EASTERN REGIONAL HEALTH AUTHORITY

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Parental Attitudes to Childhood Immunisation

Eastern Regional Health Authority

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"Those who choose not to vaccinate their children are actually, in a sense, relying on those of us who do, to keep the general population's immunity up. And you know, it's a choice that can be made as long as enough people vaccinate"

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Parental Attitudes to Childhood Immunisation

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List of Abbreviations

AHB	Area Health Boards
BCG	Bacille Calmette Guerin Vaccine
DtaP	Diphtheria, Tetanus and Acellular Pertussis Combination Vaccine
ERHA	Eastern Regional Health Authority
FRC	Family Resource Centre
GP	General Practitioners
Hib	*Haemophilus influenzae* type b Vaccine
IPV	Inactivated Polio Vaccine
MeSn C	Meningococcal C Vaccine
MMR	Measles, Mumps and Rubella Combination Vaccine
PHN	Public Health Nurse
SAMO	Senior Area Medical Officer

Parental Attitudes to Childhood Immunisation

Executive Summary

Ultimately, the aim of this report is to inform the strategies for increasing the uptake of childhood immunisation in the Eastern Regional Health Authority. Parental attitude towards disease is known to be a predictor of vaccine uptake. This study sought to understand these attitudes by asking parents to share their opinions, experiences and behavioural practices. Parents participated in the research with great enthusiasm and had many positive ideas and valuable contributions to make. Their insight enables the ERHA to identify and build on areas of strength and to address any barriers that inhibit the uptake of immunisations.

The main findings are that the majority of parents vaccinate their children but do so with a high degree of anxiety and apprehension. In this respect, parents of small children have a number of attitudes and experiences in common with one another despite their backgrounds and socio-economic status. The negative media publicity surrounding MMR has had a large effect on parents' confidence about this vaccine compared to other primary vaccinations. Parents, who easily immunised older children previously, were found to be hesitant about younger children in the past five years.

The study highlights the importance of key influencers and the ability of health professionals to reassure and provide information about immunisations. Positive messages of the benefits of immunisation are well received by parents, and it should not be necessary to appear defensive in the media. Parents are key advocates in the immunisation debate and should be provided with information and reassurance.

An important finding is the extent that parents delay immunisation for their children. These delays can be a substantial deviation from the recommended schedule. Specific mechanisms should be used to track delay and encourage parents to vaccinate in a more timely fashion.

We recommended that parents be recognised as a key part of the process for advocating for immunisation. In order to do this we must provide parents with good, accessible information and train health professionals to take time to reassure and discuss immunisation with their patients. It is essential to address delay by parents in immunising children by providing reminders to parents. Health professionals mus clearly explain the implications of delay and directly address the issue of "immune overload" and schedule change directly by both proactive and opportunistic media work.

Parental Attitudes to Childhood Immunisation

Chapter 1

Introduction

The prevention of serious childhood illness through immunisation is a major public health action that protects the health of children in Ireland and throughout the world. In order to prevent outbreaks of communicable diseases such as measles and mumps, the uptake of primary childhood immunisation should be 95% or above.

Vaccination programme uptake

Immunisation uptake rates at 12 and 24 months of age for primary childhood immunisation are not reaching levels needed to provide protection from outbreaks in the Eastern Region. The most worrying observation occurs in relation to MMR immunisation as the uptake rate at 24 months of age dropped by 21% from 80.5% at the end of 2000 to 59% at the end of 2001. These rates are now 70-80% (FIG 1/2) [1] but some areas have lower uptake rates. These low uptake rates greatly increase the risk of an outbreak of measles or mumps or the re-emergence of congenital rubella syndrome. Although the decline in MMR immunisation was noted nationally, it was much more marked in the Eastern Region. An outbreak of measles occurred in the Eastern Region in 2000 which led to 1230 cases, three deaths and just over 350 hospital admissions in children.

Figure 1: Primary Immunisation Uptake Rates at 12 months of age for children born from January 2000 to December 2002

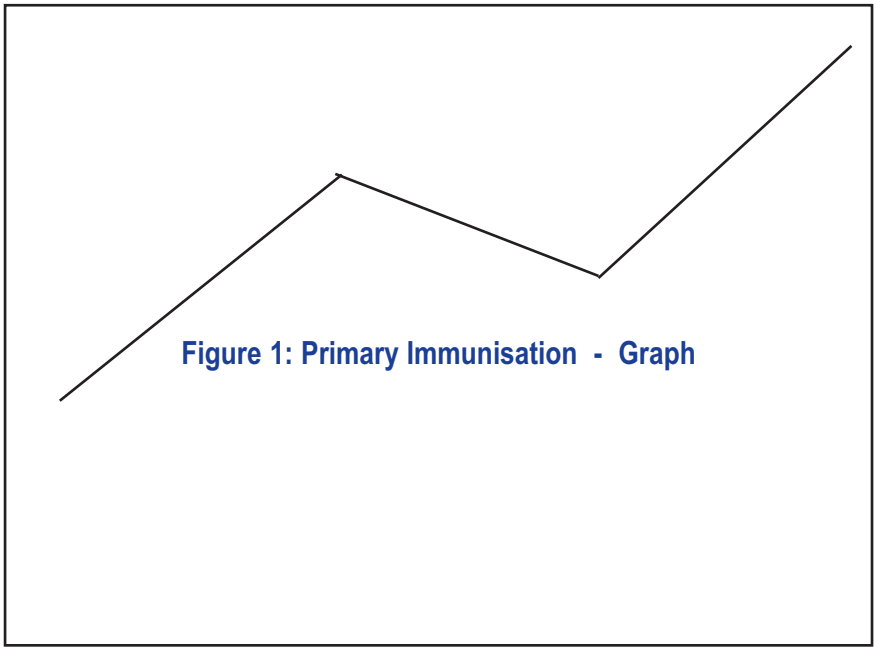

Figure 1: Primary Immunisation - Graph

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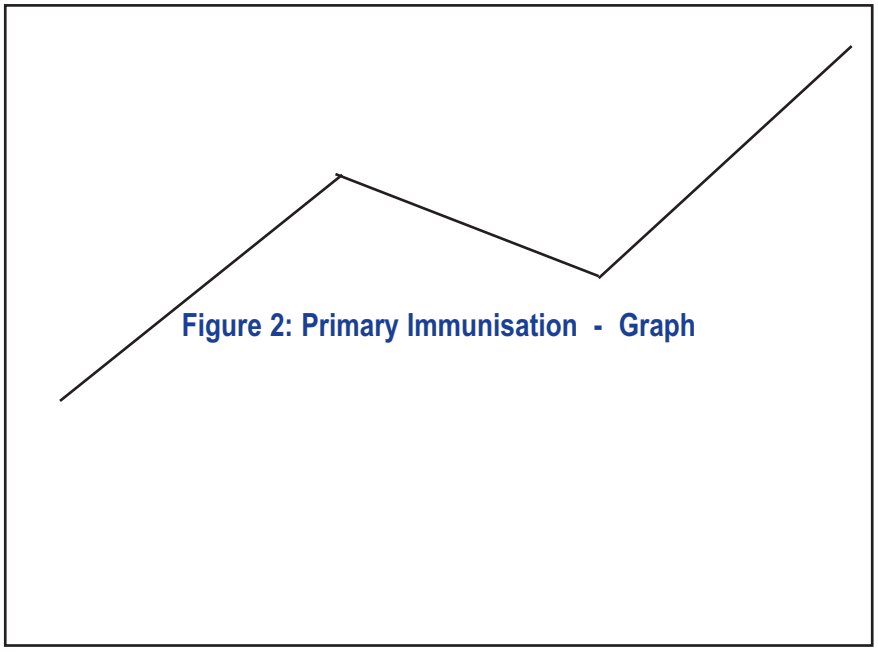
Figure 2: Primary Immunisation and MMR Uptake Rates at 24 months of age for those children born from January 1999 to December 2001



Reasons for low uptake

Many factors contribute to the low immunisation uptake rates recorded in the Eastern Region as in other areas. These factors include:

- recent ongoing negative media publicity surrounding the MMR vaccine
- fear among some parents regarding vaccine safety
- incorrect assumptions that immunisation against once common vaccine-preventable diseases are no longer important

In addition, many parents are poorly informed about vaccine-preventable diseases and of the benefits of vaccination. Research has shown that many health professionals feel poorly equipped to answer parents questions. [2.3]

Responses to low uptake

Eastern Regional Health Authority immunisation committee

In a response to low uptake, an Eastern Regional Health Authority immunisation committee was convened in February 2002 to address immunisation issues in the Region. Strategies to improve the uptake of primary childhood immunisations were recommended. The aim of the committee was to increase the primary immunisation uptake rate in the Easter Region to 95% and to maintain it at this level. Research on parental attitudes to immunisation was one recommendation made by this committee under its communication strategy. As parents are, in a sense, the consumers of immunisation for their children, it is essential to ask parents for their opinions as well as implementing other improvements to the system. Information gained assists in identifying the beliefs and attitudes of parents towards childhood immunisations and addressing any concerns or barriers to uptake of childhood immunisations that they may have.

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National Review Group

A survey undertaken by the National Review Group of Immunisation / Vaccination Programmes [4] indicates that provision of accurate and reliable information is key to generating maximum confidence in immunisation programmes. Other contributory factors include the mode of communication, the media perspective, and the involvement of health professionals in imparting information, as wel as the importance of having well-planned and organised communication strategies and adequate IT networks for dissemination of information.

The National Review Group identified deficiencies in the communication strategy and made recommendations, including:

- making information on benefits of vaccine, risks from diseases and changes in immunisation schedules available to parents in a standard manner
- providing health professionals with up-to-date information about vaccine developments, so that they can answer parents queries

The review also noted that the mechanism for communicating vaccine shortages, changes in the immunisation schedule and controversial issues regarding vaccines is not satisfactory and does not meet the needs of professionals and the public. The role of communication is an essential one where immunisation is concerned. Information must be provided for parents to ensure that they can make informed decisions about whether or not to immunise their children. A pro-active approach to the benefits of immunisation should be encouraged in all those involved in this area. [5] Some of the recommendations of this group are currently being implemented and a review will be conducted.

Importance of parental attitudes and behaviour

Parental attitude towards disease is known to be a predictor of vaccine uptake. The tracking studies of the Health Education Authority in the UK have found that parental attitudes to vaccination indicate that confidence in the safety of MMR vaccine has fallen in parallel with vaccine uptake. [6]

Observations from a survey of parental attitudes towards measles immunisation after a measles outbreak in a predominantly un-immunised community found that vaccination campaigners should emphasise the safety issues of the vaccine and its effectiveness in a balanced argument rather than the severity of measles as an illness. The study found that scare tactics are not effective, as they do not resonate with people's experience of the disease. Most people have experience of the disease in its mild or moderate form and do not view it as a severe illness in most children. [7]

A qualitative study in the UK examined the decision-making process of parents. Three responses were commonly described:

- a routine response to immunisation, i.e. having children immunised as a matter of course on advice of health professionals
- an emotional response - relying on emotional instinct as to whether or not to immunise and delaying the decision by entering a questioning phase where a process of seeking and evaluating information is conducted and a decision is made
- a reflective response - taking a period of time to reflect on their decision

This decision making process occurs over a period of time, and it is dynamic and unique to each vaccination and individual child being immunised. [8]

In another study, four key factors influenced parents decisions:

- beliefs about risks and benefits of MMR compared with contracting the diseases
- information from the media and other sources about the safety of MMR
- confidence and trust in the advice of health professionals and attitudes towards compliance with this advice
- views on the importance of individual choice within government policy on immunisation

This study also noted that parents found the MMR decision-making process stressful and that many felt pressurise from health professionals to take vaccinations. [9]

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In addition to well known factors in decisions not to vaccinate, such as perceived dangers of the vaccine and low susceptibility to the disease, new factors have been identified, including:

- perceived ability to control children's susceptibility to the disease and the outcome of the disease
- ambiguity or uncertainty about the reliability of vaccine information
- a preference for errors of omission over errors of commission
- recognition that if many other children are vaccinated, the risk to unvaccinated children may be lowered (10)

A recent Irish study found that the decision of parents on whether or not to vaccinate their children was influenced very strongly by fear and guilt. Parents felt under considerable pressure to have their children vaccinated, with pressure coming from society and the health services. Some parents mistrusted the health services. (2)

Qualitative Methodology

Focus Groups

This study utilised focus groups to explore parental attitudes to immunisation. Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data. The method is particularly suitable for exploring people's knowledge and experiences and can be used to examine not only what people think bur how they think and why they think that way. (11)

Focus group research involves organised discussion with a selected group of individuals. The main purpose of focus group research is to draw upon respondents' attitudes, feelings, beliefs, experiences and reactions in a way that would not be feasible using other methods, for example, observation, one-to-one interviewing or questionnaire surveys. These attitudes, feelings and beliefs may be partially independent of a group or its social setting, but are more likely to be revealed via the social gathering and the interaction that being in a focus group entails. By its nature, focus group research is open-ended and cannot be entirely predetermined.

Focus groups can be difficult to assemble, and it may not be easy to get a representative sample. The role of facilitator is important, especially in terms of providing clear explanations of the purpose of the group, helping people feel at ease and facilitating interaction between group members. The facilitator uses open-ended questions and a topic list as a guide. He or she may also need to challenge participants, especially to draw out people's differences and tease out a diverse range of meanings on the topic under discussion. Sometimes facilitators will need to probe for details, or move things forward when the conversation is drifting or has reached a minor conclusion, to ensure everyone participates and gets a chance to speak.

Rationale

This study explores the attitudes towards immunisation of parents with young children. Parents are the decision makers and their attitudes and experiences of immunisation are critical to influencing uptake rates. In this study, parents recent immunisation experiences, beliefs and attitudes, and preferred information sources were identified by asking them to discuss immunisation with other parents in a group setting. This approach was taken because it is a direct method of communicating and surveying the attitudes of parent of young children. (5)

This research in the Eastern Region will inform communication strategies, can be used to track immunisation interventions and will facilitate the production of appropriate information materials. Focus groups also provide insight into parental knowledge of, and beliefs and attitudes towards, childhood immunisation. The aim is to inform future initiatives so as to increase the uptake of childhood immunisation in the Eastern Regional Health Authority by giving parents, who are the primary decision makers in this process, a voice and stake in the process. This will help us to understand the reasons parents choose to immunise their children and why a minority do not.

Chapter 2

Methodology

Selection of Groups

The subjects for this research were parents with children under the age of five (this did not exclude parents who also had older children). The five focus groups selected for this research were not representative of all parents but an attempt was made to form groups that reflected different parent groups in society. It was decided that groups from poorer and higher socio-economic groups would be chosen as well as a group from a workplace setting to reflect attitudes of working parents. Due to the difficulty of assembling focus groups, we chose groups that already existed for the first two categories and assembled a workplace focus group for the working parents group. The first two groups consisted solely of women and we actively recruited men for our workplace parent group. Spousal contribution to decision making was actively asked as a topic in focus groups. A brief description of each group and its recruitment into the study follows.

Family Resource Centre

These Centres are locally based and provide a range of services to individuals in receipt of state support, for example creche, health services, information, training courses and various activities. The women that attended our focus group were in “back to work” training and were receiving skills training in a variety of areas for 20 hours a week. No men attend the group. The focus group was held with all of the participants (16) at once and was a large group. Personal information was not ascertained at the focus group but it was apparent that many of these women were in their early twenties and perhaps late teens. The group engaged easily with the topics, and there was a diverse range of opinion and practice discussed. The group knew each other, so the dynamics flowed smoothly and the discussion was lively.

Mother and Toddler Group

This group consisted of mothers who attend a mother and toddler group that is held each week in the home of one of the mothers. The women were from a high socio-economic group and many would be from professional backgrounds and presently taking time off to raise children. Three smaller focus groups (3 - 4 participants) were held in the same morning, one after the other. The other mothers minded the children of the participants while the focus group was held in an adjoining room. The women engaged easily with the process and were participating readily. A wide range of opinions and actions was recorded.

Workplace Parent Group

This group was the most difficult to assemble. We advertised twice to recruit a focus group during working hours at lunchtime in a work location. We were only able to attract one or two people, and the focus groups did not proceed. The fact that working parents are often very busy and are not meeting as an existing group were factors. A group was then recruited using personal contacts and requests. The group consisted of medical and allied health professionals who are also parents of small children and included two fathers. This group was interesting because the participants clearly had knowledge of health issues and services. Where this it potentially a source of bias, we were interested in probing any ambiguity that this group might have towards immunisation. Health professionals are also parents and are subject to the same media pressures as ordinary parents.

Characteristics of the focus groups are summarised in table 1. The immunisation experience of each parent was asked and a summary of responses is available in table 2. A topic list was used to prompt the facilitator and keep the discussion focussed (Appendix 2). Participants were encouraged to discuss any issues that were not on the list but were of importance to them. A scribe took hand written notes, and prepared and recorded the session on a hand-held tape recorder. Tapes were transcribed after each focus group.

Table 1: Characteristics of Immunisation Focus Groups

	Number of Parents	Number of Children <5 years	Average Number of Children <5 years
Workplace parents	6	6	1.2
Mother and Toddler Group	9	19	2.1
Community Resource Centre	16	17	1.3

Table 2: Immunisation Status Information

	Up-to-date	Delayed	Refused MMR	Unknown
Workplace parents	50% (3)	50% (3)	0	0
Mother and Toddler Group	44% (4)	33% (3)	22% (2)	0
Family Resource Centre	63% (10)	0	13% (2)	25% (4)*

*Due to the larger size of this group, this information was not ascertained clearly.

Analysis

Analysis of qualitative data involves the researcher comparing discussions of similar themes and examining how these relate to the variables within the sample population. It is important also to reflect minority opinions and examples that do not fit with the majority view.

Ethical issues

Ethical considerations for focus groups are the same as for most other methods of social research. Participants were encouraged to keep confidential what they heard during the group and all data and transcripts were made anonymous. Ethical approval was sought and obtained from the Royal College of Physicians of Ireland, Faculty of Public Health Medicine.

Consent

Participation was explained in detail to each group. Participation was entirely voluntary and each member signed a detailed consent form and was given an information sheet with the contact details of the research team (Appendix 3 & 4). Adapted information sheets using simplified language were used in some groups to reflect literacy levels.

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Chapter 3

Results

The focus groups assembled in this research were very different from one another: in fact, they were selected on that basis, yet we found parental attitudes to immunisation very similar. Parents of small children had a number of attitudes and experiences in common with one another. This commonality occurred despite the final decision of choosing to immunise or not. The following are all themes, which were raised in each of the focus groups and emerged as key issues for parents.

Considered decision making regarding immunisation

Most parents describe their decision process as an anxious process. They worried, gathered information, immunised and then watched fearfully. It was a consistent finding across study groups that parents with an older child had immunised in the past almost automatically as advised by health professionals. However, because of the controversary and sustained questioning by the media about possible side effects of the MMR vaccination, parents were extremely concerned when deciding to vaccinate their younger children in the last five years. Parents recognised this change and shift in behaviour themselves, and they acknowledged that they are more wary and considered their decision more carefully. Most sought information and advice.

This information and advice can come from a wide range of sources with varying degrees of credibility. This searching-for information process is not a scientific, evidence-based endeavour as a health professional might envisage. It is rather a trawl through information material such as newspapers, Internet websites, anti-vaccination material, and opinion-gathering from family, friends, medical professionals (doctors, nurses, pharmacists, etc.) and alternative and complementary practitioners. There is often an experience of being overwhelmed by the sheer volume of information, number of sources available, and conflicting information. At the same time, parents express that there is a lack of relevant information. Parents are finding it hard to find information they believe in and find convincing. They are often confused and in doubt.

"my first child was born in the States, so I got everything that was going, and ehm, I didn't debate it either. I just trusted my paediatrician and my mother. I just, I felt good enough, I didn't think twice about the MMR when he was vaccinated but now, I have another one, she's been vaccinated, but I'm more concerned. I wouldn't not have her vaccinated but I am a little bit more sceptical, nervous, you know, I don't...feel like I know enough about it. Really just since all the publicity."

Parental Anxiety

Parental anxiety and the need for reassurance were experienced in each of the groups. Many parents need encouragement while they are in the decision making process to relieve doubts and fears. Feeling of fear and guilt occurred in some parents independent of whether or not they vaccinated. Many parents also indicated confusion particularly over the MMR vaccine and fears about autism. Parents wheo were undecided and unsure often delayed giving immunisations to their children. Parents can occasionally be made to feel guilty by comments from health personnel, and this sometimes has a counterproductive effect. Parents need positive reassurance that they doing the right things. Anxiety was the predominant emotion in most parents but some parents in contrast also had a functional just get it done kind of attitude.

"because of all the publicity about it or whatever and I suppose, we would have had differences, myself and my husband, we would have had differences on, ye no on whether we should or we shouldn't and I suppose, looking at statistics and also the advice of our doctor and other friends, and that kind of thing, ah, we decided to go for it, but we were quite anxious going for it."

Parental concerns wre usually focussed in some way on the following two issues: the perceived overloading of the immune system and autism. MMR is the vaccine that caused most anxiety. Many parents had older children in the 5 - 8 year age range for whom they they did not even think about the risks of immunisation and just had it done. Sustained media attention over the MMR issue had planted doubts in parent's' minds in relation to the safety of MMR vaccine. Incorrect information is considerable. It is often the case that parents have some information or have heard something about a topic in the media, but knowledge of the details is long gone. This leaves the parents with lingering doubt, half truths and anecdotal stories along with feelings of unease.

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Attributing mental handicap, meningitis and autism to vaccine reactions was found in both poorer and higher socio-economic focus groups but the workplace work whose members were health service employees. Key factors in choosing not to vaccinate were: personally knowing an autistic child and their family, or having contact with other individuals in the family or in the community, whose child's disability was attributed by parents to a vaccine.

There was some discussion of separate MMR vaccines but no group was inclined to avail of this possibility. All groups had heard of single vaccines but were dissuaded for a number of reasons including: vaccine not licensed in Ireland, logistics of importing vaccine and paying someone to administer it, and having the child have to get three injections. Nevertheless, several women in the higher socio-economic focus groups expressed that it should be available as a choice and they would have considered it as an option if that was the case. None of the parents in any of the groups had used single vaccines.

"I remember trying to run out of the GP's office...I will just say it was one of the hardest decision I have ever had to make because it was almost like I was choosing to give them something which could potential harm them or... I could risk them cathing the disease which potentially kill, well the potential would be there, although I think we could be, I don't know, I could be completely wrong but I feel with good medical care, you probably shouldn't die in this day and age from it. If it's caught straight away."

Information

Parents indicated that there is a lack of relevant and accessible information available to them when they need it. The existing information can be confusing for some groups and not in a style that is readily accessible. There is also the problem of too much conflicting information that is not easily verified. This is why the quality and credibility of information is so crucial. Parents indicated that they would trust information from the health board if given it.

Some specific points of information that parents wanted but found hard to access were:

- explanation of vaccine reactions, including mild and moderate side effects
- literature designed in simple language
- health personnel to review leaflets with parents and answer questions

Parents expressed the desire to have some information on vaccine reactions prior to vaccination. In particular, parents would like information on how to treat minor reactions that caused discomfort in their children. Information about adverse reactions is scarce. Parents need descriptions of reactions, what it means to have a mild, moderate reaction or severe reaction and what to do if one occurs. Lack of this kind of detail can lead people to believe the health establishment is hiding something and trust can be eroded.

"Do you think the message, the information that you might be getting, is balanced?
No, it should be explained more clearly...
Yea, in our language.
They don't cater for people, like, like us, they cater for like, the middle class.
They cater for what the doctors would be telling ye. I'd rather just get a leaflet that says, Meningitis C bla bla bla...in our language, break it down to what I understand. Not like Meningitis, Immunisation...Use huge words that you wouldn't understand in the dictionary.
Ok, so you feel that they use - the words are too big?
Yea. Just tell ye what, the way we're talking now, ye understand everything...So I think everything should be wrotye down like that."

Bad batch effect

This issue emerged in all of the focus groups and was a real cause for concern for parents. Every focus group brought this up spontaneously in some form. Parents referred to two recent incidents of the failure of the immunisation system regarding BGC and Polio. Parents knew about the recall but not the details or any explanation for the failures. Parents remembered the "bad batch" but not what it was about. Mistakes erode parents confidence in the ability of the health system to keep their children safe.

"Yea, when was it? About a year ago it came out on the news that the children that were vaccinated at the time, there was some...do you remember that?
I do remember that.
P___ had gotten that particular ehm thing because I rang the GP and he rang me back and said "I'm sorry, that he got it but's it's nothing to worry about."

It was a bad batch....some kind of virus
Yea, there was something in it, do you remember that? The controversy, I was like "Jesus Christ, this is all I need".

Accountability

Accountability of the health service was especially important to the women who relied on income support. Their safety net is arguably not as good as the participants in the other focus groups. Their experience of observing disability in their own communities is of watching people struggle to make ends meet, access services and care for disabled children. They were concerned that there is no system to deal with side effects or circumstances when things go wrong. Their perception is that the health service is not there for disabled children, and parents are left to carry on. This made parents feel that the entire responsibility for the consequences of vaccination lay on their shoulders. This really an issue for the society in questioning who takes the responsibility for the more vulnerable groups within it. These poorer income women were clearly connecting some cases of disability with vaccination and concluded that when the health service is not there for disables children, parents are left to carry on.

"They'll pass the book.
Sorry, what do you mean by that?
It means like whoever is after doing it to ye, Oh, no it wasn't me and they all, Oh no, it wasn't me...
Right. OK. So you feel that that might be something that you would be concerned about.
Yea. Cos I'm the one who has to account for them if my child gets sick."

Key influencers

parents' personal experiences of immunisation indicated the importance of outside opinions in the decision to vaccinate. The key people of influence were health professionals, family, friends and the wider community. Many parents canvassed the opinion of thrie spouses, peer group and families, especially their mothers. Many of the parents in our focus groups had differing views to their spouses and this was particularly difficult if the spouse was in any way anti-vaccination.

Parents own history of contact with the health system and health professionals can have an effect on whether they immunise or not. Poor experiences, such as being patronised, not listened to, frightened or rushed in the past, can have a negative effect on the relationship. The converse is also true: when parents have a good relationship built up with their GP or public health nurse, they readily accept advice, information and reassurance. This results in a positive experience of the process of immunisation and a belief that the decision to immunise was a good one, and the likelihood that they will immunise subsequent children and advise others to do the same.

"Where did you get your information from. Like, is it from media sources or in the GP's surgery or where?
I think, ehm, a lot of us would just listen to each other, you know, the peers.
Yea.
There's leaflets and things in the doctor's place.
But it's one leaflet and that's it.
And I think they are biased in favour of it.
Yea, they are not really interested.
Yea, the doctors aren't, I think, the doctors I've come across"

Health professionals

Individuals will put different weight on the information received from many sources including the health services, but many parents are keen to be reassured by the facts presented by health authorities in leaflets and factual material. This is particularly powerful when reinforced by a health professional taking the time to answer questions, discuss issues, clarify points of confusion and offer reassurance based on professional experience and opinion. Clinics and GPs were easy to access for all groups. Participants were aware of their entitlement to free immunisation. Notification and reminder letters from the health board were also helpful to some parents as they prompted parents to seek immunisation for their children. This reminder method has previously been found to be effective. [12]

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Health professionals are also affected by media reports and can experience the same doubts and anxieties as their clients, especially regarding their own children. They are also affected by scandals in the health services that can erode their confidence in health messages. Hearing that anyone with a medical background was delaying or not immunising had a real effect on parents' decision on whether to immunise. The opposite was also true, and knowing that health professionals immunised their own children was a very credible reassurance for parents. Staff should be encouraged to act as advocates for immunisation by being provided with information and reassurance and communication skills. This includes health professionals that are not directly providing immunisations as they are often asked for their opinions.

"If you get it done and anything happened, you'd blame yourself so I suppose that's how I balance it out in my own head. Mmm, again I have a very, great GP, have a really fantastic GP who's again, got two small kids himself, and I think that really, ehm, puts you at ease, and the whole reassurance of 'Come back to me this afternoon', ye know, get it done in the morning, come back in the afternoon if there is any problems, just drop in then, that support was there, so I felt, I felt informed, I suppose as well, myself in what I was reading and then, the whole experience for the kids was as pleasant as it could be, you know. I would have concerns about it but, again as I say, I try and think what would happen if I didn't get it done".

"The doctors I've come across have all just not even wanted to go into discussion about it. What's wrong with them. Immunise them, that's all there is about it.

My GP is fabulous.
I must, I didn't really look for a lot of help from doctors or health nurses, or you know, I just made the decision on my own.
And that was it. So I can't really comment other than I spoke to my doctor and I spoke to another doctor as well, just couldn't believe I was even thinking about not giving it. You know .....
Yea
....Not that I was thinking about not giving her but I just wanted to discuss it, they didn't want to discuss it."

Characteristics of parents
In our groups, parents made choices that fell into three groups:
parents who immunised their children according to schedule
those who chose not to immunise
parents who delayed immunisation

The majority of parents chose to immunise their children and believed it was the right thing to do. A large number of parents immunised their children but delayed the process for a variety of reasons. A small minority of parents were actually anti-vaccination. As this viewpoint is counter to the wider societal view, it is often held with passionate conviction and for a variety of reasons, which are explored in greater detail below. All the parents in our focus groups were very pleased to be asked their opinion and experiences of immunisation. they participated with great enthusiasm and had many positive ideas and valuable contributions.

Parents who immunise
Most parents vaccinated their children and think it was the right thing to do. These parents are powerful advocates for immunisation. some recognised and articulated.the common-good theory and felt they were making a contribution when they chose to immunise. Some parents acknowledged that they were able to delay or not vaccinate their own children because many other parents had immunised. these compliant parents are not always seen in the media passionately defending their views. but they still consist of the majority of parents. These parents believe that immunising their children was the right thing to do and while some did it almost automatically, the majority made a considered and informed decision.

The immunisation system, through its communication strategy, should provide positive reinforcement for these parents. This majority of parents can find themselves defending their position, particularly with anti-vaccination advocates in their personal circles. Health advocates must design clear messages that answer questions and are understood by non-medical individuals. Consistent and clear

messaging would help general awareness and information raising in the general population. this would support parents and relieve anxiety by providing them with evidence-based reassurance.

"All the research recently is saying that there isn't any link really.
Oh yea, MMR, it was the MMR that did that to my kid. It is easier to have somebody to blame.
but even a week after getting the vaccine, your child stops saying Mama, Dada.
Well I don't know those people, I don't know their ....
That 's why I am not getting it. I've seen it from personal experience.
Well no, in other countries, in Sweden, Denmark, other countries have done studies as well and all the latest research is that there isn't any link.
But that's all medical research.
No, it's not, some of its independent
I don't think it is
It's independent.
No, because I read reports from, I think it was Swedish, Norwegian or Swedish.
I'm very very sceptical about the research that's given out by the government.
But whose research are you listening to then? You know.
I'm going by personal experience.
But nobody has very much personal experience.
Well I have my cousin who had her niece within a week and I knew the child, ye know, on a regular basis, I met the child, and then I had the neighbour across the road but I do feel that both children had the gene in them, the autism gene.
But autism tends to show itself around the same age as MMR anyway.
But within a week, you are not talking about six months later. You are talking within a week, the child stopped saying Mammy and Daddy.
Well I don't know enough about autism to...."

Parents who delay immunisations

"Ye I do feel a bit, kind of, when they are so tiny, just injecting them full of things just seems a bit unnerving which is probably another reason why I just kind of delayed it just a bit."

Many parents fell into this category in that they consciously or unconsciously delayed their children's vaccinations for a variety of expressed reasons. Some parents noted that no reminders were sent in the post, so they did not get around to it. Patient reminder systems were effective in improving immunisation rates in a previous American study. (12) Nevertheless, these parents would be in the minority as most parents were delaying deliberately. this delay can be a few months or until the child is three or four.

Almost all vaccinations in this group were later that recommended, but it is particularly in relation to MMR that parents re-write the immunisation schedule. There are many stated reasons: parents are too busy, the child is sick, the worry about the child being too young and not in contact with measles. But the key reasons are parental fears regarding immune system overload, too many vaccines given at once and anxiety over MMR. Anxiety is clearly a factor in parents delaying immunisations. In addition, guidelines and vaccination schedules keep changing and parents are confused about why MMR is now given at 12 months. Parents perceive this as too young so basically they just wait and immunise them later. some parents are delaying the MMR until the child is 3 - 4 years of age, though it is more common that the child would be immunised between 18 months and 3 years of age.

Parental Attitudes to Childhood Immunisation

"I waited until N___ was three. He was almost three, and I just, I wasn't sure whether I was going to do it or not. I hadn't read up enough about it. I didn't really know, ye know, I didn't really know that much about it and I read, I read as much as I could and decided I was going to give it to him because he had had no bad reaction to any other immunisations."

"I'm adamantly against it at a young age, at eighteen months. I am adamantly against it. At four years, even bringing him to the doctor's surgery at four years, I was crying going and I was crying coming out and I hovered over him for 48 hours. My husband, who would be a lot more laid back about things, but having seen those children that we know, he was hovering over him for 48 hours, very very emotional, ehm, but we'll wait with A__ and we'll get the two in one. Yea, I think, I think I probably, I've got guilts, if you like, in the back of my head which says to me. I can only afford to make the decision because so many people have had the immunisation....You know."

Parents who choose not to immunise

Parents who chose not to immunise were in the minority but were usually powerfully convinced in their beliefs. This was frequently accompanied by a personal certainty and a large amount of anti-vaccination information that is of dubious credibility. What stopped parents from immunising was experience of knowing an autistic child whether closely or through trusted sources whose autism was attributed to vaccine reaction by the parents. The certainty in which these beliefs are expressed by non-immunising parents can negatively influence parents who are delaying immunisation due to anxiety or doubt, A few parents acknowledged that they were able to delay or not vaccinate their own children because many other parents had immunised.

The view of anti-vaccine campaigners had influenced parental attitudes to immunisation. This influence is primarily to increase the concern, worry and anxiety factors for all parents, but it does not necessarily stop most parents from immunising their children. Parents will often read and consider anti-vaccination material but will still immunise. The health establishment is a powerful persuader for immunisation and we should not underestimate the power of existing messages for immunisation as we try to make them more effective. Positive messages of the benefits of immunisation are well received by parents, and it should not be necessary to appear defensive in the media.

The diverse reviews of the alternative and complementary health professionals are becoming more commonplace and not all are anti-vaccination. This community can be a source of information for parents and balanced information should be produced to review issues and claims raised and most commonly made. Parents who chose not to immunise viewed health information provided by health professionals with scepticism and considered doctors to have a vested interest. Much of this scepticism is perception, as anti-vaccination material does not seem to be as dismissed as readily.

"Sure a girl I know, it was her brother, ah, this is years ago, I don't know what needle he got but, he's handicapped now. It done something to him.
Autism.
Autism it must be, Yea.
Right and do you think that that happened as a result of the vaccination?
It was as a result of the vaccination. He was grand before the vaccination. I don't know which one it was now. It was a long time ago.
Years ago, more kids got reaction from them - Years ago, ye'd hear 'Oh, this chikl got that from that needle and...' kind of...
I haven't heard of any child getting anything from a needle, like
Well, no one in my family was ever vaccinated because of it."

"A cousin of mine had a little boy and she had him vaccinated and he was fine and then she had a little girl and the little girl...I used to see her, and she was saying Mammy and Daddy and she was interacting with the parents and interacting with us and ah...she brought her for the MMR, as she did her son, and within a week she stopped interacting, she stopped saying Mammy and Daddy, she stopped, ye know, asking for whatever she needed, and within a month, completely, totally different child, and she would in front of the wall and she would repeatedly bang her head off the wall. She's severely autistic and she goes to a special school. So...would have been about one, when that came about, so it put the fear of God into me, ye know. Now, I think she had it her all the time, but that the MMR triggered it, the autism. That's how I feel."

Chapter 4

Discussion and Recommendations

Parents are making decisions about their children's immunisations in the context of media reports and negative publicity about some vaccinations. The vaccines, other than MMR, routinely administered to children are generally of less concern to parents. This is consistent with other findings. (4) Nevertheless, there is fear and anxiety frequently being expressed around immunisation. These fears are consciously expressed by parents and within the parents' immediate circle of spouses, parents, siblings and friends. Anxiety is often also expressed to health professionals in contact with the parent. Though an abundance of information is available to parents, there is no quality control in the general media and parents and professionals can experience lack of expertise at identifying unbiased information for decision-making purposes. These fears and anxieties, particularly regarding the MMR vaccine, can also play out in an unconscious way where parents delay immunisation for a variety of reasons. This is seen clearly by the fact that uptake of immunisation for the primary vaccines is quite good, and there are few objections and little delay.

As noted in previous reports, communication of accurate, reliable and positive information on the benefits and risks of immunisation is critical to achieving and maintaining high immunisation uptake rates. This requires a multifaceted approach as several information providers must supply consistent information to many different groups, i.e. parents / guardians healthcare professionals, the public and the media. It is important that the benefits of vaccines in preventing a range of infectious diseases and their potential serious complications are communicated effectively. Direct communication and reassurance by health professionals is critical in relieving parental anxiety and increasing the message of the positive benefits of immunisation.

"*It's really down at that basic level of human interaction, in that the service provider, the GP or whoever, public health nurse, I know, one of the most important things I was ever taught in medical school was the one thing that you need to establish rapport and that you have a good rapport with the patient, ye know, just that in itself, can avoid loads of other problems that can occur, if you had a good rapport with the person...they would come away feeling better, even in you didn't do anything much, but, ye know, it's a kind of fine line between being dismissive. Having a good rapport, I think that's one of the only ways we can fight back against the media's kind of power in a sense that the media can undermine people's confidence, kind of, ye know, you could be, like even myself, I know about vaccinations and the MMR and the all these statistics about its safety for so many years, ye know, but one good documentary which was a bit dramatised starts making you think a bit, ye know, because when you're dealing with your own ,it's not just your work anymore, you take a few things to heart, and it makes you question some things but if you do have the confidence in people...they're actually delivering a service...that will allay those fears."*

The media plays a major role in determining public perception in relation to immunisation programmes. Well-organised media campaigns will provide information of immunisation, highlight the issues and counter negative / false information. Currently, the majority of media publicity focuses on the risks from vaccines in particular the MMR vaccine. Sustained action needs to be taken by health professionals to counterbalance this one-sided approach and to highlight the benefits of the vaccine in providing protection against infectious diseases.

Most parents vaccinate their children and think it is the right thing to do. These parents are powerful advocates for immunisation. They are not always seen in the media, but they believe immunisation is beneficial for their children and the wider society. They should be supported in this view by health professionals.

Parental Attitudes to Childhood Immunisation

Recommendations

The following recommendations address points specific to this study on parental attitudes to immunisation. The recommendations on communication strategies of the National Review Group of Immunisation / Vaccination Programmes and Report on Childhood Immunisation should also be implemented as soon as possible as many of the points overlap and address issues parents themselves identified through this study.

1. Health professionals need to recognise that providing reassurance to parents is very important. Time should be taken to answer questions and discuss immunisation with parents.

2. The rationale for the immunisation schedule should be explained to parents more clearly and the importance of compliance within a time frame understood.

3. Parents who delay immunisation should be targeted to ensure that the reasons for the delay are addressed and the dangers inherent in delaying are understood correctly. Reminder notices will influence some parents.

4. Information should be provided that specifically addresses parents' worries and explains the risks with regard to MMR vaccine, autism and 'immune system overload'.

5. Negative media coverage of MMR should continuously be counteracted with evidence-based information in relation to the positive benefits of immunisation. This should include correcting misinformation in the general media and having answers to frequently asked questions available.

6. Training for staff should be provided to reassure them of their ability to answer questions truthfully and accurately. Staff should be supported in maintaining their knowledge base on immunisation matters.

7. The communication of vaccine shortages, changes in immunisation schedules and controversial issues regarding vaccines does not currently reassure parents. Management of these issues in the media should be reviewed.

8. Recognition and reinforcement of parents who currently comply with the immunisation system should be encouraged. These parents are powerful advocates for childhood immunisation.

9. It should be accepted that not all parents will embrace immunisation. We should aim to minimise the damaging effect of parents who choose not to immunise have on other parents by providing reasons for immunisation and facts on safety of vaccines and risk analysis.

10. Papers addressing anti-vaccination literature and concerns should be produced. We should engage in debate in the media with anti-immunisation proponents but in a positive way.

11. Attempts should be made to engage dual-qualified alternative practitioners as advocates in the immunisation debate.

12. Information should be user friendly. It should be recognised that one-to-one communication and the opportunity to discuss and ask questions will deliver the message more powerfully.

Parental Attitudes to Childhood Immunisation

Specific Actions needed in the Eastern Regional Health Authority

1. Communicate this research to ERHA board, AHB's boards, GP's, PHN's and SAMO's.
2. Explain rationale regarding immunisation guidelines and why we recommend certain schedules.
3. Ensure reminder letters with user / reader friendly information and phone and e-mail contacts for obtaining information.
4. Address head on autism and 'immune system overload' information in a leaflet.
5. Create policy to counteract any negative publicity immediately with a positive focus.
6. Implement training for all staff regarding immunisation and frequently asked questions.
7. Form collaboration with dual-qualified practitioners who are immunisation advocates.

Parental Attitudes to Childhood Immunisation

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Appendix 1

Primary Childhood Immunisation Schedule

Table 1. Primary Childhood Immunisation in Ireland

Age	Immunisation
Birth-1 month	BCG
2 months	DTaP/IPV/Hib +Men C
4 months	DTaP/IPV/Hib +Men C
6 months	DTaP/IPV/Hib +Men C
12-15 months	MMR
4-5 years	DTaP/IPV +MMR

Appendix 2

Topic List for Immunisation Focus Groups

1. Thank participants for attendance

2. Purpose and description of focus group

3. Introduce facilitator and scribe, inform them of recorder

4. Introduce participants with a brief autobiography
    - A. What they do
    - B. Number of children
    - C. Ages of children

5. Experiences of vaccination
    - A. Personal experience
    - B. Choices
    - C. Personal attitudes

6. Convincing factors in your decision
    - A. Information
    - B. Key people
    - C. Barriers / Facilitators

7. Emotional Context
    - A. Feelings surrounding decision
    - B. Do you feel you made the right decision?
    - C. Advice to others

8. Specific issues: Comments on
    - A. Side effects
    - B. Health service
    - C. Health establishment
    - D. Media
    - E. Herd Immunity / Common good
    - F. Who do they trust?
    - G. Emotional toll
    - H. Guilt about decision
    - I. Intentions, busy / pressure / stress

9. Thank participants for meeting today and for their participation

Parental Attitudes to Childhood Immunisation

Appendix 3

Exploration of parental issues surrounding childhood immunisations

Why are we doing this study?

To try to understand why and how parents choose to have their children immunised and the process involved in making this decision. If parents choose not to immunise, the factors that influence this decision will be explored. The aim is to understand how parents feel about having their children immunised.

How will this study be done?

Focus groups are to be held with parents of children under the age of five. We will be using groups of parents from various settings, including: community resource centres, mother and toddler groups, and workplace groups. Our aim is to have a range of parents represented.
The discussion of topics will be in a comfortable and relaxed environment. A facilitator will help participants and all opinions will be valued. People will be encouraged to participate.

How will this study change things?

The information gained in this study will be presented to the committee on immunisation that is currently working to improve the whole immunisation system in the region. This committee is addressing many areas of the system including information systems, and delivery of service. This research will highlight the key themes that parents identify. This should include both the reasons for immunisation and the barriers to uptake.

Who else is participating?

We are hopeful that all types of parents will participate in the study. It is important to get a good cross-section of opinion, so that both positive and negative parental opinions are expressed.

Thank you very much for your time and input into this study. Your opinions and experiences are important. Your participation in this research project will in no way effect the services you or your children are entitles to or receive from the health boards. All information is handled confidentially and at no time are individuals identified. The sessions will be tape-recorded and the tapes destroyed after analysis. If you have any further questions, please feel free to contact Louise Mullen in the Department of Public Health, Dr. Steevens' Hospital (Tel: 635 2178 or E-mail: louise.mullen@erha.ie). Thank you!

Appendix 4

CONSENT

Title: Exploration of Parental Issues surrounding Childhood Immunisation

I _____, hereby consent to my participation in this focus group discussion as part on the study on "Parental attitudes surrounding childhood immunisation".

The study has been explained to me and I understand the purpose of the study. I understand that the focus group discussion will be recorded and that the tape will be destroyed after analysis. I understand that the information from this focus group will be anonymous and confidential and in the report from this study I will not identified.

Non-participation in this study will not in any way affect the services provided to you and your family by the Eastern Regional Health Authority.

Signed _____ Date _____

Signed _____ Date _____