health professionals and whether or not the parents perceive that their children are being addressed as individuals rather than a component of an overall population to be vaccinated.

In many cases the decision to have their children vaccinated or not is made quite arbitrarily. Those parents who have had first hand experience of the negative consequences of vaccine preventable diseases will have their children vaccinated against them. This is set in contrast with those parents who feel that as they have survived some of those same diseases themselves in childhood, there is too much of an issue being made of vaccinating against them. Many of the parents interviewed felt that they were under pressure to have their children vaccinated.

In essence, the safety concerns parents have about the impact of the vaccines on children is largely a reaction to societal influences and is resulting in a decrease in vaccination uptake rates. Much of this misinformation, incomplete knowledge and mistrust could be alleviated with the provision of easy to understand balanced information.

Practice Nurses

Two focus groups were held with practice nurses. Analysis of the focus groups identifies two main themes: (i) the practice nurses' perceptions of the factors influencing vaccine uptake and their role as professionals, and (ii) their perspectives on the information being given and received by parents on the vaccinations, the vaccine preventable diseases and the reputed effects. Several of their perceptions concur with the comments made by parents. There is not, however, a consensus amongst the nurses interviewed on all issues discussed.

Vaccination uptake

Several issues emerged under this main theme. They are discussed as identified above, under the perceived factors influencing vaccine uptake and under the practice nurses' roles as professionals.

Factors influencing parents

The practice nurses have observed that the reasons parents got their children vaccinated included that they were told to do so by friends, their GP or the practice nurse; because they believe it to be the best thing to do; or that they feared the consequences of not vaccinating them.

"Some say 'well I'd be afraid not to vaccinate' they fear the consequences of not giving them [the vaccine]"

Practice nurses feel that there are several reasons why parents do not have their children vaccinated. They identified general issues such as fear of the vaccines, side effects from them, just forgetting, difficult for working mothers and not realising the importance of the vaccinations. The nurses also felt that the parents do not know what they are protecting their child against, that the parents do not know what it really means to have polio or diphtheria. In addition, they stated that parents are afraid of their children acquiring diseases such as polio or autism as one of the reasons they refuse the vaccines. The nurses observe that parents refuse to have their children vaccinated if they have had, or know of anyone who has had any bad experiences with vaccines. One practice nurse commented on a parent whose first child had a syndrome and associated it with the MMR vaccine.

"mostly MMR, we have defaulters...one mother refused...her first child had side-effects and now she refuses...another child...the cousin of the child [above] her mother also refuses [MMR]"

*"aware of it just after child got MMR...she associated it with MMR" **

In addition, the nurses observed that parents worry about the ability of their child's body to cope with the vaccines they are receiving.

"one thing that worries people...fear of multiple vaccines, they think the immune system can't deal with it"

The nurses feel that the type of message conveyed should be stark and used as necessary.

"When you tell parents some stories [real life ones about cases] it reinforces it [the need for vaccinating their children]"

*"[the message] nothing subtle...people need to be aware..."**

The nurses expressed concern, however, at the media coverage.

"headlines scare but further down [on article] OK [but not read]"

The practice nurses comment that there are ‘defaulters’ in areas due to the transience of the population.

“in [name of area] coming and going, a lot of travelling community”

The practice nurses identified single parents and members of the travelling community as being amongst those who do not have their children vaccinated.

“Travellers are not used to appointment system...do make appointments but do not arrive, some young ones do though”

*“unmarried mothers are bad [for vaccinations] if large family or mother no transport, single young mothers”**

The nurses comment that asylum seekers are good to have the vaccinations given to their children.

On the whole, the practice nurses feel that ‘defaulters’ could not be linked to any one group, socio-economically or educationally, as there are ‘defaulters’ in every group.

“fall in every group...couldn’t be categorised”

The practice nurses identified administration issues, which they also attribute to the vaccination uptake rates. The nurses felt that the ‘defaulter lists’¹ are very useful in helping them identify those parents whose children have yet to be vaccinated. However they observe that there are delays in getting the information from the health board.

*“we should be quicker to fill in defaulter form²” ... “seem to be behind in health board” ... “we need more updates as well”**

“[practice computer system] is great, helps us screen and send in returns and identify defaulters”

The practice nurses also commented that it can be difficult keeping track of patients if they change GP.

“If parent changes GP it would help a lot if the health board would let us know [so that they could take them off their books] as it stands the onus is on us [until they can identify that they have changed GP]”

The role of the practice nurse

The practice nurses discussed parents signing the ‘refusal form’³ and felt that it was good as it made parents really think about their decision but one commented that it can be hard to get parents to come in just to sign the form.

“some will sign, one mother refused and signed refusal form...she had read up an awful lot and refused it” another nurse continued *“I find it hard to get them to come in*

¹ GP practices are sent a list of defaulters, i.e. children who are late with their immunisations, from the health board office, which they use to follow up these children

² A ‘defaulter form’ is completed by the GP to provide the health board with additional information on children who are late with their immunisations.

³ When a parent decides they do not want their child immunised they are asked to sign a ‘refusal form’, which is sent to the health board office.

especially to sign the refusal form” another nurse stated “it’s good to have them sign the refusal form, it puts the onus on them”

In one of the focus groups the nurses said that there should be a central reporting system for all children vaccinated or due for vaccinations. They comment that local offices sometimes report that they have *“no record of this child”* and the nurses find this frustrating and cannot understand it.

“gets dangerous...danger of doubling up on vaccines... [children from UK] no idea of vaccines”

The practice nurses feel that a regular vaccination ‘routine’ facilitates uptake but that if the routine is missed then it very difficult to make up the shortfall. They make every effort to contact and ‘pursue’ parents who have not yet had their children vaccinated.

“fairly good, 75-80% all vaccines, 2 monthly routine ensures most of it” the nurses continued *“give date [for later appointments] but [parents] forget to look at it”*
“will ring 3 or 4 times, will write 3 or 4 time... phone call has more impact” another nurse continued the discussion *“contact by telephone, send letters 2nd month [of defaulting] 3rd letter is stiffer” **

Nurses in the second group also conscientiously pursued ‘defaulters’ and this group also recognised the benefit of having an established vaccination ‘routine’.

“two other mothers, sisters, refused for a long time...kept chipping at it...will get it there eventually”
“[the proposed change back to the 15 month schedule] will be a nightmare...will be in the paper again”

The nurses also try to instill awareness of the need for parents to vaccinate their children.

“keep talking about [vaccines]...start at 6 week check...[to prepare parents for vaccination]”

It is interesting to note that the nurses observe that parents do not always appreciate their efforts.

“some mothers ate the head off me [when practice nurse phoned them up]”

The nurses also commented in the focus groups that they take advantage of ‘opportunistic vaccination’. They reported that if there is a case of meningitis in an area, parents who have not had their children vaccinated *“flock in”* and they use this opportunity to *“catch up”* on other missed vaccines.

Communicating information

The role of the media and how the need for information was affecting vaccination uptake were discussed at some length in one of the focus groups in particular. The second group made similar points, although in less detail. Both groups questioned the response of the medical profession to concerns raised by the media.

The practice nurses in both focus groups felt that the message communicated to parents, through any medium, but particularly the media, can be ‘positive’ or ‘negative’. They have observed that sensationalist reports are very effective and considered it ‘positive media’ when the Minister for Health told parents that two children had died in Dublin from vaccine preventable disease.

“I’ve said that...if it was maybe publicised a bit...on the news or in the paper [when community cases occur] ...more attention should be given in the media to make people aware of the possibility of getting illnesses”

However, the practice nurses also observed that there is scare mongering in the media and commented on “*negative media*”.

*“Scare-mongering in media...people will pick out what they want...the heading is so important”**

*“During the polio scare... did an awful lot of harm, once they hear it logic goes out the window...any little seed of doubt [will cause a drop in uptake levels]”**

The practice nurses stated that positive messages are communicated through friends. The media is not the only source of information. The nurses, however, have differing perspectives on the value of information leaflets.

“Reassurance from other people...word of mouth...friends...they realise the importance of it”

“I wonder do people even read the leaflets...” During the discussion one nurse stated that the parents of a child in the town where she works who got meningitis had read the leaflet and knew about the tumbler test, the child was brought in early as a result and that *“all his friends came in to get it [meningitis vaccine]”*

The practice nurses in both groups also felt that the media can be sensationalist but felt that the medical profession does not do enough to counter it.

*“Parents often quote from the paper but don’t listen to medical advice”**

*“[name of radio programme] is sensational... no one rings in from medical side”**

Discussion arose in the second group about an anti-vaccine campaigner who was in Cork a couple of years ago and spoke to parents *“how she twisted it...I don’t think the Health Board answered ...didn’t defend it with more scientific information”*

Both focus groups however believed that the media has the potential to be a very important medium to promote childhood vaccination programmes; to be “*positive media*”, but it is interesting to note the comment of one nurse relating to a popular television programme in this context.

“Need to put in ads, positive media...repeat ads...repetition of the reassurance...doesn’t register at first but eventually gets through to them”

“on ER [television programme] child died from measles...I expected to get a lot in ...but didn’t”

Practice nurses also expressed the view that more information is needed to inform parents about what they are really protecting their children against.

“really inform and educate them about what they’re protecting their child against”

Parents, they felt, needed to be given more factual information about the vaccines and the reputed side effects. One group made the following comments.

*“the whole issue of autism needs to be put to bed, need simple leaflet stating the facts”**

*“one father [who was in getting his child vaccinated] was saying in recent ‘New Scientist’ magazine something about MMR...he was totally convinced [about the need for it]”**

The practice nurses also commented that parents are receiving confusing messages. They observed that although the vaccination cards are good they feel that it is confusing for parents when different forms have different schedules for when vaccines should be administered. They also observed that inaccuracies are communicated through the media.

“MMR often referred to as 3 in 1 on media [when in fact it is MMR]”

Discussion

The focus groups with the practice nurses raised some very interesting points that need some further mention. Several issues raised and observed by the practice nurses were highly consistent with what the parents commented on. The practice nurses identified, for example, that parents need more factual information about the vaccines their children would be receiving, potential side effects and more information on the vaccine preventable diseases they are protecting their children against. They commented that parents are afraid not to vaccinate and afraid to vaccinate, they are also consistent with parents in their observation that they do not know enough about the diseases they are vaccinating against. The nurses also reported that parents fear that their children’s bodies will not be able to cope with multiple vaccines.

The practice nurses feel very strongly that the message must be conveyed to parents that there are potentially very serious consequences from the vaccine preventable diseases if they refuse to have their children vaccinated. The message should be *“nothing subtle”* yet they express concern that the media is often scare mongering. The nurses feel that the media, written and visual, is often sensationalist and that parents do not see beyond the headline. The practice nurses do not identify any differences between those sensationalist reports, which they deem positive, and those they deem negative.

There are perceptions over which there is no overall consensus. The practice nurses observed that parents do not see beyond the headlines and others comment that they do. The parents themselves commented that that they do not take the information at face value. The public health nurses who discussed this issue too, were of the belief that the more informed parents are those from the higher socio-economic groups.

Midwives

Analysis of the two focus groups held with midwives identifies two main, and sometimes opposing, perspectives (i) their views as professionals and (ii) their views and experiences as mothers. Throughout the discussion in both focus groups this duality persisted.

Having conducted the focus groups it was established that the midwives do not have an active role in the delivery of the vaccination programmes and see their experiences as limited in this regard.

*“We give information about vaccines, it’s up to themselves if they do it”**

*“We don’t really know whether they vaccinate their children or not”**

Instead their views are presented simply as that, their views and opinions as they perceive them relating to any experience they may have which is often personal as mothers themselves.

The analysis of the focus groups with the midwives endorses many of the issues already raised by the practice nurses and parents as well as reiterating serious questions about levels of information and knowledge which have been raised by the practice nurses (and also the public health nurses (later in the report)).

Views and experiences as professionals

The midwives in their roles as professionals discussed several issues. The biggest of these issues was that concerning information. Several suggestions were made regarding how information should be communicated to parents and included the dissemination of leaflets through schools, through the media, in the ‘bounty bag’⁴ and through the use of videos at antenatal and particularly post-natal clinics. They also felt that there should be more information at ward level. In the course of the discussions there was an emphasis on the need to present balanced factual information.

*“A lot watch television...after the folic acid on television there was a big change...nearly all knew about it...”**

“mothers come back for bounty bag if they don’t get it”

*“[videos] even if you had it at the clinics...not to shove it down their throats...but they see it...instead of looking at the walls...I think it would be very good”**

*“at ward level need to have more information...so we could hand it to them when they have questions...even for us...”**

“...giving table with vaccine side effects and then side effects of illness”

In general, the midwives felt that giving information during the antenatal period was too early, *“mothers are just interested in a safe delivery”*.

⁴ The bounty bag was reported in the majority of parent focus groups and was well known among both mothers and midwives. It refers to a bag containing various promotional hygienic materials for babies given to each mother on discharge; it also contains information leaflets on child health issues. The contents of the bags are provided by the manufacturers of these materials to promote their products and are provided at no cost.

The midwives also observed that parents want advice on the vaccines, the possible side effects and autism, if it is safe to administer the vaccines to premature babies and have concerns about batches being out of date.

"[In the neonatal unit] many of the parents will ask about vaccinations...before they go home...want to know if it is alright for child to get vaccine in view of prematurity etc...[the nurse said that all the information they really have is about vaccination schedules] ...we just give information [leaflet]"

*"[at the last parent craft class we discuss discharge and vaccinations with them...at the classes they ask about vaccines...one mother asked about autism and then it started all the rest of them off and all 10 of them asked questions about vaccines!]" **

*"More informed mothers...higher socio-economic groups...they question everything...even konakion...they are more questioning...they are more passionate about it...about everything"**

*"Mothers who ask about side-effects...what do you say? Apart from the local side-effects...they want to know more...they kind of feel that it is hidden..."**

*"I think anti-D started it all off [concerns about vaccines, medicines generally] ...all you need is one thing to start it off...and then it dies down and then something else happens...batches of polio out of date...it stimulates all sorts of questions"**

The midwives commented that parents are generally better informed than a number of years ago and are more questioning.

*"I often think the better educated are more likely to ask more...they are more informed generally..."**

*"some mothers are really strong and they say to us 'do you really know what you are telling us to do? [recommending vaccinations] ...If your child developed autism after MMR you wouldn't be saying this...' "**

One issue that arose is that in many cases the midwives feel that they have insufficient levels of information to adequately deal with the questions asked of them by parents. They also expressed concern over their lack of conviction in advising parents to get their children vaccinated. In one of the focus groups there was a discussion about nurses giving advice when they have concerns themselves, one nurse mentioned that body language would show their lack of "true belief" in what they are advising. This nurse also said that she would have concerns about recommending someone to have their child vaccinated, she would give them information but not strongly advise them "it would be up to them".

*"as a health professional you feel you have to encourage vaccination..."**

*"we need up to date information and research...if health professional had better information they would be better able to promote..."**

*"[Generally the nurses felt that they were never really trained well about vaccines, just about schedules and local side-effects and not really about the disease themselves] we know what's given and when they're given..."**

Apart from information, other issues the midwives discussed included the major concern that parents have about the possibility of contracting autism. The midwives in one group commented

*"[MMR] if it is a preventive measure need to face the benefit versus the risk [of vaccinating]"**

*"if family friends have fears it rubs off on other members of the family"**

The second focus group also observed concerns relating to autism

*"A lot of mothers would say that they know somebody with autism [after vaccination]"**

"Within a half mile of me there is a woman saying that her child has autism because of the MMR...she tells everybody that...she has videos of her child completely normal

*before the MMR and then hours after the MMR developed autism...she said that her GP had said that if it was the 1950's he would have said it was polio...”**

The midwives also commented that parents are concerned about the amount injected and number of antigens their children are receiving.

“there must be an easier way in this day and age”

The midwives expressed concern over the combined vaccines, that having them all together was concerning

“there should be an easier way to give vaccines...” Another midwife continued *“Other than injecting them...maybe drops or something orally”*

They observed that parents are now asking a lot more questions than they would have a number of years ago.

“Each mother gets a leaflet...they take it ...before they didn't ask any questions, now they are asking a lot”

Views and experiences as parents

Although the views of the midwives cannot be definitively distinguished between their perceptions as professionals or as parents, some comments are specifically from their points of view as parents.

The midwives expressed concern about vaccinating their own children and the issues they cited are essentially the same as those expressed by parents in their focus groups and those perceived as the issues concerning parents by the midwives. One midwife commented that seeing the effects of not vaccinating can prompt parents to have their children vaccinated. Another midwife said that travelling to foreign countries would motivate her to make sure her child was vaccinated because of potential contact with viruses in other countries and the increased risk of illness.

The midwife mothers thought that school vaccinations were a good idea, they were more convenient, the children saw other children getting the injections and parents could be there if they wanted to as they received plenty of notice. They also commented that this put *“some pressure”* on mothers to have their children vaccinated if all the other children were being immunised.

One midwife mother stated that the letter sent out from the health board after the birth to mothers was a very good reminder. Before that vaccinations would be the last thing on her mind, her main concerns would have centred on bringing her baby home, feeding and changing the baby, she would not have remembered the vaccines if she had not been sent a reminder. A mother in the second focus group also felt the letters are a good idea.

“very good idea...makes it more relevant...you forget or lose what you got before...”
Another midwife took up the point *“like smears...if reminded by their GP...they'll do it...the more informed will do it anyway...after the campaign there was a big change...”*

One of the mothers also commented that the location of the clinic for the vaccinations was not suitable, that going to the clinic *“was horrendous”*, reasons for which included *“difficult to park*

and not a nice environment and a long wait". Some of the midwives felt it was tolerable for just one visit.

Discussion in the second focus group demonstrates that there is considerable anxiety about having their children vaccinated and that the midwives as mothers are confused regarding what is best for their children.

"I phoned the help line and they were absolutely useless... 'ah, don't worry, ah, don't worry'...they weren't well informed...they didn't have the batch numbers...I got it later from the Internet..." "it stimulates an uneasiness rather than anything else..." "I would have big concerns...listening to medical advice here helps to make a decision..." "I got the impression that there was a lot of confusion...when I got the letter they asked me to bring one child but they never asked me to bring the other child...they asked me to bring the book...it put me off...they should have followed up...my child still isn't vaccinated and if it wasn't for where I'm working it would be all forgotten... I wouldn't be still thinking about it...and I would never do it...but I am still thinking about it and probably will get it..." "My sister's baby got the meningitis [vaccine] and was told to wait for 10 minutes because the doctor had the antidote if it was needed...what are the complications of the meningitis vaccination?...my GP just gave it and we went off, we probably didn't go before 10 minutes anyway..." "there is no system...you hear different GP stories...different recommendations...it's probably always the way..."

One midwife mother in the first group commented that her twins got mumps 6 months after getting the MMR vaccination.

"...it just gutted me when they got mumps"

As a consequence, this mother does not want them to get boosters for MMR since they have already had the mumps disease and she does not want to vaccinate them unnecessarily.

Other issues

The midwives feel that attending the GP for vaccinations is not necessarily better than attending the clinics as they feel it is less of an incentive

"because the GP only gave vaccines whereas in the clinics they used to also get advice on feeding and other problems..."

Interestingly, one midwife mentioned hearing about "*rubella parties*" where parents put their unvaccinated children in contact with other children with rubella in the hope they will acquire it naturally. This phenomenon was also identified in the second focus group; the midwives observed that there was a preference by some people for "*measles parties*" instead of having their children vaccinated. It is interesting to note in this context that the midwives also observe that

"A lot of people think the diseases are extinct...they feel that one person not vaccinated won't make a difference..."

The midwives also made the comment that routine is important that "*no questions are ever asked about the BCG*" because there are no negative perceptions about it. On the other hand the participants of the same focus group observed that concern has been raised because of vaccine batches being out of date, which has "*caused big concern*" and that worry about vaccines is evident "*and the whole trust in it*". In addition confusion is exacerbated by changes in schedules without notice or explanation.

“[Booster dose of MMR] suddenly appeared...no information...no discussion about it...only found out with notice...no explanation”

The midwives feel that information is needed for both parents and professionals providing facts and figures.

“It’s very difficult to answer [when parents ask about vaccine side-effects]...they want a more balanced information...[one nurse said that mothers think they are being given the hard sell and only one side of the story...and that if they had real information on risks and benefits that more would be in favour of vaccinating]”

Discussion

Three main issues arose in the focus groups with the midwives that need particular attention here. These are: (i) conflict between being mothers and being professionals, (ii) misunderstandings and lack of knowledge about the vaccines and (iii) lack of understanding of the herd immunisation concept.

There is a virtual conflict of interest between the midwives as professionals and the midwives as mothers regarding whether or not children should be vaccinated. The midwives are unsure themselves as mothers whether it is safe or in the best interest of their children to have them vaccinated, as professionals they feel that they should be advocating the use and benefits of immunisation. They feel that they are not fully informed about the possible side effects of vaccines versus the possible effects of the diseases being vaccinated against.

This lack of knowledge is apparent throughout the focus group discussions. One midwife stated that she was ‘gutted’ when her children got mumps having been immunised and was therefore reluctant for them to get the booster injection. This illustrates the perception that once vaccinated a child is protected. However, no vaccine is 100% effective. It is estimated that mumps vaccine is 90-97% effective, that is, in general, only 9 out of 10 children will be protected by one dose⁴². This issue may need to be addressed in information for parents and professionals.

The third issue of particular concern raised in this section is that of the concept of herd immunisation. It is evident from the midwives observations that parents are not aware that as many children as possible need to be vaccinated to ensure that the greater society is protected. It is perceived that the diseases are no longer a threat in Ireland due to the fact that children have been vaccinated against the diseases for so many years in this country; that they are therefore extinct. The midwives stating that they would vaccinate their children if they were travelling abroad also attests to this fact.

As with all other sections in this report it is clear that considerable attention must be given to the need for more complete information, for both parents and professionals.

Public Health Nurses

Three focus groups were held with public health nurses. One of these groups was with senior public health nurses for immunisations. These senior posts had been in place for about six months at the time of interview. The focus group for the senior public health nurses is discussed separately.

Senior Public Health Nurses

There is a senior public health nurse (SPHN) for immunisations in each Community Care Area. Their responsibilities include: improving uptake, identifying areas of poor uptake and checking defaulters, and, providing immunisation advice to the public health nursing service. Their discussion of the issues reflects this role and demonstrates that they are well informed. Several of the issues they discuss reflect what has been identified by other professionals and by parents. They do not question the validity of having children vaccinated, which marks them out from other professionals interviewed.

The computer system and follow up of defaulters

Much of what the SPHNs discussed concerned logistical and administrative issues. One of the main concerns identified by the SPHNs was that of the computer system for tracking immunisations. The SPHNs felt overall that the current computer system was insufficient to meet the needs of the programme *“even fully immunised children are not being consistently tracked by the system”*. They felt that the computer system does not reflect immunisations uptake, which they feel, is *“partly because of the slowness of entry but also because of inaccuracies and losing information”*. They feel this is partly because *“GPs in single-handed practices or without admin staff are less likely to return notifications”*. They comment, however, that this *“slow notification entry”* is not a problem in some areas.

The defaulter list is sent regularly to GPs and public health nurses. However, at times it may be inaccurate and not reflect the vaccinations given, which is frustrating as the public health nurses feel unable to justify delays and inaccuracies which *“makes their position difficult”*.

The SPHNs also identified two main factors which makes it very difficult to be categorical about the number who do not have their children vaccinated; the movement of people and late uptake. People also *“just don't get around to it”*.

“we have no control over the movement of people...if moving area we should have a national media campaign...for example ‘if moving area please notify your GP or your health board...’”

“this needs to be addressed...[the movement without notification]...they forget to tell you and they're surprised when the PHN doesn't come to visit them...”

“some people are not really defaulters but are just waiting until later for the immunisations...until 18-19 months...if you look at uptake at 24 months you see this”

In addition the SPHNs observed that addresses are incorrect, even though they would have sent in correct addresses. They also commented that GP names cannot be updated and are incorrect.

“no way to change GP name”

“should be able to change the GPs name”

“parents regularly need to change GPs”

The computer is *“only a waste of time, there has to be a national system, a number that shows up on the system [a unique identifier]”*. The SPHNs had other comments about the computer system

“change of addresses is not accepted, it seems to be a separate system, ...I have to actually manually hand it over...it can be changed in the system but it has to be done”

“GP’s should do weekly returns, in the Midwest they have pre-paid envelopes ...it’s as cheap to give a prepaid envelope if you can facilitate people to send it in, it promotes good will; also among the PHNs it gives an incentive...”

One nurse felt that although there were numerous problems with the computer system it did not necessarily affect rates; it did, however, seem to require an enormous amount of unnecessary time and energy to try to sort out problems.

“The problems with the computer systems does not necessarily influence the vaccinations uptake...”

In relation to defaulters, the SPHNs feel that vaccinations are not a priority for many. The nurses referred primarily to members of the Travelling Community and people living in deprived areas and one nurse commented that they should be vaccinated *“opportunistically as far as possible”* although another nurse felt that *“they don’t bring the children to the GP unless they’re ill...”*

“it’s way down the list of priorities of some of them...when their electricity is turned off and they have rats running across their floors ...”

“they don’t see a tomorrow and they only see today...”

“in the Eastern Health Board they have a mobile unit that goes out to Travellers...it would be wonderful for working class areas and Travellers' halting sites here...”

The SPHNs expressed differing views on having a mobile unit. They also expressed some reservation about having the vaccinations in the GP’s practice.

“the good thing about GP sites for vaccinations over the mobile unit was the GP’s knowledge of the family...[one nurse felt that mobile units were not a good idea] the GP knows the family history and the GP is there to pick up the pieces if there is a problem...I’m finished at 5 pm but the GP has to mop up that end of it...”

“if it’s working in the ERHA we should do a needs assessment, work with GPs and then assess the feasibility of it”

“one mother said she loved coming to the clinics...everyone was well...now someone next to you is bronchitic...”

As has been commented in the other focus groups with both professionals and parents, the SPHNs have identified that some of the problem with uptake levels is due to the changing vaccination schedules. The SPHNs, however, observed that generally there does not appear to be a problem with parents accepting the Men C Vaccination in the programme of vaccinations within the first year of life.

“certain amount of parents were waiting until 1 year old just for one shot...but now the vast majority are now accepting them [in first year of life]”

As well as the problems caused by changing schedules, the SPHNs expressed a belief that parents tended to forget about the MMR and that the gap between the vaccines made it more difficult to get them to accept it because there is less contact with public health nurses as the child gets older.

“the gap between the primary and the MMR is a problem...you have contact up to 9 or 10 months [with the mothers and babies] and then none after this...”

“Before, in [name of centre] we sent a leaflet with the reminder [to come in for the 15 month vaccination], and then stopped, because we ran out of leaflets and they were out of date...it will be starting up again with new leaflets, but now they’re out of date again...[because of replacement of OPV with IPV]”

Information

As was identified in all of the focus groups, information was a major issue for the SPHNs. They felt that public health nurses have more contact with mothers antenatally now than they would have had previously but they had different views regarding the level of input regarding immunisation advice they should have. Some felt that the midwives have a greater role to play but that there could *“perhaps be closer liaison with the midwives and the public health nurses”*. What follows is some of the discussion that took place concerning advice during the antenatal period.

“maybe we need to go into the [antenatal] hospitals to talk about vaccines...” “if we had a sheet that they [midwives] could give to [parents] say that there is a resource person [public health nurse] in their area...” “the ideal place is when they go into the clinics...” “I think they only take in on board when they have their baby and take it home...” “I think the PHN is the key person, she’s on the ground...” “not all the district PHNs know every pregnant mother in their area” “people still don’t know what they’re getting [vaccines] ...we should be recommending that they have videos” “but that’s the job of the antenatal clinics and not for the senior immunisations nurses to be recommending”

Two main issues arose in relation to information: what information is needed and how it should be delivered. The SPHNs felt that parents want more information about reactions and side effects and they observe that parents are happy if professionals admit they do not know the answer but will try to find out and get back to them.

“Parents want more information, the percentage of children who have reaction, what are the components...”

“there’s not a person in the country who does not know someone who has been effected by autism...”

“once you talk to parents [who call up after the scare stories] it helps...you say you will get back to them if you don’t know and they’re OK”

In addition, the SPHNs reported that not every public health nurse is convinced of the safety of the vaccines.

“yesterday at the health centre the public health nurses were talking about immunisations [among themselves]. One of the public health nurse’s children was admitted to hospital after vaccination...she was convinced it was related to the 3 in 1 vaccine...even though they told her in the hospital that it was a viraemia she was convinced, she said she was not going to get the next immunisation for her child...I couldn’t honestly say they were selling immunisations in that clinic”

The SPHNs felt that people are confused about vaccines and could relate to this experience themselves.

“you can't bombard people with information...even though you've explained everything they aren't sure, they're confused about vaccines”

“they tick that they got the vaccines but sign it anyway [at school vaccinations when letters go out they sign that the child is vaccinated but sign for permission to get it anyway]”

“...they don't take it all in ...they don't take it all on board...it was only when I got my own children that I really took it all in...I was fuzzy about it before then...”

The SPHNs feel that the media reporting is all negative and feel that the health board should be faster to respond. They feel that parents appreciate it if the professionals can provide them with more information. To facilitate this they feel that the public health nurse must be fully informed and suggest the use of special information packs with frequently asked questions in sections that can be photocopied or removed as required.

“The media, it's all negativity...since we've come into our positions there's been so much, one after the other...first there was the polio vaccine, then the out of date vaccine, now the animal vaccine...”

“I don't know if the health board are fast enough in responding, there should be faster information from the Department of Public Health”

“parents appreciate if you can give information”

“information is needed, the PHN has to be up to speed, if she is it's 70% of the work [immunisation] done...now all the information we have is outdated”

“We have A4 sheets... common questions”

“not everyone wants to know...you use it for people who look for it”

“with little sections that you can photocopy...and update as needed, just taking out the relevant section and replacing it”

“something easy to pick out and can photocopy it, and can change it when it changes”

“something like the infectious disease manual they have for schools...it's a fantastic book.”

The SPHNs had a list of additional suggestions to communicate the information to parents about vaccinations.

“some handheld thing for GPs to use with patients”

“we need accessible information in whatever format”

“videos in antenatal clinics”

“In the health centres...a simple video to be running...it would be easier...they are just sitting there...”

“we did packs for all the centres, for the public health nurses...that was the reason...it worked out very well...a new nurse started and came to me and asked for information ...and I pulled out the pack and it was all there...she couldn't believe it...”

“we should all be using the same information, we should all be getting the same information, the same messages”

“we need more in-depth information about [vaccine] components and research”

They also felt that there should be adequate support and backup for the public health nurses when there is an emergency or scare concerning vaccinations.

“if there's a scare there should be a central person who is answering the phone...there should be a designated person...not just one of the administrative staff...they don't know

how to answer the questions but they are the ones who are answering the phones...even if we are there..."

"there should be a protocol on who deals with it...the management need to decide on this"

"the minute we hear something negative we should hear about it and who we can contact..."

The SPHNs, like the other groups surveyed in this study, felt that parents' perception of the diseases being vaccinated against is not well informed, they have no experience of the diseases and feel that they are some distance from them.

"[diseases protected by MMR] not seen as a very serious disease...not seen as polio...they remember meningitis"

"they've got a child of 15 months who is trotting around and healthy...[they don't think of illness so much at that time...the nurses commented that the parents are more likely to have their child vaccinated when the child is younger]...the gap is there and people forget"

Public Health Nurses

The public health nurses, like the SPHNs had particular concerns about the information available and information needs. They also identified differing and changing vaccination schedules as a source of confusion for parents.

Information

The public health nurses commented that parents need balanced information that is timely and relevant. The comments of one group included:

“Some of the well educated group think we are insulting them with the off hand information they get...we need to make information less biased so they can make an informed decision”

“We need up to date information, it is already out of date, and sometimes we don’t have any for them...and when we do have it is already out of date”

“The new information leaflet is too long it is too dense, no one wants to read it”

“ You need age appropriate information, they don’t want information about the vaccines at 4 years old when they are just 8 weeks old...they need the relevant information for that age group”

The nurses in the second group felt that parents also need to be advised on what to expect as a result of their child being vaccinated.

“a lot of people got a sore arm after the Men C vaccine...years ago with the BCG...I remember the festering sore...but that was expected...people still have memories of TB”

They also observed that parents are suspicious of the health services and need to feel that they are being adequately informed.

“There is a distrust of the government, fear and suspicion, lack of trust”

“They always ask you if you have children and would you give your children these vaccines”

“they feel they are not getting balanced information”.

“We need an independent source to give information, who is impartial, someone who is not

promoting vaccines (not health board, no dept of health)” [when asked who they thought would be a neutral impartial person one PHN suggested] “ academics from universities, hospitals, virus reference laboratory who did not have a stake in vaccinations”

The nurses in the second focus group concurred; they felt that trust is an important issue.

“if we are being accountable ask about side-effects...then they feel they can trust you...”

“Someone needs to balance the information....people getting an awful lot of information why they should not vaccinate, but not a lot on why they should give...”

The nurses commented that parents want information that is apparently unbiased.

*“A lot of decisions are made by politicians...this is not good...for the Oireachtas committee report on MMR you had [name of politician]...it should have been a medical person...how can a politician come to a medical decision? It does not look right”**

*“You also get pharmaceutical people talking and politicians...there have been too many cover-ups for them to be trusted”**

*“There has been a lack of accountability, just look at the blood tribunal”**

On the issue of trust however, the second public health nurse focus group felt that parents put great trust in the nurses and in their GP. They also felt that parents like the responsibility to be taken from them.

"It's hard for people to take the responsibility [for their child; some nurses felt that some parents prefer the decision to be made by the doctor or nurse...]"

In addition, in one of the focus groups one nurse said that she thought that compulsory vaccination was a good thing as it takes the decision out of the hands of the parents and the worry that they might be doing some harm to their child. This point was taken up in the second focus group. Parents are reported to have said 'whatever the doctor and nurse tell me I'll do'. One nurse reported that most of her parents 'would trust the doctor and nurse if they said it was 99.9% safe' but that she is worried about autism and would like to be better informed.

"if it was 99.9 % safe...but I'm worried about autism...I could do with a handout..."

The nurses felt that the nurses themselves should be more informed.

*"We need a quick guide to side-effects of vaccines"**

*"Our own knowledge needs to be improved"**

"what I personally would like is to understand the response of the immune system to vaccines...and the effects of these substances"

They also felt that they have to be adequately informed in order to answer the questions parents ask them.

"you need to know the information to answer the questions...autism is a big issue"

"Parents ask 'what is the risk?' We need to respond. Research has shown...there is a risk of temperature...."

The nurses also made suggestions for the dissemination of the information to parents.

*"Needs to start early, in post-primary with school health education"**

*"We need to speak with mothers, need to tailor it, many of them can't take it in at the first home visit, you have to see what they are able to take in and give it to them at an appropriate time. You know when they are ready for it"**

*"video on vaccinations in waiting rooms would help get parents talking"**

"there's no Irish made video for mother-toddler groups or antenatally...they are a sitting target at antenatal classes..."

Other nurses observed that parents are receiving mixed messages, which creates confusion; and that the schedules for receiving the vaccines keep changing. The nurses reported that there are inconsistencies in reporting and actions. They recounted the story of one GP in the area did not recommend the MMR vaccine for a child whose sibling was recently diagnosed with autism, even though the mother did not attribute the autism to the vaccine because the child had shown earlier signs of the condition. However, the fact that the younger sibling was not given the MMR vaccine by the GP fuelled the rumour circulating in the community of an association between the MMR and autism. The nurses report that the mother had said 'I will be guided by you [the GP]' and that he said it would be better not to give it.

*"Some parents ask to space the vaccines and in other places it is the GP who suggests spacing vaccine. This is conflicting information for the parents, they are getting mixed messages".**

"the ground rules are changing all the time"

"[Concerning confusion about changing schedules] they have leaflets from both years [with different vaccine schedules]"

“Schedules change, that confused parents...suddenly ground rules change, that really upsets parents, they wonder ‘why the change’ and ask if the health professionals were remiss or wrong about earlier recommendations...it needs to be explained and given a reason for change”

Other comments

Parents are also concerned about the number of vaccines the child is receiving and some parents express a preference to have the vaccines split according to the nurses.

*“Parents are concerned about the number of vaccines being given at one time, particularly to the younger children...they tell you... ‘they are getting all of this at just 8 weeks old!’”**

*“For the older children it is more likely to be the number of needles they worry more about. Although in schools most children will still get the 2 shots rather than the one shot”**

“some parents are going to wait until children are one year [...for meningitis vaccine, only need one dose then]”

“many GPs split vaccines, parents worry about combined vaccines”

In addition, the public health nurses commented that parents *“don’t know about the severity of the diseases anymore, they have never seen it, even the GPs have never seen diphtheria...”**

*“We need a video of the diseases so that they can see them, if they saw a child with whooping cough it is a terrible illness...”**

“in ER a few weeks ago child died of measles...many parents said that they had not known that people could die of measles...”

The nurses commented that parents are concerned about possible side-effects of the vaccines as well as reactions to the injections.

The nurses expressed concerns about the media and its effect on immunisation take-up rates. In discussing the media they also made reference to their views that Social Class has an impact on the extent to which parents have informed themselves about vaccines.

“Media affects uptake rates, especially among lower socio-economic groups who just read the headlines and not further, they are also more likely to talk about anecdotal reports of adverse events”

“The more literate upper socio-economic groups are more likely to have read up more about vaccines”

“in [name of different region] the ones who didn’t get the message were the lower Socio-economic classes, we are not getting the message across”

“They [all parents] are influenced by outbreaks and reports of illness e.g. meningitis, rubella vaccine [advertisement], measles”

The second focus group also discussed the role of the media:

“unfortunately we’re in a media bite society....”

“people read headlines...and not the articles in depth....”

“soaps have major impact “

“there was a lot of hype about the polio vaccine”

There was a perception amongst the public health nurses that parents who default in having their children vaccinated are generally *“alternative”* lifestylers. Only minimal reference was made by one of the focus groups regarding those who default.

“Parents who tend to refuse tend to be the alternative type...”

"People with alternative lifestyles, people with 'organic, earthy lifestyle' they are often from other countries or other parts of the country"

The second focus group gave more details regarding their perceptions and understanding of those who default.

"We were told that there was a high proportion [10%] of alternative lifestyle parents...they have done a lot of research...decided if their child gets sick what they will do...[use homeopathic remedies]"

"New Agers do not get vaccines, they give homeopathic medicine, they give polio...they feel it is not as invasive". Another nurse said "they believe in natural immunisation"

"Some of the natural back to earth community have homeopathic remedies for tetanus and also for pertussis"

"Parents who are very into their children, into child development, they choose not to vaccinate"

"Often professionals, often nurses..."

The nurses in one of the focus groups gave a list of reasons they perceive as disincentives for parents to have their children vaccinated.

"Waiting in clinic"

"Sitting beside someone coughing all over you, everyone coughing"

"They need a separate waiting room for vaccinations"

"It needs to be more consumer friendly"

"If they had a clinic once a month and you knew it was then..."

"So much time is spent in going for vaccines...I don't want to spend three annual leave days going for vaccination."

"If a child is chesty they parent puts it off..."

"It is difficult for fulltime working mothers...it's easier for part-time mothers they are very organised."

"Education is needed at the crèches...they don't know about vaccines and what is recommended."

One of the nurses stated that it would be an advantage if they had the single vaccine product to give to parents.

"it would be easier if we had single vaccines..."

The public health nurses felt that time would be well spent discussing the issues with parents.

"Among those parents who are unsure about vaccines if you talk with them nearly 60% will decide to go with vaccination, you need the time to talk with them. Nothing can replace time".*

*"GPs need to help promote uptake...they are so busy, they are in and out like a shot, they fit in the vaccines between seeing other patients. The practice nurse draws it up and then the GP breezes and out in 10 seconds..."**

The nurses also commented that a child health record would be great.

"A child health record would be great...they regard it as a passport. Anyone who has been in the UK or Germany brings it in...they have all the records there..."

Discussion

The senior public health nurses and public health nurses expressed quite different perspectives on the issue of childhood vaccinations. The SPHNs did not question the validity of having children vaccinated and did not express any doubts about its safety. Their concerns were primarily centred on administrative issues such as the inadequacies of the computer tracking system. They also, like every other group interviewed, expressed concern over the type, amount and dissemination of information being conveyed to parents. Like other groups too they expressed concerns over parents' perceived distance from the vaccine preventable diseases and their perceived lack of comprehension of their potential severity.

The public health nurses on the other hand were more typical of the other professional groups and parents interviewed and made several observations consistent with what has been stated by those groups. These issues included an observed suspicion of the health services, incomplete information, the feeling that the nurses themselves could be more informed and that parents are receiving mixed messages.

The issue of trust merits some further attention. The public health nurses were the only group to identify the perception that parents are happy to leave the decision to someone else to make and are willing to put their trust in the health professionals. However, it was evident that they do not all universally have trust in vaccines, strongly influenced by media reports and with limited knowledge with which to counteract this information. Therefore, it is highly unlikely that such nurses can be strong advocates of vaccination and instill trust among parents with rational and scientific evidence. Unless all health professionals are well informed about vaccines, parents will continue to receive information from nurses that is lacking in conviction and their mistrust will continue.

The public health nurses also expressed the view that the lower socio-economic groups were those most effected by media reports and those to whom they felt the health services were not succeeding in conveying the message about the need for immunizations. The higher socio-economic groups were more likely to read more about the vaccines. These comments were made about the extent to which these groups are informed about vaccines but the level of uptake was not differentiated between the groups. In order to improve uptake levels it may be necessary therefore, to consider differential dissemination of information to parents from different backgrounds.

Part 4

Postal Survey of General Practitioners



Postal survey of GPs in Cork and Kerry

In the final phase of this study, a survey among a sample of 128 GPs (50% of GPs routinely vaccinating children in the SHB area) was undertaken. The questionnaire sought to determine the extent, level and type of parental vaccine concerns expressed to GPs. Additional information was also sought on vaccination coverage and methods of estimating this in each practice. One hundred and one GPs responded to the survey (i.e. response rate 79%).

Estimated vaccination coverage

The majority of GPs (68%) provided estimates of vaccination coverage - the median complete vaccination coverage for children aged 24 months was estimated at 85% (range 5-100%). Estimations were based on SHB feedback or record review by the majority of GPs (21% for both), with lesser numbers using computer (13%). Ten percent revealed that their estimate was based on a guess.

Parental vaccine knowledge and concerns

The majority of GPs reported that parents were only moderately well informed about the benefits of vaccination and that more than 90% of parents were anxious about vaccination, with 42% considered very anxious (Table 1).

Table 1. GP survey. Parental attitudes to vaccinations (n=99)*

Question	Very n (%)	Moderately n (%)	Not very well n (%)
How well informed are parents about the benefits of vaccines?	19 (19)	68 (69)	12 (12)
How anxious are parents about vaccines?	42 (42)	48 (49)	9 (9)

**not all respondents completed this section*

Major reasons for parental concern

GPs reported that the major cause for concern among parents was generated by concerns related to perceived unknown long-term vaccine side-effects and the MMR vaccine following recent controversies. The majority of GPs also considered that short-term side-effects and the number of injections (needles) at one visit were a cause of parental concern. A substantial minority considered that parents were concerned about the number of antigens at one visit (the perception of over stimulation to immune system) and DTP vaccine (pertussis component) appeared to cause some parental concern. A minority reported concern relating to the newly introduced meningitis C vaccine, vaccine components, or the duration of protection provided by vaccines (Table 2).

Table 2. Major reasons for parental concern relating to vaccines (n=101)

Reasons for parental concern (no. responding)*	Agree	Neutral	Disagree
	n (%)	n (%)	n (%)
Long-term unknown side-effects of vaccines (n=100)	77 (77)	11 (11)	12 (12)
MMR vaccine (n=101)	78 (77)	13 (13)	10 (10)
Short-term side-effects of vaccines (n=100)	58 (58)	27 (27)	15 (15)
Number of needles (n=101)	54 (53)	24 (24)	23 (23)
Pertussis component DTP (n=101)	44 (44)	28 (28)	29 (29)
Number of antigens at one visit (n=101)	43 (43)	20 (20)	38 (38)
Newly introduced meningitis C vaccine (n=100)	24 (24)	25 (25)	51 (51)
Vaccine components (n=97)	22 (23)	18 (19)	57 (59)
Duration of vaccine induced protection (n=100)	5 (5)	16 (16)	79 (78)

* number responding to individual questions varied.

Main reasons for children not getting vaccinations

The impact of negative media coverage relating to vaccine issues was considered to be the most important factor influencing parents against vaccination. Influence of family or friends, and recent vaccine scares (e.g. 'polio scare' related to news release of oral polio vaccine [OPV] components potentially derived from a vCJD donor and administration of out of date OPV) was also substantial. A substantial minority of GPs reported that parents concerns were related to information acquired from researching the subject, that parents delayed childhood vaccinations (until children were older), that parents did not believe in vaccination and that parents were too busy and did not prioritise vaccination (Table 3).

Table 3. Major reasons GPs thought that children did not get vaccines

Reasons for defaulting (n)	Agree	Neutral	Str. Disagree
	n (%)	n (%)	n (%)
Negative media influence (101)	89 (88)	7 (7)	5 (5)
Negative family/friend influence (101)	74 (73)	17 (17)	10 (10)
Recent vaccine scares (101)	64 (63)	21 (21)	16 (16)
Researched & major concerns (101)	35 (35)	30 (30)	36 (36)
Delay vaccines until older (96)	31 (32)	28 (28)	42 (44)
Philosophical objectors (100)	29 (29)	21 (21)	50 (50)

Too busy, don't prioritise (101)	22 (22)	35 (35)	44 (44)
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Vaccine information

Overall, vaccination information available was considered insufficient to meet the needs of those requiring it, for both health care professionals and parents. Among respondents, the GPs (or practice nurses) were considered to be the major source of vaccine related information for parents. Respondents believed that neither parents nor GPs/nurses received sufficient information from other health services. A need for factual vaccine information was particularly expressed. Few respondents considered that media scares/negative information about vaccines were adequately dealt with by authoritative experts in the field (Table 4).

Table 4. Information provision

Adequacy of information	Agree	Neutral	Disagree
	n (%)	n (%)	n (%)
Information for parents from GPs/nurses (101)	52 (51)	35 (35)	14 (14)
Vaccine information for GPs/nurses (101)	48 (48)	28 (28)	25 (25)
Rapid access to information (all) (100)	40 (40)	27 (27)	33 (33)
Information for parents – SHB (101)	34 (34)	32 (32)	35 (35)
Information comparing disease effects vs. vaccine side-effects (101)	26 (26)	32 (32)	43 (43)
Expert, authoritative response to media (101)	21 (21)	20 (20)	60 (59)
Information from maternity hospitals (99)	9 (9)	30 (30)	60 (60)

Discussion

The majority of GPs considered that parents were moderately informed about vaccines but only a minority of parents were well informed. The vast majority of parents were anxious about vaccines/vaccination – confirming anecdotal reports and our findings in the focus group discussion. Despite this high level of anxiety surrounding vaccination most parents do have their children vaccinated as reported by the GPs who estimated that vaccination coverage for most vaccines was greater than 90%. The fact that parents are extremely concerned but still have their children vaccinated when it is recommended by their GPs/health professionals is not unusual and has been found in other studies^{29,43}. The role of the primary care provider in informing, advising, reassuring and providing support for parents is fundamental to immunisation services and the achievement of high rates of vaccine coverage.

Parental perceptions of vaccine related disease, vaccines and both real and perceived adverse events is influenced by many factors and many sources of information feed into the process governing beliefs and attitudes. The impact of media and voiced lay community opinions do

affect parents' trust and belief in a vaccine - a finding very much acknowledged in this study. During the mid-1970s when pertussis vaccination was causing concern and was much discussed both in the media and among the lay community vaccination rates similarly fell with a substantial rise in pertussis cases . It has taken nearly 30 years for the uptake of this vaccination to recover.

Public perception of risk of serious disease versus that of vaccine is a major influence on vaccination coverage. One example is that of the new meningitis C vaccine. Despite it being such a new vaccine, often a cause of concern to parents, it appears that parents are willing to vaccinate their child because they know the consequences of not vaccinating are serious. The fact that the other vaccines (MMR, DTP) appear to cause more concern may be related to the fact that these diseases have been on the decline as a result of routine vaccination for the past couple of decades. As a result, parents (and often health care professionals) are no longer aware of the potential severity of these illnesses. A reluctance to vaccinate when risk of disease is perceived to be low has been documented in other studies⁴⁴.

Vaccinating children requires giving injections and causing some degree of pain for the child - unpleasant for both parents and doctors/nurses to witness. Although this study asked only about parental attitudes to the number of needles (and reported moderate levels of concern) other studies have found that parents are not necessarily averse to it when the rationale is clearly indicated and this finding may reflect GP perception^{25, 28}.

The concept that children are unable to deal with the immunological load at vaccination has been expressed in the popular media and during the focus groups and was explored in the survey of GPs. A substantial minority of parents are perceived to be concerned about this – the evidence that this actually happens has not been documented and currently available data looking specifically looking at this area finds no evidence to support this. In contrast to vaccines administered 20 years ago, today's vaccines have approximately only a fraction (approximately 1%) of the number antigens previously administered³⁵ and concerns that vaccines are associated with increased risk of infection and type 1 diabetes is lacking⁴⁶.

Rapid, understandable and easy to access expert, authoritative information is considered to be of major importance in influencing vaccination uptake – both for parents and health professionals. In this study GPs expressed dissatisfaction with the adequacy of information available to them. Because of the brevity of the questions it is difficult to determine if this refers to quantity or quality, but information collected during the telephone interviews suggests that both are implicated. GPs considered themselves to be more likely to provide adequate information to parents than either SHB sources or maternity services. Their important role in providing information to parents is undisputed. Therefore, provision of relevant information, that is rapidly accessible, is a priority and high profile media support from experts is needed to counteract media scares.

Part 5

Discussion and Conclusions

Recommendations



Discussion

The study was undertaken to improve understanding of the issues, which influence parents' decisions whether or not to have their children vaccinated. What was found is that parents experience and express fear, pressure, mistrust and confusion in abundance. A better understanding of parental concerns will help us address the issues that have reduced vaccination uptake to such a level, as to be a threat to the health of the population as a whole. The minimum 95% uptake required to prevent outbreaks occurring is not being reached⁴⁷.

The majority of the findings are not particularly surprising or unexpected and support anecdotal reports. Significantly, the comments and perceptions are held consistently between all the different groups interviewed. Even more significant, is the similarity of the reasons identified by the health professionals with those of parents. This is not, however, to disregard those observations made in isolation by any one group or profession. One such finding was that of the senior public health nurses for immunisation who, unlike any other group, made no reference to having any hesitancy or reservation about the need for the vaccinations. This group was only in place about six months at the time of interview and was very well informed. They were the only group interviewed who did not state that they themselves needed more information. A second 'isolated' finding was the phenomenon identified by the midwives of 'measles parties'. Interestingly, this phenomenon was identified separately by both midwife focus groups but not by any other group interviewed.

Information

The study identified several reasons, which, are perceived to explain why vaccination uptake is low. The single greatest issue throughout the study was the feeling by parents that they are given insufficient information about vaccines: the benefits and disadvantages of immunising their children; what short-term side-effects to expect in the period immediately after receiving the vaccination; and information relating to the alleged links with autism or other conditions. Inadequate information was also identified in a recent UK based study³⁴. In analysing the research it became apparent that parents are also poorly informed about the diseases that their children are being vaccinated against, a point recognised by the service providers. The parents complained that the health professionals are not giving them as much help or information as they would like. They are given 'instructions' not information. However, the professionals interviewed, with the exception of the senior public health nurses for immunisation, felt that they themselves were poorly equipped to answer the concerns of the parents, and as parents themselves, they expressed concern over the safety of the vaccines.

Fear

The decision of parents on whether or not to vaccinate their children is influenced very strongly by fear; fear if they do and fear if they don't.

Fear of the consequences of their decision arose throughout the study. Parents who refuse to have their children vaccinated do so out of fear of perceived long-term side-effects. Most

concern was expressed in relation to the MMR vaccine. GPs observed that such fear is often deeply entrenched and is therefore difficult to change. Some parents who may be in favour of having their children vaccinated have serious reservations about the safety of the multiple antigen vaccines, feeling that this is where the main danger lies and that their children's body mass cannot cope. There is a need for better communication between health professionals and parents, in order to allay parents' fears. Both parents and health professionals commented that there is insufficient time given to informing and reassuring parents. Time must be afforded to and by health professionals to enable them adequately discuss parents' fears.

Fear is emotive and parents and health professionals react accordingly. Reports of vaccine preventable disease in the community frighten parents and often result in an increase in vaccination uptake as they take action to prevent their child acquiring the disease. GPs expressed some hesitation to pursue defaulters, as they fear litigation. This issue is important too because it points to the doubt some health professionals have regarding the safety of the vaccines.

Parents also fear disapproval from other parents if they choose not to vaccinate which adds to the pressure they face in making the decision whether or not to have their children vaccinated.

Although parents in this study are not differentiated on the basis of whether or not they had, or were going to have, their children vaccinated, they did frequently state their position during the focus group sessions. It is relevant to note that parents of both viewpoints expressed feelings of fear in making their decision. This echoes the UK study³⁴.

Mistrust

The parents expressed considerable mistrust of the health services and intimated a fear of issues being covered up, a point also identified in the UK study³⁴. Parents question the agenda of the health services, politicians and the pharmaceutical companies. Parents also look at previous mistakes made by the health service and wonder if current policy is also going to prove to be a mistake. The recent controversies over out-of-date vaccines have made the situation worse. Parents feel that they are not being listened to, either about their concerns or their reporting of adverse reactions. Being unable to elicit informed answers from many of the professionals they have contact with exacerbates their mistrust. This in turn is acknowledged by the professionals who observe that parents are often happy when they are told they do not know the answer to the question but will try to find out. Throughout the research there was a consistently repeated call by parents and professionals for 'balanced' and 'factual' information to be made available, outlining the benefits and possible risks of the vaccines. Adequately redressing the information needs of the health professionals would have the added benefit of improving the trust of parents in the health services.

Although parents expressed some appreciation of the need for population immunity, their priority is their own child. Their primary interest is what is best for their child and will make their decision on this basis. Their expressed perception is that the health services do not see their child as an individual but felt that policy was directed towards the population as an entity with little attention given to the individual. This

dichotomy must be recognised and addressed by the health services in discussions with parents and in the communication of information to parents.

Confused messages

These factors are compounded by parents receiving 'confused messages' from a variety of different sources, but particularly through the health service itself. Several of the groups interviewed identified the changing of vaccination schedules as a perpetuating factor. Parents have also observed different practices between countries and between regions. This is combined with health professionals being unable and by consequence, appearing unwilling, to provide answers to parents' questions. Some professionals, by their own admission, are unconvinced of the safety of the vaccines; it is therefore difficult to appear convincing to parents. This apparent conflict of interest is eliminated when the professionals are well informed. The senior public health nurses for immunisation demonstrate this point; they are very decided on the need to vaccinate.

Many parents effectively 'shop around' for information from different health professionals, both because they want to feel that they are being fully informed and because often, those they first ask, are not able to give them the reassurance they need. It is important in addressing the information needs of the parents, and by consequence the health professionals, to target those professionals not directly involved in the immunisation programmes. This should include professionals caring for mothers during the antenatal period as well as any other staff that might come in contact with the parents of young children.

Media

These issues are made worse by the perceived role of the media. The vaccines, other than the MMR, routinely administered to children in the early years of life are generally of less concern to parents, as less 'negative press' has been attributed to them. The role of the mass media as a method of communicating information to parents was repeatedly discussed as an issue. Various suggestions by the professionals were made concerning the best use of the mass media to convey information but there was an awareness that we are living in a 'sound-bite' era and a perception that people tend to take the headline as the whole story. Concern was raised in the study that some parents are only reading the media headlines and not reading the entire article. The parents, however, commented that they do not take everything at face value, something which was recognised by at least two groups of professionals: the public health nurses and the practice nurses. We should also be aware that parents who are researching the topic in greater detail are not necessarily getting a balanced picture. Much of what was alluded to in the study concentrated on arguments against immunisation. The response by the health services to 'negative press' was criticised.

Pressure

The parents felt that they were under huge pressure to have their children vaccinated on a variety of levels: personally, from society and from the health services. In some cases parents react

against this pressure by not having their children vaccinated. It is interesting to note that the professionals, particularly the practice nurses do in fact make every effort to pursue ‘defaulters’, to ensure that their children are vaccinated. Some of the professionals interviewed identified characteristics of ‘defaulters’ but the one consensus to emerge from the study relating to defaulters is that they are not confined to any one socio-economic group; although it was felt that the levels to which parents are informed is often defined by socio-economic group.

Parents default for a variety of reasons, other than the fear of potential side-effects, and these need to be acknowledged in trying to redress the issue of poor vaccine uptake.

Adverse events

Parents reported that many health care providers did not take seriously reports of adverse events occurring in their children after vaccination – they were often told that such adverse events were normal reactions to the vaccines. However, parents who considered that their doctors took seriously the potential for side-effects of vaccines such as temperature, crying, swelling were more satisfied with the vaccination process. Although there is an adverse events system in place and run by the Irish Medicines Board (IMB), this study suggests that parents may be unaware of it and that some reports of adverse events to GPs may not be reported to the IMB. Strengthening this system may provide some reassurance to parents and build confidence in the system.

Conclusions

On the whole, the levels of knowledge and information of many parents on vaccines is poor and confused. This is not acceptable. Communication of information that is unambiguous and honest is vitally important. Parents are unclear on the concept of population immunisation and the diseases their children are being vaccinated against.

Parents are concerned about the side-effects of vaccines, particularly the MMR, and questioned why it cannot be administered in single doses. They expressed fear and mistrust about vaccines and about those advocating them. This level of fear and mistrust will not be overcome lightly. The decision to have their children vaccinated, is as much emotion based as science based; the hesitation and the ultimate decision whether or not to vaccinate is decided by fear of the consequences of this action.

Health professionals feel that they are ill-equipped to properly inform parents about vaccine related issues. They consistently expressed a need for timely and accurate information to help them address parental concerns.

It must be recognised that we are living in an information era and an increasingly questioning era. If media campaigns for example, are to be used, then messages from studies such as this must be taken on board. Otherwise, it has been a waste of time asking parents for their views. We must be ready to respond and to use this same information era to adequately inform parents of the facts in a balanced and clearly transparent manner.

Recommendations

Information – general

- **Information is key** to both parents and health professionals. Information on immunisation and vaccines needs to be produced and disseminated nationally to ensure a consistent message. Production of such information should be coordinated by one national agency in collaboration with other relevant agencies.
- **Information needs to be balanced and complete.** Data on both the risks of disease as well as the risks of vaccinations needs to be provided.
- Attention must be given to the **format and presentation** of information provided to the various groups. Adequate resources must be made available
- **Misinformation needs to be addressed** rapidly by authoritative, scientific and trusted bodies.
- **Regular and timely updates** on vaccine related issues are required for health professionals and parents.
- **Increase access to information** - both parents and health professionals should be well informed about where further, accurate, relevant information may be sourced. Consideration should be given to increasing accessibility through a number of media (information materials, information lines, resource persons, Internet).

Information – for parents

Different formats are required:

- Parents require information to address their issues and concerns. Information will need to be in different formats to suit different needs and different education levels.
- Clear and simple leaflets, addressing the main issues, are essential. These should include information regarding the following: the vaccines themselves and potential side effects; the diseases they are protecting against; the concept of ‘population protection’; risk from vaccine versus risk from disease; the use of single or multiple vaccine preparations and the child’s response to multiple vaccines.
- Information videos on immunisation for use in health facilities used by parents of young children should be considered. Further research may be needed on the format needed for various settings.
- Information material produced for the public should be tested with the relevant target group before publication.
- **Increased accessibility of information.** Traditional venues for accessing information (doctors and nurses in hospitals, clinics, practices) may need to be augmented and innovative methods for widely disseminating information explored.

- **Detailed complex information for parents.** More detailed information is required for those who wish to research the issue further. Parents now access the Internet for information on health issues and balanced, evidence-based information must be provided on Irish health service sites. Parents will expect health professionals to be up-to-date on new information

Information – for health professionals

- Health professionals on the front line of immunisation services need to be provided with detailed, up to date and evidence based information so that they can assist parents in making their decisions. Information provided needs to be relevant to the parents and their children – addressing the parents’ specific concerns as it relates to their child. Included in this group would be general practitioners, practice nurses, public health nurses and area medical officers. This information will need to be updated regularly.
- A rapid cascade system needs to be put in place to ensure that health professionals receive adequate and timely information in emergency situations or controversies. This is especially important for general practitioners and practice nurses who are usually the first point of contact for the parents. If the parents’ concerns cannot be addressed at the first point of contact this may lead to further mistrust in the health services.
- Health professionals not directly involved in immunisation services also require information. Parents are requesting information on immunisation from many health professionals, not just those directly involved. Included in this group would be midwives and hospital nurses working in paediatric wards. A cascade system may be required for getting appropriate information to these groups. As well as having a basic knowledge they need to be aware of where, or from whom, parents can access further information.
- The priority issue for provision of information is MMR (measles, mumps and rubella) vaccine. Easy to understand information addressing the concerns of parents relating to autism and Crohn’s disease need to be specifically addressed. Additional information supporting the information is also required.

Health professionals and parents – working together

- The relationship and communication between health professional and parent is vital for improving child health. Health professionals need to acknowledge and address parental fears. Personal interaction with and support from health professionals greatly influences parents' decisions regarding vaccinations.
- Methods of improving communication skills and channels among health professionals, health boards and national bodies need to be identified and developed.
- Parents’ feelings of guilt and pressure need to be allayed by supporting and reassuring them about vaccinations.

Education

- Immunisation is a crucial health issue of our time and this needs to be reflected in undergraduate and continuing medical and nursing education.

Media

- Clear, evidence based information will need to be made available to the media on an ongoing basis to ensure an informed public.

Increasing trust and confidence in vaccination and monitoring systems

- Any changes to the immunisation schedule should be preceded by an information campaign for health professionals and parents, fully explaining the rationale for the proposed change.
- The availability of clear, evidence based information addressing the current immunisation issues for both health professionals and parents will go some way to addressing the mistrust felt by parents of the health services and those who deliver these services.
- Accuracy and efficiency of record keeping is seen by many parents and professionals to be a reflection of the quality of the system – methods to improve record keeping need to be identified
- Widespread use of parent held child health records should be considered to assist both parents and health professionals in documenting vaccinations received and empowering parents in protecting their child's health
- The Irish Medicines Board (IMB) Adverse Reactions and Quality Defects Yellow Card System (monitoring adverse events) needs to be strengthened and the information regularly analysed, interpreted and disseminated both to professionals and the general public.
- Some GPs are concerned about litigation relating to vaccination – such concerns may influence support for vaccinations. Consideration should be given to a national no-fault compensation scheme for vaccine adverse reactions.

Vaccination programme issues

- Logistical problems in the delivery of the primary childhood immunisation programme need to be addressed to assist those delivering the service. The issues identified include: vaccine supply and delivery, the health board's immunisation computer system, accuracy of uptake statistics and payment issues.
- Recognised methods of optimising vaccination delivery in GP practices should be encouraged including reminder systems, follow-up of defaulters, flagging of charts and minimisation of missed opportunities for vaccination.
- Current difficulties encountered by parents and health professionals in obtaining accurate records of vaccinations should be addressed. Efforts should be made to increase

efficiency and user-friendliness of vaccination record keeping to authorised individuals. The provision and use of unique individual identification numbers and development of appropriate information system should be considered.

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