

COMMUNICATING INFANT IMMUNISATION INFORMATION RESOURCE DEVELOPMENT AND EVALUATION

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Published by the School of Communication, Journalism and Marketing

**Massey University
Wellington and Manawatu**

ISBN 978-0-9876501-0-8

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Flipchart and fridge magnet design by Martin Lee and Kerry Ann Lee, professional designers and artists. Examples of these resources are not given in this report as the images used do not have permission to be distributed publicly.

ACKNOWLEDGEMENTS

We thank the Health Research Council of New Zealand and Ministry of Health Joint Venture Partnership Programme for funding this research.

A great deal of gratitude is owed to our Whanganui community steering group members who gave freely of their time, ideas and expertise to ensure this project was successful. These organisations and key people were:

- Whanganui Regional Primary Health Organisation (Janice Handley, Sue Hina, Janine Spence, Lucia Fua'ava)
- Nga Tai O Te Awa Māori Development Organisation (Sandy Taylor)
- Te Oranganui Iwi Health Authority Primary Health Organisation (Management of Te Puawai Whanau, Rangimarie Manuel, Josephine Taiaora)
- Te Kotuku Hauora O Rangitikei – Te Runanga O Ngati Apa (Lydia Matenga, Marilyn Archibald)
- OTaihape Māori Komiti Inc. (Leah Dehar)
- Born and Raised Pasifika Early Childhood Centre (Hellen Puhipuhi, Uncle Tom Webb)
- Birthright (Wanganui) (Barbara Young, Paula Tolley)
- Whanganui District Health Board Maternity Service (Lenna Young, Raewyn Harris).

We are also greatly indebted to the Immunisation Advisory Centre, University of Auckland, particularly Helen Petousis-Harris, Director of Research, who provided advice on every stage of the project and the accuracy of the information in the resources.

A range of other health organisations and health professionals in the Whanganui District Health Board region were also involved in the study. Their assistance in recruitment of interviewees and/ or review of the working resources was invaluable. These organisations and key professionals were:

- YWCA (Allyson Ehlers, Fi Ali)
- Libby Tuthill (Whanganui District Health Board Antenatal Educator)
- Anne Metekingi (Antenatal Clinic Receptionist, Whanganui District Health Board)
- Whanganui District Health Board Antenatal Clinic Midwives
- Rangitikei Health Centre (Bev Jansen)
- Waimarino Health Centre (Enid Windle, Robyn McDougal, Katherine Hall, Sue Crabtree)
- Ann Wild (Manawatu/ Wanganui Royal NZ Plunket Society)
- Lorraine McKenna (Locality Clinic Manager, Family Planning)
- Independent Midwives (Cyd Welsh, Juin Ferguson, Cheryl Baker)
- OTaihape Health Centre Midwifery Service (Kiwi Rowlands, Margaret McKinnon, Angelique Tucker)
- Carol Ramsden (Whanganui District Health Board Physiotherapist).

We also thank Dr Bronwyn Watson for the commissioned literature review, which has not only provided a context and rationale for our method, but also interesting points for consideration in further resource development.

Finally, we extend our thanks to our focus group and interview participants who were generous enough to share their experiences and also provided feedback on drafts of the resources.

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EXECUTIVE SUMMARY

The project team, funded by the Ministry of Health and the Health Research Council of New Zealand, worked with end users and key community groups to develop and test resources designed to communicate information about infant immunisation to mothers-to-be.

Background

In late 2007, Massey University's Adult Literacy and Communication Research (ALCR) group met with the Whanganui Regional Primary Health Organisation (PHO) research facilitator. The ALCR group had developed, through a prior research project, means of using illustrations to communicate findings to participants with low literacy levels. The group wished to develop this idea further, potentially in terms of communicating health information to individuals with low health literacy levels. The resultant discussion resolved to merge two ideas: 1) the interest in developing illustrative means of communicating information; and 2) the community-identified need in Whanganui to enhance infant immunisation uptake rates.

Building the community team

Through Whanganui Regional PHO's research facilitator, a snowballing technique was used to approach health, education and family support professionals with an interest in infant immunisation in the Whanganui District Health Board region (where the project was based). The ALCR group also contacted the Immunisation Advisory Centre at the University of Auckland. Everyone approached was enthusiastic about the idea of developing communication resources for infant immunisation that engaged end-users more fully. The final project team included: members of the ALCR group, School of Communication, Journalism & Marketing, Massey University; the Whanganui Regional PHO; the Immunisation Advisory Centre, University of Auckland; hospital and independent midwifery organisations including the Whanganui Hospital Maternity Service and associated rural and urban clinics throughout the region; Māori and Pasifika health and education service providers such as Nga Tai O Te Awa Māori Development Organisation, Te Oranganui Iwi Health Authority PHO, Te Kotuku Hauora O Rangitikei – Te Runanga O Ngati Apa, OTaihape Māori Komiti Inc. and the Born and Raised Pasifika Early Childhood Centre; and Birthright (Wanganui) for sole parents.

Objectives

Funded in November 2008 by the Ministry of Health and Health Research Council of New Zealand Partnership Programme, the project had four objectives:

- 1) to develop appropriate immunisation communication resources;
- 2) to determine if the resources improved recall and comprehension of information;
- 3) to report on the outcomes in relation to immunisation uptake at six weeks and again at three months;
- 4) to evaluate the resources and suggest recommendations for modification.

Method

The project began with a contracted literature review outlining the key literature in the infant immunisation field and placing the Whanganui region in context with national and international

immunisation rates. This review also discussed the impact of health literacy and the use of illustrations on understanding of health communication materials.

Collaboratively, the project team completed a two-phase method. **Phase one** involved a series of **focus groups with end-users and health professionals** to develop end-user directed infant immunisation communication resources. **Phase two** involved **a pilot trial of the resources utilising an intervention group and a control group**. The intervention group saw the fridge magnet and the flipchart along with an oral presentation of the key points on each page, whereas the control group only heard the oral presentation. Participants in the trial were soon-to-be mothers interviewed in their third trimester and again approximately eight weeks post-birth. Immunisation uptake rates were checked through National Immunisation Register (NIR) data at six weeks and three months. The project focused on infant immunisation due to the project timeframe of 21 months. At the end of each phase, feedback meetings were held with end-users and health professionals to validate the findings and further develop the resources.

Resource development

The focus group and subsequent feedback meetings with end-users and health professionals led to the development of a flipchart and an accompanying fridge magnet. The flipchart was developed to be used as a discussion tool in a one-to-one interaction between a health professional and a client (the most preferred method of information delivery). Each page of the A5-sized flipchart represents one key message or piece of information that end-users wished to know more about. Each page has associated spoken information for the health professional to read to and discuss with the client. The flipchart and magnet use bright colours, simple wording and photographic images. Both resources also contain a simplified immunisation schedule to serve as a reminder of due dates, as well as 0800 numbers and websites for further information if required.

Tone and approach in resources

Some of our focus group participants along with other research findings (see references 1-3) indicated that parents wish to be presented with multiple viewpoints on immunisation and are upset by messages perceived as coercive. To attempt to address the need for information that is neither too overtly biased nor strongly coercive we avoided including phrases such as 'Immunisation is good'. Instead, we have taken care to use informative, non-emotive language in stating, for example, the process of events when people visit a clinic to have their child immunised, the responses to be expected and the response symptoms to be concerned about. We acknowledge that by including pictures of children suffering from the diseases (as requested by focus group participants) and by stating these are the diseases immunisations help protect against, we still imply that immunisation is good. Nevertheless, while our resources are effectively pro-immunisation, they are perhaps not as direct as some other publications in saying that people should immunise. It was important to all the participants that resources not be authoritarian in their approach.

Outline of qualitative interview findings

The antenatal and postnatal interviews generated data on a number of factors including: sources of information; information quality judgements; information needs; preferred means of receiving information; preferred times of delivery of immunisation information; impacting factors on immunisation decisions; text-messaging preferences; recall of intervention material and evaluation

of the fridge magnet (postnatal interview only); and the intention to or the incidence of immunisation at six-weeks (see section 4.3 and 4.4).

Findings specific to the resources

The control group were more likely, at the postnatal interview, to have little to no recall of the information given to them, even with prompting. The intervention group, however, were more likely to have confident recall, recalling three or more items of information without prompting. Of those who had been given a fridge magnet, 73% had displayed it in their home and stated it was a useful reminder. The project team initially sought to make comparisons between individuals with high health literacy levels and individuals with low levels. However, using the Short Test of Functional Health Literacy for Adults (STOFHLA) showed all bar one of our participants had adequate health literacy levels. Therefore, this analysis was not pursued.

Immunisation uptake rates were similar across the two groups. The entire intervention group had fully immunised their children by three months and all bar three of the control group had done so. Due to the small size of the pilot sample, it is desirable to test these resources with a larger sample to see if this small difference was due to chance, or is indicative of actual differences. Research into whether differences could be seen at later immunisation dates is also needed.

Recommendations: Changes to resources

Recommendations include minor changes or additions to the flipchart and fridge magnet suggested through feedback sessions with health professionals and end-users (Set out in 5.5.1 & 5.5.2). Work has begun on developing flipchart pages that address some of these recommendations. Subsequently, we have continued to collect improvement recommendations for a third future version.

Recommendations: Delivery of immunisation resources

These are set out in 5.5.3. Some key recommendations include:

- Information is delivered as part of a discussion – much current delivery focuses on providing brochures that remain unread.
- A flipchart tool is used to stimulate discussion and give confidence to health professionals.
- Discussions should cover basic material with avenues to more detail provided if required.
- Information should be provided in a factual way and not sound authoritarian.
- Information should be presented twice (in the antenatal period at approximately 28-30 weeks and again, in the postnatal period, at approximately 3-4 weeks).

Future research

The project team proposes to continue to trial these resources with larger samples and over longer time periods. Several District Health Board regions have expressed interest and initial discussion with midwives has shown enthusiasm for the resources. A next step would trial the delivery of the flipchart as a discussion (which was unable to be done in this study as consistency was needed between participants). Also, the timing of the delivery needs to be explored.

1. INTRODUCTION

This research project is funded jointly by the Ministry of Health and the Health Research Council of New Zealand (Grant number: 08/603). Ethical approval for the project was granted by the Lower South Regional Health and Disability Ethics Committee (Ethics Identifier: LRS 08/09/043). The study investigates the impact that simplified immunisation communication resources (specifically simplified wording and image use) have on delivering key immunisation information to those making decisions about whether they will immunise their babies. There were four main project objectives:

- 1) to develop appropriate communication resources;
- 2) to determine if the resources improve recall and comprehension of information;
- 3) to report on the outcomes in relation to immunisation uptake at six weeks and again at three months;
- 4) to evaluate the resources and suggest recommendations for modification.

The project centred on the Whanganuiⁱ District Health Board region and was active from November 2008 to July 2010. It followed longitudinal research between 2004 and 2007 into adult literacy and employment in the Whanganui region conducted by members of the Adult Literacy and Communication Research (ALCR) group, School of Communication, Journalism and Marketing, Massey University in collaboration with the key community partner Wanganui District Library (for examples of the project reports see references 4-6). In this prior study, illustrations had been used as one means of communicating findings to participants with low literacy levels and had been well received by participants, tertiary providers and politicians alike. The ALCR group was keen to trial pictorial means of communicating key messages.

The topic of infant immunisation emerged from a community need identified by the Whanganui Regional Primary Health Organisation (PHO) research facilitator in discussions with members of the ALCR group. The Whanganui Regional PHO, representing the majority of the area's General Practitioners, suggested that there was a need to improve the communication process for infant immunisation. It is recognised that childhood immunisation is "one of the most cost-effective public health interventions"⁷. However, the current rate of childhood immunisation in New Zealand (NZ) at 84% of two year old children⁸, falls well below the 90-95% coverage rate considered necessary for immunisation to be effective⁹⁻¹⁰. In comparison, the United States, United Kingdom and Australia all report immunisation coverage rates of more than 90%¹¹⁻¹³, although disparities exist in the measurements used. Seeking to contribute to raising New Zealand's coverage level, we sought to develop ways to communicate key messages about immunisation that were easily understood and could sit alongside current, more detailed information. Prior to November 2008, other community groups were approached and readily endorsed the idea of creating a locally relevant pictorial resource to enhance infant immunisation communication practices.

We came to the project with a primary purpose of better informing the general public about infant immunisation, with a secondary purpose of attempting to increase immunisation uptake. The research was guided by two assumptions: 1) that immunisation is something that should be

ⁱ Wanganui can also be spelled Whanganui. The spelling used differs by organisation and region.

encouraged; and 2) that if the process and information behind immunisation is made more understandable, it may be more accessible for those who may otherwise be unsure whether to immunise or not.

The research was conducted in two phases: first, developing the resources in conjunction with the community partners and end-users; and, second, pilot testing the resources with two groups of soon-to-be mothers (utilising an intervention and a control group). From our prior research, the University researchers knew the importance of a community-based collaborative process in developing relevant resources. Models of collaborative partnerships for improving community health do appear in the literature (e.g., see references 15-19). The strategies used in the current study reflect these approaches as well as those of other university/community collaborative research projects, including cross-cultural collaborative strategies²⁰⁻²¹.

In the report that follows, we first present a literature review positioning childhood immunisation rates nationally, internationally and with specific reference to Whanganui. Barriers to childhood immunisation are discussed as are ways to improve immunisation coverage. A section on health literacy follows. The literature review concludes with a discussion of the use of illustrations in health communication resources.

The review is followed by an outline of our methodology and details regarding the methods used. Project outcomes are reported following the outline of each method. This structure reflects the iterative nature of the process of developing the tools and validating findings through feedback meetings. It also shows how each subsequent stage of development of the resources built on previous stages. Following this, a short discussion of key aspects of the results is presented, along with several recommendations for design, delivery and future immunisation communication work.

2. LITERATURE REVIEW

The aim of this review is to examine literature surrounding the use of illustrations in health communication, with specific reference to immunisation and health literacy. Firstly, research on early childhood immunisation coverage is presented. While the main focus is New Zealand data, some international research is included to provide comparisons. The review examines a range of immunisation issues including: 1) childhood immunisation coverage rates in New Zealand and how New Zealand's immunisation coverage compares internationally; 2) barriers to immunisation, including caregivers'ⁱⁱ concerns about the safety and efficacy of immunisation and the lack or bias of information on immunisation, emotional factors, access issues and attitudes, systems and funding of health care providers; and 3) ways of improving New Zealand's childhood immunisation coverage, a health professional team approach to informing caregivers about immunisation, immunisation education for health professionals and caregivers, the importance of 'timeliness' of immunisation and health practice systems and funding.

Secondly, the review looks at some of the extensive discussions on health literacy including: 1) a brief look at how health literacy is defined; 2) an examination of analyses of links between health and literacy; 3) a review of discussions of health literacy as a means of empowerment; and 4) a survey of links made between health literacy and immunisation.

Thirdly, the review examines the literature surrounding the use of illustrations in health communication. Research surveyed here has focused on five major issues: 1) the impact of illustrations on patient recall of health material; 2) the impact of illustrations on patient comprehension of health materials; 3) the impact of the use of illustrations on patient adherence; 4) the cultural relevance of illustrations; and 5) the use of illustrations in immunisation communications.

2.1 Childhood immunisation in New Zealand

2.1.1 Childhood immunisation coverage levels in New Zealand

According to the New Zealand Ministry of Health, while immunisation has been shown to be "one of the most cost-effective public health interventions"^{7(p.2)}, 90 to 95% coverage levels are needed for immunisation to be effective. A 1991/2 survey of New Zealand children found that fewer than 60% of two-year old children had received all the vaccination doses on the immunisation schedule. This had climbed to 77% by 2005⁷. The National Immunisation Register (NIR) was rolled out nationally in 2005 with the aim of further boosting immunisation levels. By the end of March, 2010 full immunisation coverage level at two years had risen to 84%⁸. Nevertheless, this is well short of the national target of 95% set by the Ministry of Health for 2000⁷ and again for 2012²² ⁱⁱⁱ.

ⁱⁱ Throughout this review, the terms 'caregivers' and 'parents' are used interchangeably. Likewise, terms such as 'family practices', 'health care providers', 'primary care practices' are interchangeable.

ⁱⁱⁱ The data show a consistently higher percentage with full immunisation at 12 months^{7,8,23}. Some children received delayed immunisations between the ages of two and four, giving full immunisation coverage of 82% for four-year olds that year, the same as at 12 months⁷. This may indicate that by age four, full immunisation in 2010 may also be around the 87% it is at 12 months. However, this would still be short of the 95% goal.

Of particular concern is the 78% full immunisation coverage for two-year old Māori children at the end of March 2010⁸. Although this is a marked increase since the 69% coverage of Māori children at age two years evident in the 2005 survey⁷, it is still well below the national coverage. Researchers note that such low immunisation coverage is especially worrying as Māori are among those most likely to suffer from the burden of immunisation-preventable diseases²⁴. Moreover, this continuing low coverage is despite the introduction of the NIR and other interventions proposed specifically to improve Māori immunisation rates²⁵. Similar interventions for Pasifika children, whose immunisation coverage had also been below the national rate²⁵, appear to have been more successful as by the 2005 survey Pasifika children's full immunisation coverage was the highest of all ethnic groups: 80% at two years and 87% by four years⁷. By March 2010, the two-year old level for Pasifika children had risen further to 86%, although by now the New Zealand European level had risen to equal this coverage, while Asian children's immunisation coverage was the highest at 91%⁸.

With specific reference to Whanganui (the centre of this research), a 2005 survey showed fully immunised coverage at two years in Whanganui was significantly lower than any other NZ district, with 55% coverage compared with the national coverage of 77.4% and with Taranaki at 83% and South Canterbury the highest at 93%⁷. By the end of March 2010, however, fully immunised two-year old children in Whanganui had risen to 85%, just above the national of 84%⁸. This put Whanganui at twelfth of 21 District Health Boards (DHBs). A singular improvement has been seen among the Whanganui district's Māori two-year olds, who rose dramatically to full immunisation of 85% in 2009, although dropped back slightly to 84% in the year to March 2010⁸. Whanganui's Pasifika two-year coverage of 100% in March 2009 was exceptional. But, like the Asian group at 75%, they represented fewer than 10 children¹⁴. Nevertheless, to date in 2010, Whanganui Pasifika children's coverage of 86% is equal to that of Whanganui's NZ European children and still above the national rate⁸. Whanganui Asian children, now also at 86%, while above the overall national coverage, lag behind the national Asian coverage of 91%.

Interestingly, while the national immunisation coverage levels show an association with the national Deprivation Levels, with immunisation coverage dropping as Deprivation Levels rise, in Whanganui there is no such clear relationship. On a scale of 1 to 5, with Level 5 representing those who suffer the greatest deprivation, those with the lowest immunisation coverage in Whanganui are those ranked at Level 2: their coverage is 81%, compared with 87% at Levels 1 and 3, 84% at level 4 and 86% at Level 5⁸.

2.1.2 International childhood immunisation coverage comparisons

The latest statistics comparing New Zealand's immunisation uptake with the rest of the world are based on 2005 estimates from the United Nations Children's Fund (UNICEF)⁹ and the World Health Organisation (WHO)¹⁰. The UNICEF survey shows New Zealand in the top 10 of 25 in their "league table of early childhood education and care in economically advanced countries"^{9(p.2)}. However, New Zealand's position in the table appears to rest largely on meeting several recommendations for the provision of early childhood education, such as the training levels of staff and staff/children ratios. We do not meet other recommended conditions, including spending at least 1% of GDP on early childhood services, of reducing childhood poverty levels to less than 10%, or of reaching near-universal outreach of essential child health services.

Importantly, among this last group of markers is our low standing of 24th of 25 industrialised countries for immunisation protection against measles, polio and diphtheria/pertussis/tetanus for 12 to 23-month old children. To give an idea of our position in relation to those countries we often compare ourselves with, while New Zealand's immunisation coverage rate for these particular diseases was cited as 86%, the United Kingdom (UK) in 23rd position had 88% coverage, Australia at 17th place had 92% and the United States (US) at 13th equal with Denmark had 93% coverage. The top nation, Hungary, stood at 99%⁹. While it is important to remember that disparities exist in the measurements used, in New Zealand we clearly need to develop strategies that lift our performance to align ourselves with these other nations.

2.2 Barriers to childhood immunisation

As is so often evident in studies of the social world, research examining reasons why infants are not immunised presents a complex picture with multifactorial conclusions. Sometimes the conclusions may depend on whether it is caregivers or health providers whose views are presented. Alternatively, surveys show different factors to the fore among health provider perceptions. For example, a New Zealand survey of family physicians found 53% believed parental fear to be the greatest barrier to children's immunisation²⁶. In a survey of New Zealand primary health care providers, more than half of the doctors believed parental fear or ambivalence to be a barrier²⁴. But in this later survey, the largest percentage of health providers (70%) perceived the highest barrier to immunisation to be parental apathy. A survey of family practice nurses identified parental fear as the greatest barrier (68%), but also identified parental apathy as a barrier²⁷.

On the other hand, a survey of parents' views on immunisation²⁸ did not note parental apathy as a barrier. Instead, the report finds that participants had sought information on immunisation from a range of sources regarding their immunisation safety and efficacy concerns. However, for almost a half their lead maternity carer (LMC) was not one of the sources they recalled. The reason for some was that, "They viewed information from the Ministry of Health as biased"^{28(p.1)}. Also far from finding parental apathy, other researchers claim that regarding immunisation, "whatever decision is made, parents do not undertake the process lightly. Indeed, decisions regarding their children's wellbeing were made with considerable thought, questioning and discussion"^{3(p.7)}. Further research found that parents actively weigh the perceived benefits and risks of immunisation before deciding whether to have their children immunised².

Another suggested contributor to low immunisation levels is that the cost of childhood immunisations to family health care providers may discourage providers from making repeated recall reminders or from providing ongoing staff training in immunisation issues^{26,29}. A New Zealand survey uncovered a considerable cost to general practices above the government subsidy provided for each immunisation²⁹. The 'net cost' to the practitioner grew with each recall reminder required. Further, the net cost to providers included repeated recall reminders and follow-ups that did not result in immunisation and were, therefore, not "offset against the Immunisation Benefit"^{29(p.76)}. This cost to the health provider is contrary to the claim in the World Health Organisation report that in New Zealand, "Immunization spending financed using Government funds" is 100%^{10(p.R248)}.

In the Ministry of Health's *National Childhood Immunisation Coverage Survey 2005*, reasons for incomplete immunisation coverage are divided into four main categories: 1) provider practice; 2) caregiver practice; 3) demographics or social determinants; and 4) national immunisation support systems⁷. In their view, provider practice is the most influential factor and national support systems are paramount to success through implementation of such resources as an immunisation register to provide national surveillance of immunisation coverage.

What follows is a review of research, focused on New Zealand, suggesting reasons why young children may not be completely immunised. These reasons are divided into four broad groups, each of which covers a range of more specific issues. The first two groups of reasons include parents' conscious decisions not to immunise as well as general concerns held by some who still choose to immunise, while the last two include systemic issues:

1. Caregivers' concerns about the safety of immunisation, including: the safety of particular vaccines; vaccine efficacy; the effects of vaccines on children's immune systems; the possibility of both short- and long-term serious side-effects; whether the risks of the vaccine outweigh the risks from the disease; caregivers' emotional issues or 'omission bias'; and caregivers' concerns over whether another illness at the scheduled vaccination date is a contraindication to immunisation;
2. Caregivers' concerns that they are presented with insufficient or biased information about the benefits or risks of immunisation;
3. Access issues, including problems of transport and cost;
4. Attitudes, systems and funding of health care providers.

2.2.1 Caregiver concerns about the safety and efficacy of immunisation

New Zealand research often notes that caregivers' concerns about the safety and/or efficacy of immunisations contribute to an avoidance of immunisation for their children^{2,7,27,28,31-34}. The main fears expressed by parents in the research are: the possibility and impact of side-effects; that immunisation might damage the child's natural immunity, especially if the child has another illness when the immunisation is due; that the immunisations are unnecessary because the parents do not view the illnesses as serious; and that the parents may feel more guilty if the child suffers adverse impacts from the immunisation than if they contract the disease. Petousis-Harris et al.³² argue these concerns need to be addressed as the high level of lack of parental confidence of immunisation "may be sufficient to prevent the target vaccine uptake rate of 95% set by the Ministry of Health"^{32(p.246)}.

According to the Ministry of Health⁷, although nearly 80% of caregivers believed that serious side-effects from immunisation occurred only rarely, more than 50% of caregivers were still concerned about the possibility of such side-effects. A small survey of New Zealand caregivers, however, found that 85% were concerned about the risks of side-effects, both short- and long-term, including the risk of children developing autism, Crohn's disease and/or asthma²⁸. A fear of side-effects was the reason given by 72% of caregivers who did not immunise their children in another survey². Further

surveys of New Zealand mothers^{1,31}, practice nurses²⁷ and data from an immunisation hotline³⁴ support this claim as their data show evidence of caregiver fears of possible adverse impacts of immunisation, particularly when the child was presenting with any other illness at the scheduled immunisation date. From their research, Petousis-Harris et al.³¹ consider that parents' concern for their children's safety was their overriding motivation in whether or not to immunise their children.

A possible side-effect concerning parents is that immunisation may damage the child's immune system or 'natural' immunity²⁸. Preference for allowing their children's immunity to diseases to develop naturally and, conversely, a fear that the diseases might become resistant to the immunisations were pregnant women's reasons for non-immunisation². Researchers note that some parents viewed immunisations as 'artificial', counter to their desire to build their child's immunity through natural means such as breastfeeding, diet and good hygiene¹. Similarly, Australian research³⁵ indicated parents feared that immunising children would compromise the natural immune system, which was considered to be 'fragile, not fully formed' at the age for the earliest scheduled immunisations. For this reason, the authors suggest, parents were likely to miss immunisations at the scheduled time if the child or anyone in the family was suffering from minor illness³⁵.

Related to these parental concerns about side-effects, Wroe et al.² consider parents' emotional reasons for their immunisation decisions. They suggest that parents' emotional reasons for refusing immunisation may include fears over harming their child through a decision or action they take. Linked to this is 'omission bias', where "harm resulting from action is considered to be less acceptable than harm resulting from inaction"^{2(p.34)}. Such beliefs may lead parents to "find it more disturbing to consider harm that happened because they took the child to have an immunization than to consider harm that occurred because the nonimmunized child contracted the disease in question"^{2(p.34)}. The same emotional response was found in research on UK parents' concerns about the risks of immunisation³⁶. One solution to this problem may be for LMCs to encourage parents to "realise that both deciding to immunize and deciding not to immunize are active decisions"^{30(p.540)}.

For many caregivers, fear of the possible impact of immunisation overwhelms their ability to understand the impact of the diseases being immunised against. Around 12% of mothers in one survey were not convinced of the efficacy of immunisation or that measles is a serious disease². Non-immunisers in another survey were more concerned about the possibility of long-term side effects of immunisation than about consequences of the diseases: most understood the serious nature of the diseases, but believed their children were unlikely to contract them³⁵. For some parents, fears of the short-term pain of the injection and possible adverse reaction or long-term damage hold more immediacy than the seemingly remoter possibility of disease³¹. Therefore, for immunisation rates to rise, parents need to believe that their children are more at risk from the effects of disease than from immunisation³¹. This view supports the finding that parents who immunise their children are more likely to believe there to be greater personal and community benefits from immunisation and less likelihood of risk to their children from immunisation than from non-immunisation².

2.2.2 Caregivers' concerns about lack or bias of immunisation information

Following a survey of mothers of young children, Petousis-Harris et al.^{1(p.241)} argued that "Parental knowledge of vaccination and the diseases that vaccines protect against is an important determinant

in the decision to vaccinate their child". Several surveys of New Zealand parents have shown that parents believe that they either do not have sufficient information about immunisation and its risks or that the information they are given is biased^{1,2,3,28,31,34,37}.

A study of New Zealand mothers compared types of LMCs and where the mothers recalled receiving their immunisation information¹. According to the authors, the LMCs for the largest group (62%) were midwives. Of those mothers, only 61% recalled receiving immunisation information. Doctors were the LMCs for 20% of the women and of those 81% recalled receiving information. Eighteen percent of the women saw a specialist and only 20% of them remembered discussing immunisation. A much smaller survey sample of parents shows broadly similar results: 46% of the women with a midwife LMC, 100% with a doctor LMC and a third with a specialist LMC recalled receiving immunisation information²⁸. The first survey shows that 19% recalled receiving information from sources other than their LMC, with 53% of those being from Plunket¹.

The mothers in the first survey were divided over the usefulness of the information they had received: 70% believed they had received enough information to make an informed decision; 43% believed there was insufficient information on the possible risks, while 48% did not; more than a third found the information useful but insufficient; and more than a fifth felt the information was being used as a means of coercing them into immunisation, although most of those felt the decision was still being left to them. Overall, 76% responded that they intended immunising their child¹.

An even more disappointing result was found in a survey of parents attending antenatal classes³⁷. Seeking to learn what immunisation information parents were given, the authors found that while 85% of their participants recalled receiving information, only 48% believed they were given sufficient information to make an informed decision about immunising their baby. Fewer than half (44%) of those who recalled receiving immunisation information received material they recognised as coming from the Ministry of Health and a fifth received known anti-immunisation material either with Ministry pamphlets or by itself. Furthermore, after attending their antenatal classes, while 63% stated that they were very likely to immunise, a mere 33% were very confident about their decision.

Caregiver mistrust of immunisation information presented is a further factor regarding their decisions about immunisation. For example, Wroe et al.'s² survey participants desired to receive more information about both the benefits and the risks of immunisation. However, the authors were even more concerned that 10% of participants did not have sufficient trust in the immunisation information provided by the government to immunise their children. They argue for the need to address the issue of trust in order to build "confidence in public health strategies"^{2(p.40)}. This point of needing to build parents' trust both in the information and in health professionals is raised by other New Zealand researchers^{3,31,37}. Nevertheless, the problem is not confined to New Zealand. It is also an issue of concern for international researchers^{35,38,39}.

Mass media campaigns to promote vaccination, using disturbing images such as videos of a baby badly affected by meningococcal disease, do raise awareness and lead to increased immunisation³. On the other hand, they tend to lead to greater mistrust of the Ministry of Health. After noting this parental dissatisfaction, Watson et al. state:

Parents who consented to vaccinate and those who declined, frequently described the Ministry of Health media publicity as ‘scare mongering’, ‘controlling people through fear’, ‘fear driven’, ‘not balanced’ and ‘one-sided’. Even those with a more positive view made comments such as ‘presenting the Government’s received view’ and ‘needing in some way to twist it to force people to immunise’^{3(p.4)}.

Such mistrust of official immunisation information may also be linked to parents’ emotional response or ‘omission bias’, discussed above.

Researchers in New Zealand note that a contributor to parents’ mistrust of official immunisation and concerns about the safety of immunisation is an abundance of anti-immunisation literature distributed either with or instead of official, evidence-based resources^{26,31,34,37}. Petousis-Harris et al.^{31(p.400)} state: “The activities of the anti-immunisation lobby can create fears and myths about immunisation for other parents, especially those who are not confident about immunisation”. This view was supported in a survey of New Zealand family physicians, some of whom believed that patients’ immunisation fears are fuelled by “misinformation about immunisation distributed by both midwives and anti-immunisation lobby groups”^{26(p.2342)}. To counteract parents’ fears of receiving insufficient or biased material, “Information should be provided with reasoned scientific rationale and cues for safety such as showing healthy immunised babies should be considered”^{31(p.400)}.

2.2.3 Access issues

When researchers have sought to uncover reasons for the continuing low levels of immunisation coverage in New Zealand, some have asked about possible caregiver barriers to accessing immunisation services. Both health providers and parents surveyed have largely tended to downplay access as a possible factor. For example, 14.7% of family practice nurses in a survey agreed, compared with 78%^{iv} who did not agree, that patient difficulties in accessing services constituted a barrier to improving immunisation²⁷. A survey of family physician perspectives shows a similar view, with 13% of participants agreeing and 73% disagreeing that parental access to services was a barrier to immunisation²⁶. However, Goodyear-Smith et al.⁴⁰ found that, where general practitioners *did* perceive parental access to be a barrier, timeliness of immunisation coverage improved.

In a survey of parents’ views, Petousis-Harris et al.^{31(p.399)} found that “difficulty in accessing vaccination services did not emerge as a major issue”. However, the authors state that Pacific parents were not included in their research because “It was expressed by health providers working with Pacific parents that their low immunisation rates are due to structural rather than emotional barriers”^{31(p.401)}. Supporting this statement, Paterson et al.^{41,42} identified transport to immunisation services as a barrier for Pacific mothers. In their view, ‘rising parity’ (number of children) among Pacific women is associated with less likelihood of complete immunisation, which may be attributed in part to difficulty of organising travel to immunisation centres. They conclude that “the relatively large percentage of mothers reporting logistical difficulties warrants further investigation and attention if we seek to further increase immunisation rates”^{42(p.4887)}.

^{iv} Petousis-Harris et al.^{27(p.2727)} actually show 138 (92%) of nurses disagreed that access was an issue. However, it seems apparent from the data that 117 (78%) are the figures intended.

The Ministry of Health 2005 survey showed “significant demographic differences between ethnic groups”^{7(p.vii)}. According to their data, for example, the children of Māori caregivers were more likely to have moved house more than twice since the birth of the child, were more likely to be with a caregiver living alone and were less likely to be fully immunised at two years than other ethnic groups⁷. Paterson et al.⁴² suggest that targeting Pacific women to improve their low utilisation of antenatal classes and child immunisation opportunities may help raise their awareness of the related health issues. However, Grant et al.²⁴ point out:

Socioeconomic deprivation, rather than ethnicity, was the dominant determinant of practice immunization coverage. Much of the apparent association between ethnicity and immunization coverage was explained by the confounding effect of social deprivation. This practice level analysis confirms that poverty and factors associated with poverty are powerful and persistent barriers to immunization^{24(p.12)}.

This finding is supported by the immunisation statistics presented by the Ministry of Health^{14,23} and also by research showing that “Socioeconomic deprivation explained 30% of the variance in practice immunisation coverage”^{43(p.2)}. Their survey results led Paterson et al.⁴¹ to argue that focusing on immunisation education alone will not be sufficient to improve immunisation coverage, that issues of deprivation and social equity must also be addressed. It appears evident that further research into structural factors such as access may be relevant.

2.3.4 Attitudes, systems and funding of health care providers

Research focusing on reasons for poor [immunisation] coverage has tended to focus on the characteristics of the child, family, or household. Internationally however, it is well recognised that a significant contribution to gaining and maintaining high coverage lies with health systems and their providers. The identification of health system barriers has been used to support improvements in immunisation coverage in both Australia and the US^{43(p.4)}.

The above statement reflects results of a survey by the US National Vaccine Advisory Committee⁴⁴ who found that under-immunisation was far more likely to be the result of poverty and provider practices (including inadequate recording and reminder systems) than because of caregiver concerns about immunisation safety or efficacy. Turner⁴⁵ suggests that the role of primary health care providers may contribute more to improving immunisation coverage levels than attitudes or attributes of parents or caregivers. One paper cites seven overseas studies that point to high links between health provider characteristics and immunisation coverage rates³³.

Several New Zealand reports also point to health care provider practices as a vital factor in improving immunisation coverage levels in New Zealand^{24,26,27,33,36,40,43,47}. Three major areas of concern mentioned are: 1) health provider lack of knowledge regarding both risks and benefits of immunisations and contraindications to immunisations and the importance of adhering to the national immunisation schedule; 2) the costs to health providers of immunisation; and 3) the need for those in the wide range of health services to work as a team to promote immunisation rather than working in isolation. Literature regarding the first two concerns will be examined briefly here

and all three areas will be reviewed in the following section (see below, *Improving immunisation coverage in New Zealand*).

Although international research shows “that poor knowledge of immunisation by health professionals, rather than attitudes, is the single biggest factor in vaccine uptake”^{26(p.2343)}, New Zealand surveys found that physicians^{26,33} and practice nurses²⁷ did not recognise the importance of their own knowledge gaps. In fact, physicians in one study “rated their own lack of knowledge as the least likely factor in low immunisation coverage”^{26(p.2343)}. However, Jelleyman and Ure³³ identified a lack of professional certainty about whether, for example, the MMR vaccine is implicated in autism or Crohn’s disease. This is despite available scientific literature assuring providers of the safety of the MMR vaccine and the participants’ claims that they believed “quality scientific research was the most important basis for recommending vaccinations and considered current recommendations to be well supported”^{33(p.10)}. This led the authors to argue for recognition of the need for continuing professional education, especially regarding immunisation benefits and risks. Moreover, UK researchers state, “all healthcare professionals involved in immunisation provision require training to ensure that parents are provided with accurate and consistent information to allay any concerns or misconceptions about vaccines” (emphasis added)^{48(p.6828)}.

Almost half of mothers who had failed to complete their children’s immunisation cited medical reasons in one study⁴⁸. Several New Zealand surveys^{26,27,33,40,47} found medical practitioners surprisingly lacking in certainty of contraindications to some vaccines. The authors argue that lack of health professional knowledge of contraindications to immunisations and their resulting inability to effectively explain risks and benefits, contributes to caregivers’ lack of confidence in immunisation. In their view, to convince others of the benefits and safety of immunisations, the professionals themselves must be certain. Supporting this claim is research revealing higher immunisation coverage in practices “where staff were confident about immunization and where immunization was an organizational priority”^{24(p.13)}. Similarly, researchers argue that the poor knowledge of GPs in some areas may be offset by the work of practice nurses in New Zealand as it is they who tend to organise patient recalls, perform immunisations and attend immunisation training courses⁴⁰. These authors suggest, “Timeliness is probably more related to commitment at each interaction and taking advantage of opportunistic moments ... and it is GP attitude more than their knowledge that is a more important factor”^{40(p.406)}.

Lack of funding to health providers was perceived as the second highest barrier to immunisation, following parental fear, according to 44% of the family physicians in one survey²⁶. However, while the Ministry of Health noted strong evidence of the effectiveness of provider reminder/ recall systems in their 2005 survey, they “did not assess cost-effectiveness or other implementation issues”^{7(p.6)}. Therefore, as in earlier research²⁹, the level of funding available still did not cover costs of appropriate vaccine storage or patient recall reminders, leaving providers with a ‘net cost’²⁶. Moreover, 28% claimed that they lacked time to offer immunisation services²⁶. Together, these factors suggest that many physicians believe health providers have an important role in promoting and facilitating childhood immunisation but that to do so with the funding levels at the time of the study would entail subsidising it through time (including for attending training courses), vaccine storage and recall reminder costs.

2.3 Improving immunisation coverage in New Zealand

New Zealand caregivers are most likely to make the decision regarding childhood immunisation during the antenatal period^{2,24,28}. In two studies, 88%² and 67%²⁴ of survey participants had decided before the baby's birth whether they would have their baby immunised. However, as discussed above (in *Caregiver concerns about lack or bias of immunisation information*), a disturbing percentage of parents surveyed claimed to have received no information regarding immunisation during the antenatal period, especially from midwives and specialists. Of the caregivers surveyed in one study, for example, only 62% recalled receiving immunisation information in the antenatal period²⁴. Moreover, 29% of those caregivers reported the information had discouraged them from immunising their children. This finding is supported by Hamilton et al.²⁸, who revealed that more than a third of their participants had decided in the antenatal period to not immunise their children.

This section first examines research that looks at who informs caregivers about immunisation; this is followed by a look at discussions around the immunisation education of health professionals and the resources needed for both caregivers and health professionals. Next is a review of reports on the importance of 'timeliness' of immunisation uptake and recommendations for the re-involvement of family practices in antenatal care in achieving this. Suggestions for establishing family practice systems to facilitate the improvement of immunisation coverage are discussed and, finally, this section looks at calls for a review of immunisation funding levels to family practices.

2.3.1 A health professional team approach to informing caregivers about immunisation

Immunisation has traditionally been discussed with caregivers "within the general practice environment"^{26(p.303)}. The recent shift of antenatal and early postnatal care from general practices to midwives or obstetricians as LMCs has reduced antenatal opportunities for immunisation discussion within general practices²⁶. As Jolleyman and Ure³³ argue, the responsibility for caregiver immunisation education must now widen to also include midwives, obstetricians and antenatal education classes along with Plunket, Māori health workers and other early postnatal care agencies, public health nurses and hospital providers. This requires a concerted team effort among these groups to ensure consistent information about and promotion of, immunisation³³. But, because the groups outside family health practices have not been involved in providing immunisation services they have "not been targeted in immunisation education programmes"^{26(p.304)}. While Hamilton et al.^{28(p.5)} state, "Lead maternity carers are obliged only to provide Ministry of Health information to mothers and are free to offer anti-immunisation information from groups such as the Immunisation Awareness Society", Petousis-Harris et al.²⁶ note that there has been no legislation requiring immunisation education in antenatal classes.

One New Zealand research team⁴⁹ offers an example of caregiver immunisation education and awareness as a team effort among the wider health professional community. In their view, promotions for nation-wide immunisation campaigns, such as the Meningococcal B Immunisation Programme, should be used to raise awareness of the value of immunisation generally. For instance, "the increased public presence of trained community vaccinators"^{49(p.2201)} provides opportunities for increasing childhood immunisation coverage by reaching and teaching those who have otherwise missed immunisations and by providing links with appropriate childhood immunisation agencies⁴⁹.

2.3.2 Immunisation education for health professionals and caregivers

As mentioned above (in *Attitudes and systems of health care providers*), New Zealand research has identified LMC and other health professionals' uncertainties and concerns regarding benefits and risks of and contra-indications to, immunisation. Combined with caregiver concerns about the lack or bias of information regarding immunisation benefits and risks, these professional ambivalences have opened the way for a perhaps greater than otherwise influence on caregivers of anti-immunisation literature. As Petousis-Harris et al. note, "People with extreme anti-immunisation views are likely to be a small minority. However, their activities have the potential to influence a much larger group of parents"^{34(p.5043)}. Likewise, Bond et al.³⁵ are clear that parents have the right to be informed about immunisation:

Information needs to be developed which provides detailed discussion of the diseases and immunisation for parents who require this depth of information. To be effective, the basic literature and advice given to parents should contain an acknowledgment that some of these diseases can be experienced in relatively mild though unpleasant forms, but it should also emphasise that there can be serious complications, even in healthy children. Because it is the young children who are at greatest risk of complications from diseases such as whooping cough, the benefits of age-appropriate immunisation must be emphasised^{35(p.446)}.

Furthermore, New Zealand researchers^{1,2,28,31,33} argue that, as part of a united team approach to immunisation by all LMCs and health providers, health professionals require further ongoing immunisation training. That is, if health professionals are to effectively participate in immunisation education of caregivers, they must first fill the gaps in their own knowledge, especially in regard to immunisation risks and contraindications.

A need for improved resources "to more effectively address parental fears and misconceptions"^{26(p.2340)} and provide more balanced information about immunisation benefits and risks has been expressed by family physicians²⁶, practice nurses²⁷ and parents^{2,30,35,36}. Parents given information that clearly details adverse effects of immunisations and risks of diseases were less likely to be anxious about perceived adverse impacts, more likely to understand the risks of the diseases and more likely to immunise their children³⁰. However, there are warnings against developing information or mass programmes based on fear to persuade parents to immunise as it may lead to feelings of coercion and distrust³. Similarly, researchers recommend avoiding the use of blame or guilt in immunisation messages but to instead focus on "Messages that position children as the centre of the family (its *tāonga* or treasure) and stress the importance of the wellness of children for the family"^{31(p.401)}. A possible method of optimising the impact of immunisation decision-making interventions is to give them to parents during the antenatal period because "giving increased information in the antenatal period with a decision-making aid does follow through to a significant increase in timely immunisation coverage in the infant"^{45(p.2)}.

As well as the National Immunisation Register (discussed below in *Health practice immunisation systems and funding*), two nationwide initiatives contribute to developing an understanding of and promoting, immunisation issues among caregivers and health professionals in New Zealand. One is the Immunisation Advisory Centre and the other is the Immunisation Hotline. The Immunisation

Advisory Centre (IMAC) is a nationwide organisation based at the University of Auckland within the School of Population Health. The IMAC website has two major sections, one caregiver-focused and the other health professional-focused. Among the services provided are information for caregivers about the benefits and risks of particular vaccines, including answers to frequently asked questions; a current immunisation schedule that caregivers may consult; the toll-free phone number for the Immunisation Hotline; and an email reminder service of when immunisations are due. Members of the IMAC team have been and continue to be, involved in conducting valuable surveys and research into immunisation issues^{24,27,34,43,47}.

The Immunisation Hotline, funded by the Ministry of Health and based at the University of Auckland, is a toll-free hotline, established in 1998. Its purpose is to provide information on immunisations to both the general public and health professionals³⁴. A survey of the use of the hotline between 1999 and 2003³⁴ found that the use of the service had more than trebled over the period. It had been used by caregivers seeking reassurance and by health professionals seeking information to enable them to respond appropriately to concerned caregivers. As the authors note, one drawback to even wider use of the hotline by caregivers is the need for “knowledge and confidence in the use of a call centre”^{34(p.5043)}. Lack of computer access may be even more likely to constrain caregiver use of the IMAC website by those of lower socioeconomic status.

2.3.3 The importance of ‘timeliness’ in immunisation

‘Timeliness’ of immunisation emerges as one of the major factors to be considered in increasing immunisation levels with delayed immunisation appearing to be a main contributor to New Zealand’s low coverage figures. For example, by the end of March, 2010, age-appropriate immunisation coverage for New Zealand babies aged six months was at a very low 68%⁸. While there may be a degree of ‘catch-up’ immunisation after the 23 month period⁷, New Zealand and international research shows that departure from the national immunisation schedule (especially a delay in commencing the schedule) leads to the likelihood that the immunisation schedule will not be completed^{24,47,50,51,52}. There is also evidence that delaying scheduled immunisations leads to increased likelihood of children developing the diseases, with increases in hospitalisation and cases of long-term ill-effects and death from the diseases⁵³. In one survey, there was a five-fold increase in hospital admissions with pertussis among children where any of the three scheduled pertussis immunisations had been delayed⁵³. Australian research found an increase in infant morbidity where immunisation was delayed⁵⁴. The New Zealand Ministry of Health cite several further studies showing “the strongest predictor for incomplete immunisation was failure to commence the immunisation schedule on time or late vaccinations”^{7(p.6)}.

Encouraging ‘on time’ immunisation from the beginning of the immunisation schedule is cited by several authors as vital to the health of the most vulnerable and very young babies^{50,51,55,56}. Guyer et al.⁵¹ suggest a shift in focus on immunisation status from the milestone age of 24-months to the status of babies in their first six months. The reason is that this was the period during which these authors noticed a sharp decrease in immunisation coverage⁵¹. Of particular concern, is where there is a pattern of delayed immunisation “for diseases where multiple vaccine doses are required for protection and disease risk below 6 months of age is significant”^{7(p.4407)}, as has been shown is the case in New Zealand with regard to pertussis^{50,53,55}.

As family health practices are responsible for administering immunisation services, Turner et al.⁴³ link immunisation timeliness to the age at which babies are enrolled with a health practice. Their research shows that where a relationship is developed between a health practice and caregivers during the antenatal period the baby's immunisation is more likely to start at the scheduled time. Because most caregivers make their immunisation decisions in the antenatal period and caregivers tend to view their primary health practice as "the most important source of information about immunisation"^{26(p.2341)}, several New Zealand researchers^{24,26,43} recommend re-engaging or re-involving family physicians and family practices in antenatal care as a means of improving immunisation coverage. For example, immunisation uptake was increased where families of young babies had established an early formal relationship with their primary health provider^{24,43}. Grant et al.²⁴ attribute this to the opportunities within the family practice for promoting immunisation during the antenatal period, which also has the advantage of possibly being able to "remove the opportunity that the anti immunization lobby currently appears to have for their message to be heard first"^{24(p.14)}. Therefore, Turner et al.^{43(p.12)} recommend that "early engagement should extend into the antenatal period".

2.3.4 Health practice immunisation systems and funding

As well as working as a team to provide immunisation information to caregivers, health professionals need to work as a team to create opportunities for immunisation^{27,33,47,57}. Some authors argue that within primary care practices, also, immunisation should be viewed as a team responsibility⁴⁷. Integral to a successful team approach are health practice systems that target immunisation uptake because "Improvements in the infrastructure of immunization service delivery are key to the increase in immunization coverage"^{47(p.1)}. One suggestion is that practices use an electronic tagging system to alert the health practice team when an immunisation is due or overdue⁴⁷. This would enable each member of the practice team to take opportunities available, such as during patients' visits for other reasons, for 'opportunistic'⁷ immunisation advice and referral.

Likewise, the National Vaccine Advisory Committee recommend routine checks of the immunisation status of babies whenever they are seen in family practices for other reasons, creating a 'one-stop-shop' process where immunisations are offered at the same time as other checks⁴⁴. Following this advice may help avoid the missed immunisation opportunities that occurred in nearly a third of primary care practices audited by researchers⁴⁷. Researchers^{34,43,47,57} consider that where there is "an efficient practice management system"⁴³ in place, practice nurses are often in the position to play an important role in reassurance and education of caregivers and thus to lower the rate of missed immunisation opportunities. Turner et al. add that, along with access to and effective use of, high quality immunisation information, "regular audit and feedback"^{43(p.14)} of such practice systems should further contribute to the improvement of immunisation levels.

A further recommendation to increase childhood immunisation coverage is for the establishment of a national system of recall reminders^{7,43,44,46}. The Ministry of Health cites improvements in immunisation coverage through such national reminder systems in Scotland and Australia⁷. To this end, the Ministry of Health's National Immunisation Register (NIR) was established across New

Zealand in 2005, providing an easily accessible national database of immunisation information^v. According to the Ministry of Health, the NIR's "functions include provider or client reminders of recalls and information for parents and it can facilitate co-ordination between services"^{7(p.8)}. However, it seems apparent from subsequent research⁴³ that while the NIR offers invaluable immunisation data, which it provides to Immunisation Outreach Services, recall reminders and other services such as auditing of immunisation coverage, still largely depend on the efforts of primary health practices.

A final point on improving family practice provision of immunisation relates not to their own practices, but to expectations of what practices will provide. As discussed in *Attitudes, systems and funding of health care providers*, researchers found that immunisation services funding provided to family health practices is inadequate to cover the effort involved in a range of areas including storage of vaccines, staff immunisation training and making recall reminders, especially when repeated reminders do not result in immunisation because funding covers only positive outcomes. The authors argue that the nature and hours of work involved in immunisation services are undervalued and that the current underfunding of family practices for immunisation services is a barrier to increased immunisation coverage levels^{26,28,45}. In their view, the work by family practices is vital to improving immunisation levels and must be adequately funded.

2.4 Health literacy

2.4.1 What is health literacy?

The 2006 Adult Literacy and Life Skills Survey showed that the literacy skills of 43 percent (1.1 million) of New Zealanders aged between 16 and 65 years were "below those needed to participate fully in a knowledge society"^{58(p.27)}. The same survey found that Canadians had a slightly smaller percentage (40%) with low literacy skills, while in the US more than half (52%) of their adults were found to have inadequate skills. Moreover, the survey indicated that 51% of adult New Zealanders, compared with 48% of Canadian, 50% of Australian and 59% of US adults were found to have low numeracy skills⁵⁸. Such a high proportion of the population with low literacy skills is a cause for concern in many areas of social life, including the health sector because, as Williams et al. point out:

[M]any patients have difficulty understanding what physicians tell them. Even immediately after leaving their physicians' offices, patients are able to recall 50% or less of important information just given to them. Patients with inadequate literacy skills, particularly those with a poor understanding of common medical terms and written health materials, probably account for a substantial portion of these patients^{59(p.383)}.

Subsequent to the 1992 National Adult Literacy Survey (NALS) in the US, which found that more than 47% of adult Americans had low literacy skills, studies have raised questions of the implications for the health sector over the disparity between the reading levels of health-related materials and the

^v It is from the NIR's database that the Ministry of Health statistics on immunisation discussed above, in *Childhood Immunisation Coverage Levels in New Zealand*, are obtained.

reading skills of the intended audience⁶⁰. These, in turn, have led to the research field of health literacy with numerous and ongoing attempts to define health literacy.

In discussing definitions of health literacy, Kickbusch⁶¹ notes that some definitions have a rather narrow focus, such as the functional definition which defines health literacy as “the ability to read, understand and act on health care information”^{61(p.292)}. Other narrow definitions cited by Kickbusch situate health literacy in medical and healthcare settings. These include a view of health literacy as “a constellation of skills, including the ability to perform basic reading and numerical skills required to function in the health care environment”^{61(p.292)}.

Ratzan and Parker⁶² broaden the definition to include the health literacy of individuals in the wider social sphere. They view health literacy as: “The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions”^{62(p.vi)}. Nielsen-Bohlman et al.⁶⁰ argue that the advantages of this definition are that first, individual potential as well as skills are acknowledged and second, health literacy is recognised as the product of interconnecting factors in cultural, social and individual arenas. However, they acknowledge that this definition “appears to limit the problem of health literacy to the capacity and competence of the individual”^{60(p.37)}. From this perspective, they state,

The impact of health literacy arises from the interaction of the individual and the health context.... Both the causes and the remedies for limited health literacy rest with our cultural and social framework, the health and education systems that serve it and the interactions between these factors^{60(p.32)}.

The World Health Organisation (WHO) provides a further comprehensive definition of health literacy. The WHO’s definition includes the role of an individual’s potential but also suggests that, in the interests of social justice, there is a social responsibility to promote better health literacy for all:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment

cited in 63(264)

In unpacking the layers of meaning and both individual and societal implications in the complex WHO definition, Nutbeam⁶³ makes an argument for the need for social action:

This [WHO] definition ... indicates that health literacy may have both personal and social benefits and has profound implications for education and communication methods. In terms of ‘content’, efforts to improve people’s knowledge, understanding and capacity to act, should not only be directed at changing personal lifestyle or the way in which people use the health services. Health education could also raise awareness of the social, economic and environmental determinants of health and be directed towards the promotion of individual and collective actions which may lead to modification of these determinants^{63(p.264)}.

According to Nutbeam, health literacy is a “key outcome from health education”^{63(p.259)}. He positions it as an umbrella term for a composite of three forms of health literacy: ‘functional health literacy’, ‘interactive health literacy’ and ‘critical health literacy’^{63(p.265)}. Kerka summarises this model:

(1) functional health literacy – basic reading and writing skills to understand and follow simple health messages; (2) interactive health literacy – more advanced literacy, cognitive and interpersonal skills to manage health in partnership with professionals; and (3) critical health literacy – ability to analyze information critically, increase awareness and participate in action to address barriers^{64(p.1)}.

2.4.2 Literacy and health

The link between health and education has long been of concern among health researchers and health professionals, worldwide⁶¹. A US study of adult students at a publicly funded literacy training programme found that those with low literacy levels have poorer physical and psychosocial health than those with higher literacy levels⁶⁵. Results from a study of US hospital patients show that patients with inadequate functional health literacy were more likely than those with adequate literacy to report having had poor health and more frequent use of expensive health services, such as hospitalisation and emergency department care⁶⁶. One review cites studies showing that those with lower health literacy are less likely to receive preventive services, are less likely to follow health care instructions and more likely to suffer worse health outcomes with more complications and advanced cases of disease⁶⁷. This means that, although more research is necessary to prove causality, it is possible that those with low health literacy will incur higher medical costs⁶⁷.

A study in Arizona found strong correlation between low literacy and higher health care costs⁶⁸. Weiss argues that “The relationship between limited literacy and poorer health and higher costs is strong and independent of other socioeconomic factors”^{97(p.297)}. However, Baker et al.⁶⁶ suggest that the poorer health status of those with lower literacy levels is the result of ‘indirect effects’ from a complex interrelationship between low literacy levels and many aspects of their socioeconomic positions. For example, low literacy levels may both result in and be the result of, such factors as poorer (and less desirable or safe) employment opportunities, poorer income levels, poorer housing and poorer nutrition⁶⁶.

On the other hand, several researchers believe that while there is an issue of health disparity where those with low literacy are more likely to suffer worse health outcomes, in today’s complex health system, health literacy is not entirely dependent on levels or years of education^{60,64,66-68,74,116}. For example, Kerka argues:

Adults at all literacy levels must cope with conflicting media reports ... myths and misconceptions about communicable diseases such as smallpox, anthrax and SARS; pharmaceutical company advertising about new drugs; and the vast amounts of health information available on the Internet^{64(p.1)}.

Likewise, Nielsen-Bohlman et al.^{60(p.2)} state: “Even people with strong literacy skills may have trouble obtaining, understanding and using health information: ... a science teacher may not understand

information sent by a doctor about a brain function test and an accountant may not know when to get a mammogram". Kerka⁶⁴ points out that those with high literacy skills may become low-literate patients through cognitive or physical impairment.

A recent shift in societal expectations where health care has increasingly become an *individual* rather than a health-care *system* responsibility further underlines the importance of health literacy. Particularly relevant, according to Kerka⁶⁴, is the move from a paternalistic model of health care to a partnership model where individuals are expected to take more responsibility for their own health, in terms of making informed choices and of managing preventive and chronic health conditions.

Demands for the population to take more responsibility for their own health care, occurring alongside a rapidly escalating array of treatment options, make improving health literacy a social imperative⁶⁹. Wilson et al.⁷⁰ note that, in view of the expectation that parents participate more actively in decision-making for their family health care, more needs to be done to ensure they are supplied with appropriate information. They write, "Parents can only make informed choices when they are presented with information that makes sense to them"^{70(p.11)}. Age is another factor in considering the impact of low health literacy on the ability for patient self-care and the need to make informed choices. Williams et al.⁵⁹ claim that health literacy may be particularly low among those aged 60 and over. One study they cite found that more than 80% among those over 60 years had either inadequate or marginal functional literacy. With our increasingly ageing population, this is of particular concern if the elderly are to lead independent healthy lives, without the need for long-term expensive health care.

Related to the need for making informed choices is the role of health literacy promotions in drawing attention to the impact on health status of access to education and population literacy levels⁷¹. Nutbeam and Kickbusch argue, "improving overall levels of literacy in the population will do much to improve people's capacity to make healthy choices"^{71(p.183)}. Underlining this point, Ratzan neatly sums up the argument, writing: "Health literacy can be described as both a goal and an outcome, becoming the currency and capital needed to develop and sustain health"^{69(p.210)}.

A further issue related to literacy and health is that of compliance with, or adherence to, health care instructions. This issue will be discussed in more detail below (see *The impact of illustrations on patient adherence*). Of concern here is that research shows a direct correlation between low literacy and lack of patient compliance with recommended health instructions⁷⁰. Further, "High literacy levels are no guarantee that a person will respond in a desired way to health education and communication activities"^{72(p.52)}. Education and/or literacy levels are arguably not the only factors to consider when assessing the likelihood of patients following health care instructions⁷³. Other factors include: "1) Perceptions of risks; 2) Perceptions of self; 3) Environmental conditions, both physical and social; and 4) Perceptions of costs and benefits of recommendations"^{73(p.13)}. Interestingly, considering our focus on the use of immunisation as a preventive health measure, Gordon⁷³ stresses that these factors apply to *preventive* health behaviours as opposed to *sick-role* behaviours.

A final literacy and health issue will also be discussed in more detail below (see *The cultural relevance of illustrations in health communication*). This issue relates to the importance of considering the impact of cultural relevance on how patients understand or respond to health care

materials and instructions. Kerka⁶⁴ cites research showing the problems caused by expecting health literacy to transcend diverse cultural beliefs, social practices and translation from one language to another. Examples are problems of miscommunication and tensions between a system that requires individual responsibility and social customs that view health as a collective responsibility. These factors need to be evaluated when assessing health literacy⁶⁴. Or, readability assessments need to acknowledge both the prior knowledge and the motivation of patients⁷⁴. Cultural and social practices and beliefs, then, must be considered during the development phase of health care materials.

2.4.3 Health literacy and empowerment

The WHO definition of health literacy includes the goal of empowerment: “*Health literacy fosters participation. Access to education and information is essential to achieving effective participation and the empowerment of individuals and communities*”^{75(p.351)}. Wilson et al.⁷⁰ note that the goal of any health literacy promotion must have a higher aim than the mere dissemination of information. For example, information in a health literacy programme for parents, should simultaneously provide them with understanding and choices that “enable them to achieve the optimal level of health for their children”^{70(p.11)}. Kickbusch⁶¹ states that unless the role of power in health literacy is understood, health literacy promotions may be in danger of addressing only issues around patient compliance, overlooking the primary goal of empowering patients to make informed choices. To enable empowerment, she argues, “access to information and knowledge, informed consent and negotiating skills must constitute part of the overall development effort”^{61(p.294)}.

2.4.4 Health literacy and immunisation

Interestingly, much of the recent research examining health literacy in relation to immunisation is looking at the impact of including illustrations in health materials. Therefore, while there is a brief overview of the research here, literature relating to the use of illustrations will be discussed in more detail below (*Using Illustrations in Health Communication*).

Ratzan⁶⁹ describes health literacy as more than simply a matter of ‘health knowledge’. It is, he says, an ongoing learning process, with opportunities for learning different aspects of health arising throughout our lives. He gives two examples especially pertinent to this study. The first is that there are opportunities during immunisation to disseminate wider understanding of its benefits⁶⁹. This is an important insight in view of the immunisation uptake statistics for New Zealand which show a higher level of immunisation at 12 months than at 24 months^{7,23}. Ratzan’s⁶⁹ second example is to use any health visits by young adults to underline the benefits of immunisation. This suggests beginning education about the role of immunisation during health visits, even before pregnancy.

Concerned at the low rate of immunisation among infants from low-income urban homes in the US, Wilson et al.⁷⁰ wondered if one factor might be lower literacy parents having problems recalling the immunisation schedules. They conducted a pilot study with three aims: 1) to learn the self-reported literacy levels among the mothers; 2) to use standardised tests of reading (the REALM^{vi} test) and comprehension (the CLOZE test) ability to discover if there was a discrepancy between the mothers’

^{vi} For details of the REALM and CLOZE tests, see ⁷⁰.

self-reported and actual literacy levels; and 3) to test the effectiveness of immunisation information material with a simplified reading level. They found that while the average reported literacy level was US 12th grade, participants' literacy test results showed that half were at 8th grade or lower. Further, their simplified immunisation intervention did not achieve a significant improvement of parental immunisation knowledge over those who received standard vaccination leaflets. While simplifying health materials may not alone make a difference, Wilson et al. argue:

[Parents] cannot make decisions without access to information they can read. Furthermore, the lack of appropriate immunization education materials for poor readers further promotes the inequalities and disparities in health and health care. Because multiple vaccines are given simultaneously, parents are asked to read and comprehend several immunization informational documents that may lead to further confusions about the vaccines that their children are receiving^{70(p.11)}.

To help overcome these deficiencies in immunisation communication, the authors recommend that health clinics: 1) identify low literacy levels among all member parents; 2) develop appropriate, easy-to-read health materials; 3) ensure that written information and instructions are used alongside face to face communication; 4) tailor educational materials and advice to individual needs⁷⁰.

Opportunistic immunisation is where immunisation is suggested by a health professional and accepted by a patient attending health services for another purpose. It is cited as one means of improving childhood immunisation levels^{33,47}. Jacobsen et al.⁷⁶ used this method with an illustrated, low-level literacy health leaflet on pneumococcal immunisation. Their aim was to empower patients with low literacy levels by showing them how to ask their health practitioners questions about issues and services. The leaflets were handed to patients arriving at a clinic for other health reasons. The contents of the leaflet were not discussed with the patients who were simply told to give the leaflet to the health practitioner if they had questions or were interested in being immunised. The authors wondered if being given a leaflet would encourage patients to raise the issue of immunisation with their health practitioner. They found that a far greater number who were given the leaflet did discuss immunisation with their doctor. Moreover, about half of the participants who did so went on to be immunised. The success of presenting an unscheduled opportunity for immunisation combined with the literacy resource suggested that developing more effective communication between patients and health providers may be critical to improving immunisation rates⁷⁶.

2.5 Using illustrations in health communication

Not all health communications are read by people who could benefit. Racks of informational brochures in doctors' offices are often ignored and, even when brochures are given to patients by health professionals, not all are read. Even spoken instructions by health professionals are not always attended to by patients or families because they are stressed, distracted, or confused. One contribution of pictures to health education is to *attract the attention of patients and families and to stimulate them to attend to the information* (emphasis added)^{77(p.175)}.

In this section, the focus is on literature evaluating the use of illustrations^{vii} in health care materials. First is a brief overview of the reasons given by Doak, Doak and Root⁷⁸ for including illustrations in health care materials. Next is a summary of the findings by Houts et al.⁷⁷ and Katz et al.⁷⁹ in their reviews of the literature surrounding the use of illustrations. Added to these are relevant suggestions from other papers^{76,80-82}. According to Houts et al. and Katz et al., the purpose of any health material is threefold: It is to enable patients 1) to understand the information or instructions; 2) to recall the instructions; and then 3) to act on, or comply with, the instructions^{77,79}. Therefore, the summary points from the reviews are followed by a closer look at literature evaluating patient comprehension of health material, patient recall of the material and whether illustrations have been found to improve patient adherence to the instructions in health material. Next, this section presents literature which looks at the importance of cultural specificity of the illustrations used. And finally, is a discussion of the use of illustrations in immunisation health communication.

In their book *Teaching Patients with Low Literacy Skills* (1996), Doak et al.⁷⁸ argue that simplifying the language used in health care materials may help the comprehension of better readers, but on its own it is not sufficient to enable those with very low to no literacy levels to comprehend the health messages presented. The authors recommend also incorporating 'visual strategies', including:

- using at least size 12 font;
- presenting information in bullet point format;
- minimising the number of concepts per page and grouping them under headings;
- using lots of white space around text; and
- using illustrations that give the readers cues to the text.

Suggested additions to these strategies are mixed-case font and a question-and-answer format⁷⁴.

Doak et al.⁷⁸ discuss the value of and ways to use, their visual strategies, including illustrations, to enhance the likelihood of attracting the reader's attention and make information more easily understood and remembered. Briefly summarised, their main points are that the use of appropriate illustrations and other visual strategies may:

- cater for those with a visual learning style, as poor readers, in particular, tend to rely on visual and audio messages;
- help capture attention, prompting readers to decide whether to take notice of the message;
- help readers interpret and understand the message where the illustrations use a familiar context, acting as a bridge across language barriers;
- simplify complex concepts and help minimise the number of written words;
- aid recall through providing a greater emotional impact than words;
- help keep the focus on the key message and actions to be taken; and
- provide motivation to act on the message or information.

^{vii} The authors reviewed use various terms for visual images: pictographs, pictograms, pictorial aids and icons tend to refer to simple line drawings; cartoons are often also line drawings but likely to include humour; photographs may be specified. 'Pictures' or 'illustrations' are used here as coverall terms.

Two useful and comprehensive reviews of literature on research into the use of illustrations in health care materials outline three major areas the authors identified as important in health communication: 1) patient comprehension of the messages in health material; 2) patient recall of the messages in the material; and 3) patient adherence to or compliance with the instructions presented^{77,79}. Houts et al.⁷⁷ reviewed literature researching the use of illustrations in health care materials to discover how combining illustrations with spoken or written text affects patients' health communication through gaining their attention and aiding their recall and comprehension of the health message and whether it leads to increased adherence to the message. Following this, Katz et al.⁷⁹ examined published evaluations of the role of illustrations ('pictorial aids') in patient medication instructions. Their focus was also on patient comprehension, recall and adherence.

The results of the reviewed research were mixed: some authors found easy-to-read text plus pictures were more beneficial to better readers; some that they were beneficial to readers at all levels; and some reported more success among readers with lower literacy skills when illustrations were added to simplified text^{77,79}. Further, both reviews show that, while there may be different responses by participating groups to the use of health materials incorporating pictures, the differences tend to relate to a combination of factors including the placement of text and pictures, the level of inference required to interpret the pictures and the cultural specificity of the pictures. Interestingly, these factors closely reflect those mentioned by Doak et al.⁷⁸ and listed above.

From their review, Houts et al.⁷⁷ suggest the research shows that including illustrations in health materials may enhance recall as well as understanding of and adherence to, the key messages being conveyed. The literature reviewed on the use of illustrations in medication instructions led to the conclusion that "the use of pictorial aids enhances patients' understanding of how they should take their medications, particularly when pictures are used in combination with written or oral instructions"^{79(p.2396)}. These authors found that, although the use of pictures was not successful in all the research they reviewed, "pictures have generally proven useful for improving patient *comprehension* and *adherence*" (emphasis added)^{79(p.2391)}. However, illustrations did not impact so markedly on improving patient *recall* in the literature reviewed by these authors.

The key recommendations for optimising the impact of health materials using illustrations arising from Houts et al. and Katz et al.'s reviewed research are:

- continual consultation and evaluation between health experts, education experts and the target audience throughout the planning process of health materials;
- using pictures wherever possible to support key points;
- using the simplest drawings or photographs possible, designed by health professionals, not artists and with no distracting, extraneous images;
- labelling illustrations and supporting them with simplified text linked to the images;
- using culturally or locally specific illustrations; and, where possible;
- supporting illustrations and written material with oral instructions^{77,79}.

Added to this might be a consideration of the brevity of health materials as participants of all reading abilities in Davis et al.'s⁸⁴ research preferred an illustrated pamphlet with reduced reading time.

A further point raised by researchers is that illustrations should contain “adult rather than childlike images”^{80(p.10)}. As Doak et al.⁷⁸ explain, using such images as a dump-truck delivering sugar to blood cells may confuse the message by demanding inference skills the reader does not have. Also, it may lead to the message being ignored because adults may assume that the material is for children.

Morrow et al.⁸² found that the use of icons in health literature helps patients’ understanding and recall as long as the patients (especially older patients) do not have to draw inferences from the pictures; that is, the pictures need to be fully self-explanatory. For example, an image of the number of pills to be taken should be alongside an image showing the time to take the pills. In addition, the authors stress the importance of supporting illustrations with text; used alone they are unlikely to convey the entire message and may lead to misunderstanding⁸².

2.5.1 The impact of illustrations on patient comprehension of information

Research into the impact of illustrations on patient comprehension of health material has shown results to be largely positive. In one example of such research, those receiving materials with pictures had higher comprehension levels for two questions asked; 93% correctly answered the question on how to take the medicine, while only 47% without the illustrations answered correctly. For a second question asking the times the medication needed to be taken, 73% with illustrated text answered correctly, while only 3% without illustrations were correct^{cited in 77}.

Nevertheless, some results are contradictory. For example, Weiner et al.⁸³ note that in research they reviewed, the effectiveness of illustrations appeared to depend on the type of illustration used and the literacy level of both the readers and the text. Moreover, the research does not all agree on how the ability of the readers impacts on the effectiveness of the use of illustrations. One example is a survey of patients at a rural US trauma centre⁸⁵. The patients were given discharge instructions, some with and some without illustrations. Patients were then questioned to discover their comprehension of the instructions. The patients who received illustrated instructions were one and a half times more likely to give 50% or more correct responses. Analysis of the patient responses showed that the greatest effect was among patients who were “nonwhite, female, or have no more than a high school education”^{85(p.317)}. In similar results, Delp and Jones^{86(p.269)} found that participants with “less than a high school education” were most likely to benefit from the use of simplified text plus illustrations. Among low-literacy patients given material with the same text, but either with or without cartoon illustrations, those who received the illustrated material were far more likely to consider their instructions very easy to read⁸⁶. Other research^{cited in 77(p.180)} also found that while all patients are likely to benefit from the addition of illustrations, comprehension gains were greater for those with lower literacy levels than for better readers.

This is in contrast to the finding that higher-level readers obtained greater understanding from illustrated material with simplified text. Davis et al.⁸² developed a simple to read, illustrated pamphlet with information for parents on the need to immunise their children against polio. They tested its usefulness in improving comprehension against an existing pamphlet with simplified language and illustrations provided by the Centre for Disease Control and Prevention’s (CDC) pamphlet for the same purpose. The developed pamphlet fulfilled many of the health literacy recommendations⁷⁸ discussed above: it was prepared with input from parents from a range of socio-

economic backgrounds; was at Grade Six reading level; used bullet points, bolding, underlining, numbered brief key points; was in question and answer format; was in bright colours; and included a variety of pictures of boys and girls of different ethnic groups and ages to represent the need for immunisations for all children at four periods during their childhood. While the existing CDC pamphlet was at the same reading level, it was black and white, had more than twice the number of words which were set out in paragraphs in columns using narrative text and included only two pictures. Davis et al. found that their pamphlets were more popular among the participants at all literacy levels and that overall there was a statistical improvement in their comprehension over that of participants using the CDC pamphlets. However, those with higher skill levels benefited the most; among the poorest readers the improvement was not “to a clinically acceptable level”^{82(p.33)}.

The minimal improvement of those with low literacy led Davis et al.⁸² to recommend involving low-literacy patients in decisions on content as well as format of health materials. Plimpton and Root⁸⁷ who created illustrated, easy-to-read health materials, also emphasised the need to consult with the target audience at all stages of planning for all health care materials. In their view, health care material target audiences include readers at all levels of literacy, so needs input from readers at all skill levels. Their research showed that when we are ill or faced with making health decisions that impact on our own lives or those of our children, we tend to feel stressed. In stressful situations, people at all literacy levels may find it difficult to understand written instructions or information. Health care instructions, which often include unfamiliar terminology, are particularly problematic. Therefore, Plimpton and Root conclude:

Half the adult population needs easy-to-read materials and the other half who do not need them wants them anyway. People under stress have limited ability to understand and otherwise-able readers prefer their information brief and concise^{87(p.91)}.

Several researchers mention the importance of simplicity and avoidance of superfluous details for illustrations to best aid comprehension of health materials^{77,83,88,89}. Hill⁸⁸ developed a complex set of pictograms into ‘visual concept mapping’ to depict a sequence of instructions. When she tested this on a group of medical students, representations with the least “visual clutter”^{88(p.7)} were the most easily understood, even by these students with high literacy skills. For Weiner et al.⁸³, the inclusion of facial expressions in the illustrations was particularly helpful. This detail aside, the unembellished illustrations were more effective than more complex ones. They recommend reinforcing simple illustrations with a few repeated simple key words as the best means of improving understanding.

Moll⁸⁹ also notes the importance of simplicity of detail. His study of the impact of different forms of illustration found that overall, the highest comprehension scores among participants were achieved by material using cartoons, followed by that with matchstick drawings and then that with photographs⁸⁹. Houts et al.⁷⁷ suggest the reason may be that simple drawings eliminate distracting details likely to be present in photographs: “Research has shown that people with low reading skills are more likely to attend to irrelevant details in illustrations than are people with higher reading skills”^{77(p.180)}. They recommend simple pictures in a familiar context with no extraneous details accompanied by easy to read captions explaining the meaning as the best means of aiding understanding and avoiding distracting attention from the message.

2.5.2 The impact of illustrations on patient recall of information

To determine whether illustrations might help the recall of health care instructions for non-literate patients, Houts et al.⁹⁰ studied the short-term recall of a group of junior college students using pictographs with oral health instructions and no written text. They found that participants given pictures during both the instruction and testing periods recalled a mean of 85% of the information correctly, while those given oral instructions without picture cues recalled only 15% correctly⁹⁰. Following this research, Houts et al.⁹¹ tested low-literacy adults for longer-term recall using pictographs to accompany a greater number of oral instructions (236 compared with 50 in the original test)⁹¹. Their results showed a recall level of an average of 85% immediately following the training and of an impressive 71% four weeks later. Moreover, recall using pictures was similar for both school students and low literacy participants, suggesting pictures help recall for all levels of literacy⁹¹. Referring to this by the educational term ‘pictorial superiority effect’, Houts et al.⁷⁷ note that in a majority of research they reviewed, the use of pictures in health materials improved patient recall, even when no pictorial ‘cues’ were given to aid recall during post-intervention tests.

However, some research shows that while the inclusion of illustrations is likely to lead to higher recall among younger people, the impact on older people’s recall may be less successful. For example, Houts et al.^{77(p.184)} cite research where pictures used with spoken instructions aided recall in younger patients, but were not so successful with older participants. Older participants in another study were also less likely to successfully recall instructions in illustrated health materials, although Moll⁸⁹ attributes this to possible age-related memory loss.

In a search of educational literature, Houts et al.⁷⁷ found overwhelming support for the addition of pictures to both written and oral instructions as an aid to recall. While some research found that illustrations were more likely to improve the comprehension of verbal than written information, Houts et al. suggest this may be because the greater dependence by poorer readers on oral explanations means “they need help in remembering what they hear”^{77(p.174)}. In addition, one study cited by Houts et al.^{77(p.180)} found that the inclusion of illustrations dramatically improved the rate of long-term recall, possibly suggesting, as discussed below, a greater engagement with and repeated reviewing of, the illustrated material.

On the other hand, while illustrated health materials are more effective than text alone, spoken interaction between patient and health provider is of even greater importance in improving patient recall of and adherence to, instructions^{76,82}. This claim follows the use of an immunisation pamphlet with illustrations and simplified language to help parents understand the implications of immunisation for their children⁸². The researchers conclude that material with illustrations had wider appeal but that without the addition of spoken interaction there was no improvement in recall for “a substantial number”^{76(p.650)} of participants. Therefore, they recommend supplementing illustrated easy-to-read text with “repeated oral instruction”^{82(p.36)}. Shohet inverts the emphasis, saying “written communication should supplement physician-patient conversations”^{cited in 64(p.2)}.

Supporting this finding, Dowse and Ehlers⁹², nevertheless, add a reminder of the complexity and costs of solving health literacy problems. They point out that, while illustrations are an effective resource for aiding comprehension, they should not be used as the only source of patient

information, but require guidance from health providers. They state: “Using visual aids to facilitate the communication of medicine information to low-literate patients requires extra time for explanation and places extra demands on health professionals”^{92(p.69)}.

Some research found that more is not always better when it comes to including illustrations in health materials. In one resource, the inclusion of too many illustrations confused the message, impeding recall⁸³. Similarly, some researchers warn against including too many pictures in health materials⁹³. A test of the use of humorous cartoons in instruction booklets for gout patients, found very little difference in recall between those who received material with and without illustrations⁹³. However, there was a difference in impact between a booklet with a few illustrations and one with many more. The authors found that the material with a few illustrations was more effective, “creating maximal interest and enjoyment, [the material with] 89 cartoons on the other hand representing an overkill”^{93(p.228)}. In their view, including too many pictures per page meant their necessarily much smaller size detracted from their impact. A further point of interest Moll et al.⁹³ raise regarding the use of humorous pictures is that only a few people have a skill for remembering the punch line of oral jokes and that this may be the case with visual jokes too. They suggest, therefore, that humour in illustrations may be a distraction to the message in the written material.

Junior college students in the US were tested to see if the use of pictographs with oral medical instructions would help the recall of spoken instructions⁹⁰. When it was found that the use of pictographs raised the students’ mean recall levels from 14% to 85%, a group of adults with low literacy levels was tested in a subsequent study⁹¹. Their mean short-term recall was also at 85% with the use of pictographs and when the participants were further tested after four weeks their recall was still a high 71%. From this, Houts et al.⁹¹ make three deductions: first, pictures should be used during both learning and recall periods; second, the simpler the concept expressed in each picture the more likely it is to be recalled; and third, to increase comprehension, however simple pictures are, they must always be explained. Goldstein^{cited in 90} makes a further point on effective use of illustrations by noting that they are more likely to enhance recall of health instructions when shown before or during oral explanations rather than afterwards.

2.5.3 The impact of illustrations on patient adherence to health instructions

As important as learning whether adding illustrations to health communications with simplified literacy levels improves patients’ understanding and recall of the messages, is discovering whether inclusion of illustrations in health materials is likely to facilitate patient adherence to, or compliance with, medical instructions. Patient compliance is a two-step process involving, “accepting the message as something the person should act on and then actually carrying out the recommended actions”^{77(p.185)}. In a review of health literacy literature and the implications for medication compliance, Eagles et al.⁹⁴ suggest that health professionals may be unaware of the high proportion of patients with low literacy levels who do not follow health care instructions because they fail to recall accurately spoken instructions and are unable to read written instructions. They write:

What appears to be missing ... is consideration of the way in which information is provided. For example, Kefalides (1999) notes that the simple addition of a picture/pictogram to patient information can increase recall from 15% to 85%, yet many patient information

brochures do not include this as part of the medication use material. Aspects of the presentation of information, including layout/design elements and the suitability of the material presented for the needs of the patient appear to be significant factors in effective comprehension and thus compliance^{94(p.5)}.

Several researchers^{86,90,92,95,96} argue that one key to patient adherence to instructions is through capturing their attention or engaging their interest and thus involving patients in their own health care. These writers explain how including illustrations in health materials contributes to such engagement with patients with low and/or high levels of literacy skills. For example, Coulter and Ellins^{96(p.24)} suggest aiming to “engage patients in their own and their family’s individual clinical care” as a means of improving health outcomes through patient adherence to instructions.

Delp and Jones⁸⁶ discuss behavioural changes that occurred through patient engagement with health material in emergency department (ED) wound care instructions. They tested material with amusing cartoons depicting the injury and steps to be taken in wound care. Some pamphlets included the cartoons while the others did not. These were followed three days later with a telephone interview to test patients’ recall, understanding and compliance of wound care instructions. Higher levels of compliance (77% compared with 54%) among those who received the material with the cartoons, led the authors to conclude that “cartoon illustrations are an effective strategy for conveying information and may improve patient compliance with ED release instructions”^{86(p.269)}. The reason, they suggest, is that such illustrations “engage the interest of the audience”^{86(p.265)}, especially among those with less education.

Similarly, a group of non-literate Cameroon women, given pictures by Ngoh and Shepherd⁹⁵ to take home showing when to take medication, were motivated to follow instructions more frequently than those who received no pictures following spoken instructions. In support, Dowse and Ehlers⁹² found that including pictograms on antibiotic medicine labels for low-literate Xhosa women increased the rate of adherence to instructions to 90% for those receiving material with illustrations compared with 70% for those who did not receive illustrations.

The research of Delp and Jones, Ngoh and Shepherd and Dowse and Ehlers, then, found that those with lower literacy levels were more likely to follow illustrated health care instructions. Houts et al.⁹⁰, though, suggest that those with higher literacy skills are also more likely to comply with illustrated health instructions. Their reason is a higher chance of readers’ attention being repeatedly engaged:

Some literate persons may find the pictographs more engaging than written words and therefore pay closer attention to instructions. For example, a page of pictographs plus written instructions on the refrigerator door may attract more interest and attention than a page of just writing – thereby facilitating frequent reviews of instructions and increasing the likelihood that care is carried out as directed^{90(p.87)}.

2.5.4 The cultural relevance of illustrations

A range of research shows that the effectiveness of pictures in positively modifying health behaviour depends on several complex factors, including: 1) the cultural and emotional response of the viewer

to the pictures; 2) whether the pictures are of people similar to the viewer; and 3) whether the objects and actions are familiar to those used by the viewer⁷⁷. Further, because of the impact of seemingly minute differences in objects and situations, pictures need to be chosen in consultation with the target audience to be effective. One example of such particularity is: “Participants liked primary colors, ethnically neutral graphics and drawings of mothers and children. They referred to the vaccine as ‘the drops’ and ‘the shots’ rather than OPV and IPV”^{82(p.27)}.

The importance of the cultural relevance of illustrations is mentioned by several researchers^{92,95,98-100}. In research evaluating visual aids for communicating prescription drug instructions to non-literate patients, Ngoh and Shepherd⁹⁵ note that illustrations need to be culturally specific to each user population because interpretation of illustrations is based on cultural understanding. With culturally appropriate images, their research participants scored ‘significantly higher’ than participants who did not receive the visual aids⁹⁵. For optimum results, the authors continue, “The visuals must be simple, practical and related to what the patients know and understand. In a simple but vivid way, the picture must reinforce the spoken word”^{95(p.255)}.

Research based in South Africa developed pictograms for medicine labels with local input to increase the understanding of messages by those with low literacy levels or no literacy at all^{92,98-100}. Pictograms made with local input achieved greater understanding than illustrations from an international source such as the United States Pharmacopeia (USP), “particularly if they are developed in collaboration with the target community and cultural influences are acknowledged”^{98(p.93)}. As Houts et al. point out, viewing this success using the local pictures alongside the fact that the differences between the two sets of pictures appear to be minimal emphasises the importance of collaboration with “the target population ... at all stages of design and evaluation”^{77(p.180)}.

A survey of Finnish children using USP pictograms found no statistically significant difference in the understanding of medical information between those who were given a leaflet with pictograms and those whose leaflet had no pictograms¹⁰¹. This is contrary to the findings of de Guzman^{cited in 101}. Houts et al.⁷⁷ suggest the reason may be that there was already such a high understanding of the issue in question that there was little room for improvement. Nevertheless, as de Guzman was writing in the US and Hämeen-Attila et al. in Finland, both using US pictograms, their findings appear to support the claims of Dowse and Ehlers⁹² that to be effective, pictures need to be culturally relevant or specific, however minimal the differences may seem to be.

The use of humour is a matter of cultural concern⁸⁹. Moll questions the appropriateness of using humorous cartoons in material related to serious, painful health conditions. He suggests that rather than engaging patients in health material, the use of cartoons might be counter-productive, by “generating irritation among patients who interpret cartoons as being inappropriate in a field that is far from humorous”^{89(p.207)}.

2.5.5 Immunisation, health literacy and illustrations

Concerned at the continuing problem of childhood under-immunisation, Evers¹⁰² developed an “easy to use and duplicate” pamphlet with information about childhood immunisation. The pamphlet was designed in consultation with health professionals and based on Doak et al.’s strategies⁷⁸ (discussed

above) aimed at informing readers with low literacy skills. Among the strategies included was the use of realistic, familiar illustrations. A small group of postpartum mothers at a hospital was given the pamphlet after they had been pre-tested on their immunisation knowledge. The mothers were asked to read the pamphlet while they were in the hospital and invited to “clarify any questions with the nurse during a discharge teaching session”^{102(p.256)}. They were then asked the same questions in a post-test. The improved knowledge and understanding shown in the post-test results led the health professionals and Evers to include the pamphlet in the hospital’s discharge teaching practice.

Another example of an illustrated pamphlet to help parents understand immunisation issues is by Davis et al.⁸⁴. They tested their easy to read, illustrated pamphlet on polio immunisation against the CDC pamphlet available at the time. The CDC pamphlet used text requiring a much higher level of literacy skills (12th grade) and took around 12 minutes to read compared with the researchers’ pamphlet (6th grade) which could be read in about four minutes. The participating parents at all literacy levels preferred the developed pamphlet. However, on a test for comprehension, although readers with higher literacy skills scored better, the comprehension of those with low literacy skills did not improve sufficiently. This led the team to suggest that a pamphlet should be created at a 3rd grade level for those with very low literacy levels⁸⁴.

Following this experiment, Davis et al.⁸² developed another pamphlet. Again, the aim of this pamphlet was to present parents with information on immunising their children against polio. This time the comparison CDC pamphlet included simplified text, but while shortened, included very few illustrations. The Davis et al. pamphlet used simplified text presented with ‘visual aids’, such as bullet points and bright colours. When the pamphlet was tested with participating parents against the comparative CDC pamphlet, the authors made three discoveries: 1) all participants preferred the more highly illustrated pamphlet; 2) those with higher literacy levels gained more understanding than those with lower literacy skills; and 3) participant understanding improved significantly over that of the comparative CDC material only where there were “instructional graphics”^{82(p.25)}. Pertinently and reflecting the recommendation that illustrations be linked to the text⁷⁸, Davis et al. stated that, “many parents mentioned the graphic of the two month-old infant as especially important in helping them learn the age of the first dose”^{82(p.34)}. The authors suggest that their results show the need to develop health communication materials in consultation with the intended audience at all reading levels. However, it would also be interesting to see a later follow-up test done to find whether the heightened interest elicited by the illustrations has led to the parents revisiting the material and if this has contributed to improved understanding, long-term recall and/or increased immunisation uptake.

In the US in the late 1990s, there was a high death rate from pneumococcal disease and only around a 37% immunisation rate⁷⁶. Jacobsen et al.⁷⁶ believed that high levels of functional illiteracy among the elderly, a group particularly susceptible to pneumococcal disease, contributed to their low rates of immunisation. Attempting to address this problem, they created a brief, easy-to-read, illustrated leaflet encouraging patients to ask their health providers about preventive immunisation for pneumococcal disease. Patients receiving the leaflet were four times more likely to ask to discuss immunisation with their health provider and more than five times more likely to become vaccinated than the control group who did not receive the leaflet⁷⁶. Although the authors attribute the increase

in immunisation levels to the leaflet, they do not discuss whether the use of illustrations was a contributing factor.

Similarly, Wilson et al.⁷⁰ included illustrations in a simplified pamphlet with information for parents on childhood immunisation. The pamphlets contained drawings representing “the diverse populations in urban public clinics”^{70(p.8)}. However, these authors do not mention the illustrations or assess whether they might have had any impact on the participants’ understanding.

Still in the area of illustrated interventions for presenting immunisation information, but using a different form of illustration, Dunn et al.¹⁰³ created a 15-minute educational video. They aimed to create an intervention for use by health providers to assist parents with informed consent about polio vaccines and immunisation schedules. The messages presented followed those in the CDC information pamphlet and used a combination of narration, visual graphics, on-camera comments and vignettes where parents discussed immunisation issues with a health provider. The video plus the CDC leaflet were presented to one group of parents and the leaflet alone to another group. The authors found that 62% of those who received just the leaflet read it. A possible reason for non-reading, they suggest, is that parents may be given the leaflets immediately prior to immunisation when they may be distracted by their child or children and also have insufficient time to read the information or ask questions. In the non-video group, the 62% who read the leaflet scored higher in a post-test than the non-readers. However, the parents who watched the video scored higher than those who received only the leaflet.

Leiner et al.¹⁰⁴ also developed a video aimed at informing parents about childhood immunisation, but theirs was an eight minute animated cartoon. The video was produced by “a multidisciplinary team that included physicians, nurses, a marketer and graphic designers”^{104(p.593)}. There was, however, no apparent consultation with the target audience. Using the same words as a written handout, the video presented the information in a story form showing a mother taking her child to be vaccinated. It covered such issues as the child’s hesitation, how there is little actual discomfort, possible risks, plus contact information if adverse effects occur. One group of parents was shown the video and a comparison group was given the written material. The authors pre-tested and post-tested both groups. They found that the knowledge of both groups had increased. But, while 30% of those who viewed the cartoon presentation correctly answered all questions, none of the comparison group was able to answer all questions correctly. This was American research and both video and pamphlet were presented in English and Spanish versions.

In summary then, there are three main reasons for providing health communication materials: 1) to aid understanding of health messages (or instructions, in the case of medication, for example), 2) to aid recall of the messages and 3) to improve adherence to, or compliance with, the messages. In evaluating the inclusion of illustrations in health communication materials, the surveyed literature shows mixed results. Some found that illustrations were more likely to help those with lower health literacy skills, some that they seemed to make a greater difference to those with higher health literacy skills, while others found that they helped those at all levels of health literacy ability. Further, some found that the use of illustrations improved rates of comprehension, recall and adherence, while others found that although they improved understanding and compliance, they did not increase rates of recall. However, the overall finding seems to be that health communication

materials that include illustrations are preferred by those at all levels of health literacy ability and are, therefore, more likely to engage attention.

3. METHODOLOGY

3.1 Collaborative research: The University-Community team

3.1.1 Establishing the University-Community team

International research has shown the importance of building community relationships and developing broad, interdisciplinary partnerships as approaches to increasing community health and health literacy^{cited in 60}. There have also been calls for collaborations among academic, governmental and non-governmental organisations with the aim of furthering “community health research and action”¹⁶. To this end, we identified major stakeholders by snowballing, a qualitative research sampling technique that works well in a relatively coherent smaller community such as Whanganui¹⁰⁵. Potential stakeholders were approached by the research facilitator of the Whanganui Regional PHO, a registered nurse with strong connections in the local community, rather than the University researchers who might be viewed as outsiders. The facilitator approached the stakeholders known to her and they, in turn, suggested other stakeholders they believed might be interested in the research.

Eventually, the collaborative team consisted of a University team and a wide range of community-based members representing governmental and non-governmental organisations, health professionals, educators and service providers. The University team comprised: project leader, project manager, research facilitator (who also conducted the interviews), qualitative data analyst, Māori consultant, research assistant, focus group facilitators and focus group/interview transcriber. The community groups included: urban and rural health organisations; hospital and independent midwifery and maternity service organisations including the Whanganui Hospital Maternity Service and associated clinics throughout the region; Māori and Pasifika health and education service providers such as Nga Tai O Te Awa Māori Development Organisation, Te Oranganui Iwi Health Authority PHO, Te Kotuku Hauora O Rangitikei – Te Runanga O Ngati Apa, OTaihape Māori Komiti Inc. and the Born and Raised Pasifika Early Childhood Centre; Birthright (Wanganui) for sole parents; the Immunisation Advisory Centre based at the University of Auckland; and a key community leader, the Whanganui Regional PHO.

3.1.2 Working together: Issues and solutions

University/community collaborations have been found to encounter a range of “challenges and obstacles”¹⁸, depending on the nature of the collaboration and the purpose of the research. Three of the challenges most frequently mentioned in the literature centre on overlapping and intertwined issues related to time, power and communication. The first challenge is the commitment of time required, a) to establish the collaborative team, b) for frequent meetings to develop familiarity and trust among the team and c) to carry out the research^{15,16,18,19}. The second challenge is ensuring that both the environment and opportunities are provided for airing and resolving issues stemming from perceived power differentials^{15,16,18,106}. The third challenge lies in developing open communication, where all members feel free to speak, ask questions and be listened to with respect^{16,21}. A fourth challenge, bringing together issues of time, power and communication, lies in allowing decision-

making through consensus^{17,19,20}. Our encounters with these issues will be discussed in the outline of the research process that follows.

Before the Massey University team and the Whanganui health and education professional organisations could begin to work together as collaborators, there was an extensive period of relationship-building. Prior to a project funding proposal being written, meetings were held with community stakeholder groups and cultural leaders and elders, to outline the general research aims, the roles they may perform and the benefits to them and also to learn of their views and expectations. This is a vital aspect of collaborative research, outlined by authors who admit the lengthy 'lead-time' required to set up their collaborative research initially caused feelings of frustration over the time spent for little apparent progress¹⁶. However, they argue that it was the very length of time that allowed for the growth of mutual trust and respect among the research partners, creating both an "environment where knowledge could be shared and ... genuinely collaborative working relationships"¹⁶. This claim reinforces Roussos and Fawcett who cite research experiences where time constraints forcing researchers to by-pass the relationship building process limited the participation of community stakeholders to the point that it was no longer collaborative research¹⁹. It was during our early relationship-building discussions that stakeholders outlined the multi-faceted nature of enhancing childhood immunisation rates, highlighting the necessity of gathering data from a variety of decision-makers (including partners, extended family and cultural leaders), rather than just mothers-to-be. In doing so, the stakeholders widened the scope and methodological positioning of the research. These early discussions led to the final research design and, subsequently, a successful collaborative funding bid to the Ministry of Health and Health Research Council of New Zealand Partnership Programme.

Instead of holding meetings at the University, the University team travelled to meetings at the premises of the community collaborators. In doing so, we followed the approach of Harper et al.¹⁸ and Ravn¹⁰⁷, who commend it as providing an environment for minimising possible perceptions of power differentials among collaborators, such as perceived differences in status, resources, skills, commitment to the project and ownership of information. The familiarity and trust developed during time taken for relationship-building also contributes to the resolution of possible perceptions of such power differentials and challenging of prior assumptions held among collaborative partners^{16,18}. In our experience, partaking of refreshments as the meetings assembled and throughout the discussions provided a relaxed atmosphere that allowed opportunity for all members to speak and be heard with respect.

Regular face-to-face communication where everyone feels comfortable about voicing concerns also provides opportunities for circumventing and addressing power issues. As Gibbs points out, "Respectful open, honest and timely communication, ideally leading to relationships of trust between researchers and researcher participants, is the foundation of successful ... collaborative research"²¹. To this end, researchers, analysing a much larger university/community collaborative research project in Toronto, note that their project meetings were co-chaired by a representative from the community groups and one from the university group¹⁷. Reflecting this inclusive approach to communication, our meetings were chaired by our project research facilitator, a community health professional whom the University employed for the facilitator role. Reinforcing the face-to-face meetings and to maintain further contact and a sense of inclusiveness, the project manager

wrote detailed notes of each meeting's discussions and emailed them to all research partners, inviting comments on, additions and/or emendations to the notes. Similarly, before each meeting agenda was set collaborators were emailed seeking items for discussion. The completed agenda was then emailed to the partners, serving additionally as a reminder of the forthcoming meeting. For those who preferred, a phone call reminder was also made on the morning of the meetings.

A further avenue of communication was through regular feedback. According to Roussos and Fawcett, "Ongoing documentation, feedback and critical reflection should be used to assess progress, celebrate successes and redirect efforts"¹⁹. We agree, except that in our experience, feedback was a two-way process and, as such, it was an element of critical reflection rather than separate from it. For example, the University team presented feedback from analyses of focus group and interview findings to the community collaborators and end-users, who in turn gave the University team their feedback from the perspective of expert insiders. Communication through feedback occurred in a variety of forms throughout the research process: progress reports were emailed fortnightly; frequent meetings were held in Whanganui and notes from the meeting emailed to the project team; drafts of the information sheet, interview questions and resources were discussed, emended according to suggestions offered by the project team and the emended versions again presented for discussion and emended in a continually iterative process until consensus was achieved and the final products agreed by all. Data analysis from focus groups and interviews generated by University team members was shared with community collaborators for discussion as it became available.

At our collaborative meetings, much time was spent in discussing, clarifying and defining meanings, refining objectives and designing resources, until consensus was reached. Using a process of decision-making through consensus is an important contributor to a group sense of power equality^{17,19,20}. Roussos and Fawcett found that decision-making through consensus is likely to increase collaborators' satisfaction, widen their participation and improve the effectiveness of the team¹⁹. While it tends to be more time-consuming achieving decision-making through consensus, it is an important avenue for keeping members 'on board' and generally leads to improved outcomes¹⁷.

Bishop's analysis of the experiences of members of a Kaupapa Māori research team^{viii}, suggests that when collaborating with Māori communities, researchers should "participate in ways that other participants use to construct meaning, ... [developing a] cultural consciousness ... of the right (tika/pono) way to do things"²⁰. Harper et al. also include a reminder to "recognise, respect and participate in the ... rituals and traditions [of the community partners]"¹⁸. In Gibbs' experience, "working with indigenous communities in New Zealand, what is important is often not so much what researchers do or don't do, as how they conduct themselves within those communities"²¹. A further point made by Gibbs is that indigenous peoples want research that addresses current issues and that serves them and their needs rather than research that is "done on them"²¹. Widening this approach to include all community members of collaborative research projects indicates the need for ensuring all community collaborators benefit from the research.

^{viii} According to Irwin^{cited in 21}, "Kaupapa Māori research practice is ... epistemologically based within Māori cultural specificities, preferences and practices". Or, as defined by Bishop, it is research with a Māori research agenda²⁰.

Mindful of these recommendations for community collaborations and with the guidance of Dr John Waldon of the Massey Research Centre for Māori Health and Development, four undertakings were made by the University team: 1) to maintain an inclusive and respectful approach as the research progressed; 2) to ensure that all members of the project team knew about and were happy with, their contribution to the research process; 3) to confirm transparent communication of outcomes; and 4) to share the benefits of such outcomes with the partners.

The rights of the community members to inform the research design, outcomes and the immunisation resources developed were assured and their contributions were recognised; simultaneously, the knowledge of the University researchers was deeply enriched by the expert knowledge of the community members. The University team is currently determining if the resources can be distributed for use within the Whanganui DHB region post the end of the study.

3.1.3 Research design

The research design was a distinct two-phase project. Phase One was to establish community research collaborators and with them and end-users to develop improved immunisation communication resources. Phase Two was to pilot the effectiveness of the resources.

Phase One began in late 2007, with building community research relationships and establishing the project team (see *Establishing the University-Community Team* above). Following extensive discussion, in early 2009, community stakeholder members of the project team, in liaison with Massey University, arranged focus groups where immunisation decision-makers discussed the immunisation information they received, the information they would like to receive and their presentation preferences. Each community group organised its own focus group and recruited its own participants (see *Focus Groups: Process* below for more details).

The next process in Phase One was creating a flipchart with accompanying spoken information and a fridge magnet. Drafts were designed and brought to meetings with the project team and to focus group participant feedback sessions. Suggestions were incorporated, emendations made and new drafts presented for discussion at team meetings over several months until consensus was achieved and the immunisation information resources considered ready to be trialled.

Phase Two involved pilot testing the newly-developed resources. To do this, 62 women in their third trimester were interviewed and then interviewed again at approximately eight weeks postnatal. These women were recruited through a snowball sampling technique (for further details see *First Interviews: Process* below). As they were recruited, the women were placed alternately in one of two groups, an 'intervention' group or a 'control' group. The women in both groups participated in a face-to-face antenatal interview where immunisation decision-making was discussed and a brief health literacy test administered. Those in the intervention group were given a scripted oral and visual presentation of the flipchart and a fridge magnet to take away. The control group received the oral presentation only.

The postnatal interview explored the six-week immunisation decision made. These interviews were conducted by phone to make the least interruption to the mothers and their new babies. During the

second interview, the participants were asked to discuss their comprehension and recall of the immunisation information they received. As all participants consented, the National Immunisation Register database was then also checked to discover the comparative uptake rates at six weeks and three months between the two groups of participants as well as to make a comparison against uptake rates for the general population.

Feedback in the form of a summary of the overall research findings has been posted to those who requested it.

4. PROJECT METHOD AND OUTCOMES: THE ITERATIVE PROCESS

4.1 Phase one: Focus groups

4.1.1 Method

Across a two-month period, there were seven focus group sessions, each with five to six participants and one face-to-face interview with a potential eighth focus group participant. Focus groups comprised 45 immunisation decision-makers who had been involved in an immunisation decision in the past, or would be in the near future. To ensure as broad a representation as possible of the target audience, the sessions were held in both rural and urban centres, with input from a wide variety of participants: Māori were strongly represented (40%), along with 31.2% Pākehā (NZ European), 15.6% Pacific peoples and 13.3% 'other' (including combinations of the above). Women made up 84.4% of the sample. Strong representation of sole mothers was also ensured through Birthright (Wanganui)'s two focus group sessions. The majority (95.5%) of participants were aged between 16 and 50, with 15.6% aged 16 to 20; 26.7% were 21-30; 24.4% were 31-40; and 28.9% were between 41 and 50 years. One participant was not responsible for any children. However, more than a third (34%) of participants were responsible for one child, 29.5% were responsible for two children and the remaining third of focus group participants cared for three to six children.

The focus groups were arranged by research collaborators: Te Kotuku Hauora o Rangitikei, Te Runanga o Ngati Apa, OTaihape Māori Komiti Inc.; Te Oranganui Iwi Health Authority Primary Health Organisation, Born and Raised Pasifika Early Childhood Centre, Birthright (Wanganui) (who hosted two sessions) and the Whanganui Regional Primary Health Organisation. Each group recruited their participants and decided how their sessions would be organised. As a result of consultation with stakeholder members and their cultural leaders, although the questions and actual data gathering procedures were standardised, focus groups were carried out in a variety of ways appropriate to the participant groups. Some focus groups resembled the traditional European model, while others involved more ceremonial elements, such as prayer, formal speeches of welcome and food blessed and served either before or after the group session. Ownership of the results of the focus groups (and subsequent interviews) was also talked through during the Community-University meetings.

There were five major aims underpinning the focus groups: 1) to learn more about the decision-making process; 2) to find out where and what decision-makers had heard about immunisation; 3) to discover what information participants wanted or needed and how they preferred messages to be delivered; 4) to gather opinions on the currently available booklets and pamphlets; and, 5) to gain views on whether a series of realistic localised cartoons (designed for an earlier research project) would be a good model for immunisation information. Appendix A contains the focus group schedule. Examples of cartoon illustrations with speech bubbles designed for the earlier Adult Literacy and Employment project⁵ were shown to the focus group participants as one potential way to use illustrations. Also, an Immunisation Advisory Centre (IMAC) flipchart designed to promote the MeNZB immunisation campaign was shown for comment, offering a different style of illustration and information presentation.

Focus group procedures and questions were developed through dialogue at collaborator meetings, and went through several iterations. For instance, design and wording of information sheets (which featured logos of major participating groups) were amended several times. Focus groups were designed to reflect a variety of ethnicities and also to draw on the experiences and viewpoints of those considered to be particularly at risk regarding their babies' immunisation uptake.

The focus group sessions and interview were digitally recorded and transcribed by a professional transcriber. The transcripts were analysed in two ways. First, a thematic analysis was undertaken looking for common themes and points of difference among the groups regarding the five research objectives. It was from the thematic analysis of the discussion on illustrations that the development of the intervention resources arose. Second, a grounded analysis of the transcripts sought to identify themes and sub-themes arising from the words of the participants themselves. This in-depth analysis technique was carried out by a Massey University team member who had not been involved in earlier aspects of the project, nor had viewed the focus group schedule. Therefore, she was able to draw out themes that arose without any pre-conceived criteria. (an inductive approach)¹⁰⁸. With specific regard to the focus groups, the data coded as 'themes' represent items of discussion that were focused on and mentioned by more than one member of the group, as opposed to individual comments to which no other group member responded or added a view.

In the focus group results sections below, we first present the thematic analysis results. We then present the detailed grounded analysis results, followed by the development process of the resources.

4.1.2 Focus group thematic analysis results

We found our participants did not go through any protracted decision-making process, with most accepting immunisation as something they should do. There were strong indications that parents felt pressured: they believed (incorrectly) that immunisation was necessary for access to pre-school; had fears of not being a 'good parent'; and were frightened of the diseases, even though they did not know what they were. A positive factor mentioned was that immunisation was free. Barriers to the immunisation process included:

- Lack of knowledge particularly with regard to the diseases and reactions to look for after the vaccine;
- Fear of hurting the child and fear of needles;
- The perception that there were too many vaccinations required;
- Perceived intimidating behaviour of health professionals;
- Concerns about side effects and the impact of misinformation;
- Confusion about the process of vaccination;
- Difficulty of finding information;
- Problems with transport and time pressures;
- Other illnesses in the family or other priorities; and
- Setbacks after missing an appointment.

There was a general lack of knowledge on what the vaccinations were for, what the process of vaccination is and where they could find out more. Participants were concerned about what they saw as inconsistent messages and message styles about immunisation. They dismissed a Ministry of Health 'Childhood Immunisation'¹⁰⁹ information booklet as too wordy, with most saying they would not bother to read it. Most recognised a smaller brightly coloured Ministry of Health pamphlet titled 'Immunise Your Children'¹¹⁰ which is given to pregnant women and were particularly approving of the immunisation schedule, although they criticised it for having "too many long words".

The immunisation information preferences mentioned by focus groups can be grouped under four themes: illustrations, presentation, information content and delivery.

Illustrations:

- Participants almost unanimously rejected the cartoon examples with speech bubbles saying they were not 'real', they did not 'relate' to them and they would be unlikely to read them;
- They also did not think localised backgrounds were necessary. Instead, they wanted:
- Photographs of real people, including babies, the wider family and the doctor's rooms;
- Pictures with relevant cultural components;
- Images of the diseases being immunised against (but not full photos, just parts of babies (such as the throat for diphtheria) to avoid it being 'too personal');

Presentation preferences:

- Bright colours, simple words and simple pie charts;
- Information to be presented in different languages; and
- Information presented in small chunks with guidance as to where they could find out more.

Information content wanted:

- More information about the risks and side effects of immunisation;
- A better balance of the risks and benefits of immunisation; and
- A reminder about the timing of their baby's injections.

Information delivery preferred:

- Information delivered in an interaction with a trusted source.

4.1.3 Focus group grounded analysis results

Similar to the results of the thematic analysis above, the more in-depth grounded analysis found three macro-categories within the data. These were: barriers to immunisation, facilitating factors for immunisation; and, recommendations for improvements to immunisation communication.

4.1.3.1 Barriers to immunisation

When taking all the focus groups into account, there were 97 occurrences (number of comments) of 'barriers to immunisation'. These included experiences connected to immunisation that were unpleasant, disconcerting, anxiety-inducing, confusing, or otherwise off-putting. These 97

occurrences have been aggregated into 10 macro-themes. Table 1 lists these ten themes in order of the frequency with which they are mentioned.

Table 1. Barriers to immunisation as recounted by focus group participants

Rank	Type of Barrier	Frequency
1.	Relevance/ Accessibility of written information	26
2.	Fear/ Anxiety about complications	15
3.	Negative experiences talking to/ visiting the GP	14
4.	General lack of information	13
5.	Anxiety about inflicting pain	8
6.	Poor funding for nurses, outreach services etc.	7
7.	Transportation access barriers	6
8.	Time constraint barriers	5
9.	Interaction with anti-immunisation peers	3
10.	Increasing number of immunisations	2
	Total	97

The most frequent barrier mentioned was the relevance and accessibility of written information. Sometimes these comments arose in response to the focus group facilitator displaying samples of written materials and seeking evaluation of them, which may be why this is the most dominant category of response. At other times, respondents spontaneously nominated written material as one of the barriers they perceived to understanding immunisation issues. The types of issues raised were generally in regard to :

- sheer quantity of the text: *“I’m turned off by the weight of it [referring to the MoH ‘Childhood Immunisation’ booklet]. Thickness. And when you’re a Mum do you really have time to sit down and read that? No, I don’t...[It needs] the right information, but not too much information”;*
- wordiness: *“This is way too big to begin with [referring to the MoH ‘Childhood Immunisation’ booklet]. Way too much information. Words, words, words”;*
- irrelevant information: *“It [referring to the MoH ‘Childhood Immunisation’ booklet] doesn’t do a lot for me. The first page like it’s got da de dah, blah blah blah and da de da de and Ministry of Health supports immunisation. How does that help?”;*
- literacy and learning style issues: *“Not everyone can read”, “Some of the words in there would be way beyond a lot of people”;*
- the tone of the material (too technical, condescending, or authoritarian): *“A lot of the information is quite...it’s really in your face...scare tactics stuff...putting the fear in and saying well, you know, if you don’t do this then that is what is going to happen, instead of saying, well, okay, this may happen and having some clear information that people can understand”.*

The second most frequently mentioned barrier related to fear or anxiety about complications from the vaccine. Many respondents had heard stories of frightening or damaging reactions after immunisation, causing them to feel uncertain about the safety of the vaccines. These feelings often appeared to signal a lack of trust in both the information provided and the whole process of immunisation. Of particular concern to respondents was the time of sitting in the doctor's office post-vaccination which was couched as a time of worry which left lingering doubts as to the safety of the vaccines:

You get quite worried about the side effects...sit in the doctor's waiting room for 20 minutes later to make sure it's not swollen or a rash develops or something like that, make sure we're not allergic to things. You're sitting there thinking 'please don't happen' and then the Doctor says 'time to go', so...maybe I should have thought about it more and do more about wanting to know why they do it so young.

The third most frequent barrier mentioned was negative experiences of visiting and interacting with their GP. Several mentioned problems with access issues such as long waiting times, changed appointments and unavailable vaccines, while others indicated a decreasing tolerance for authoritarian communication from doctors. In many cases, respondents appeared to be seeking (but not finding) a more interactive and detailed information exchange with medical staff.

The fourth most frequently mentioned barrier, general lack of information, was concerning. It is important to note here however, that the data is based on participant self-recall, so while participants may not recall receiving any immunisation information, this does not mean that they did not in fact receive it. Many respondents said they had not received any immunisation information from health professionals including midwives, whereas others had received information but had further questions and found it very difficult to locate answers to these questions. Some turned to information on the Internet even though they were wary of its quality.

The remaining barriers were each commented on less than ten times. An anxiety of needles and inflicting pain on their child, the perceived inadequate funding for nurses and Outreach teams to spend time interacting with clients, transport and time constraints and the increasing number of immunisations required are fairly self-explanatory. Interestingly, in two of the seven focus groups, interactions with anti-immunisation peers were discussed. Because of a lack of knowledge about immunisation, respondents noted it was difficult to know how to answer this type of influence.

4.1.3.2 Facilitating factors for immunisation

There were 73 occurrences of 'facilitating factors for immunisation'. These included experiences connected to immunisation seen as encouraging and constructive. Eight macro-themes have been generated from these 73 occurrences. Table 2 lists these eight themes in order of the frequency with which they are mentioned.

Table 2. Facilitating factors for immunisation as recounted by focus group participants

Rank	Facilitating Factor	Frequency
1.	Family trigger or help facilitate immunisation	20
2.	Plunket/ Community Clinic reminders & book	16
3.	Importance of trusting relationships	12
4.	GP and Practice/ Plunket Nurse interactions	8
5.	Outreach teams help anxiety and access issues	7
6.	Information received from midwife	5
7.	Perceived childcare/ school requirements	3
8.	Written pamphlets with pictures useful	2
	Total	73

While allocated separate themes, the importance of an interaction with a health professional and a subsequent discussion of immunisation is seen in these results. Respondents noted that interactions and/ or discussions with Plunket Nurses, Practice Nurses, GPs, Immunisation Outreach Teams and Midwives resulted in the respondent feeling more knowledgeable about immunisation, less concerned about the perceived or potential side effects of vaccination and helped with making sure their children were on schedule for their vaccinations. Reminders from Plunket and Community Clinics were also very much appreciated.

When all eight themes are considered separately, the most frequently mentioned facilitating factor is the influence of family members either through triggering immunisation or helping to facilitate it. Where influential family members (particularly maternal grandmothers) feel that immunisation is important, this could trigger the caregiver to consider immunisation. Family support through providing childcare, taking children to their appointments, or even holding children during the administration of the vaccine helped to facilitate immunisation.

While only mentioned twice, it was of interest that so few people found written material on immunisation helpful (this did not include the WellChild book). These written resources were influential in deciding to immunise particularly when it included a photo of the disease the vaccine in question protected against.

4.1.3.3 Recommendations for improvements to immunisation communication

Participants outlined 145 occurrences of themes about immunisation information preferences. Aggregated into nine themes, the recommendations were heavily dominated by a preference for photographs of real people and others' stories. Table 3 outlines the nine information preferences.

As was outlined above under the thematic analysis of the focus group transcripts, participants wanted to see photographs of real people they could relate to in immunisation communication resources, as opposed to cartoon-like illustrations. Further, respondents stated that images needed to be age and culture appropriate, saying, for example *"Having somebody who young people can relate to, I think, is really important, instead of having the ideal middle-class New Zealand because it doesn't meet everyone's needs"*. Photographs of babies and children were considered important and while people did not want pictures of babies actually getting injections, they seemed generally

in favour of pictures of babies or children with disease symptoms (with endorsement of the idea of just showing part of the body rather than the whole child).

Table 3. Recommendations for improvements to immunisation communication resources as recounted by focus group participants

Rank	Recommendation for Improvement	Frequency
1.	Real people's photos and stories	36
2.	Age and culture appropriate	27
3.	Short plain language	19
4.	Balanced and informative	18
5.	Suggested key messages	15
6.	Feature babies and children	12
7.	Suggested campaign channels	9
8.	Localised settings preferred	6
9.	0800 telephone numbers	3
	Total	145

As also outlined above, participants wanted short, plain language in resources and they wanted the information to be balanced. Requiring balanced information should not be taken to mean that respondents wanted anti-immunisation material shown alongside pro-immunisation material, but instead, that the statistics around the risks and benefits of immunisation be shown.

A number of suggested key messages or questions that participants wanted answered were outlined. These were mostly in favour of information including: the nature of the disease being prevented (presented in a factual way, as opposed to 'scaremongering'); the immunisation schedule; what to look for in adverse reactions; and, what vaccines are.

Campaign channels using other sources such as TV, radio and bus billboards were ideas put forward in addition to the current focus of this study. Localised settings were preferred by some, with the idea that using recognisable locales or people would *"appeal to more people in any area if they can relate to something"*. Finally, a few people specifically mentioned a 0800 number for further information if required would be useful (some of the participants were unaware of the 0800 Healthline number and most were unaware of the 0800 IMMUNE number).

4.2 Resource development

4.2.1 Initial resource development: The team

Two resources were suggested: a flip chart and an accompanying fridge magnet. The suggestion for the flip chart emerged during one of the focus group discussions about how participants would prefer immunisation information to be presented. The original intention (prior to the focus groups) was to develop a pamphlet and a fridge magnet. However, during focus group discussions it was made evident that participants believed there was already sufficient immunisation information available in pamphlet form, but that pamphlets are not always read. What was needed was illustrative information delivered in a face-to-face encounter.

The focus groups thought that a fridge magnet would be very useful, but as with illustrations, they had strong views on what they would prefer the magnet to include. They did not simply want a logo saying 'Immunise your baby'. Instead, they wanted the magnet to include pictures to attract their attention and space for the due dates to be entered, reminding them when their babies' immunisations were scheduled and where to go.

Researchers and community partners (along with IMAC) discussed these findings thoroughly, designing the concept of an A5-sized flipchart to present the more detailed immunisation information and a personalised A5-sized fridge magnet incorporating key messages from the flip chart. Both of these were completed by professional designers, Kerry Ann Lee and Martin Lee, who were willing to work with the iterative community feedback process. Because focus group participants preferred illustrations in the form of photographs it was decided, after gaining permission from the Ministry of Health, to use the already familiar material of images from their DVD and pamphlet *Immunise Your Children*¹¹⁰ for both the fridge magnet and the flip chart. Using these resources and the Immunisation Advisory Centre (IMAC) document 'In the Loop: A Guide to Immunisation'¹¹¹, a draft version of a flip chart was prepared. The flip chart, designed to be presented by a health professional in a one-to-one interaction, consisted of bright photographs and pictures accompanied by simple, short messages covering key immunisation topics. On the reverse of the flip chart were details of the fuller verbal explanation for the health professional.

The fridge magnet would incorporate a simplified version of the National Immunisation Schedule¹¹⁰ which is also included in the *WellChild Tamariki Ora Health Book*, thus reinforcing existing official public health messages. Over several project team meetings, decisions were made ensuring there was space for the baby's name, photo and immunisation due dates, plus key messages such as contact phone numbers in case of concern and a reminder of the importance of babies receiving all the scheduled immunisations on time.

As discussed above (see *Working Together: Issues and Solutions*), negotiation, compromise and finding a common dialogue were needed as the project team worked to prepare the resources. For example, initially we were reluctant to use pictures of the diseases because research had shown this could have negative consequences such as being deemed 'scaremongering'. However, our participants, while reacting to the pictures, were adamant they wanted them.

As the next step, the project team presented drafts of the proposed flipchart and fridge magnet for review by focus group participants and other interested people at focus group feedback sessions.

4.2.2 Feedback to focus group participants

Feedback was presented to the participants and other interested members of the group's community. At these sessions, the results of their group's session along with the general findings were presented. In keeping with the reminder by Nielsen-Bohlman et al. of the importance of modifying materials after testing them with intended users⁶⁰, they were also shown a draft of the flip chart and the fridge magnet that were developed following suggestions from the first round of focus groups. At these feedback sessions, the new materials were endorsed by participants who also made further suggestions for improvements.

4.3.3 Final checking: The team

As the project and discussions proceeded, especially as feedback from the focus groups was presented, the true collaborative nature of our research became increasingly apparent. The collaborative team, the health professionals in particular, responded to the feedback providing invaluable and increasingly in-depth insights into such issues as who parents should contact when they had questions, the forms and level of discomfort experienced by babies that should be considered 'normal' following immunisation, the preferred vocabulary to use in the interventions and ensuring that illustrations represented the correct placement of the needle at the injection site. As we examined the materials increasingly critically and following recommendations from health literacy experts⁷⁸⁻⁷⁹, we reduced the number of words, ensuring that the words supported the images presented rather than using the words or the pictures in isolation. As iterations progressed, we also included suggestions from the literature for maximising the font size and presenting information in bullet point format rather than in paragraphs. In this iterative process, the resources were emended and developed over several months until the final version was agreed through consensus.

In this small trial research, the resources were in English, but there is the potential for the resources to be produced in other languages if needed in the future.

4.3 Phase two: Antenatal interviews

4.3.1 Method

The pilot trial of the resources began in August 2009. The community partners provided avenues to source mothers-to-be as participants from among their clientele. The majority of the interviewees were sourced through the assistance of Midwives at the Whanganui District Health Board Maternity Service, in both rural and urban clinics. Some participants were also recruited via the assistance of Independent Midwives. Sixty-two women in their third-trimester of pregnancy took part in the project, 31 allocated to an 'intervention' group and 31 to a 'control' group. The participants were recruited through a snowball sampling technique. Bloch suggests that a disadvantage of this recruitment method is that "more isolated members of a group will not be included"¹¹². As he recommends, we have attempted to solve this problem by using "multiple starting points for snowballing"¹¹², with our research facilitator/ interviewer visiting health professionals such as midwives, primary health providers and ante-natal class tutors throughout the Whanganui district, including Whanganui, Marton and Taihape, to access women from as many sources as possible. In doing so we have also avoided the problem of interviewing only a 'homogeneous sample'¹¹³. Thus, included in our interviewees were rural as well as urban women, sole as well as partnered mothers-to-be and Māori, Pasifika and other ethnicities as well as Pākehā women. Each potential interviewee was presented with an information sheet detailing the project's aims and the members of the project team. Table 4 outlines the demographics of the interviewees by control and intervention group.

Table 4. Demographics of the interviewee sample by control and intervention group

	Control %	Intervention %
Age Group		
16-20	9.7%	16.1%
21-30	64.5%	48.4%
31-40	22.6%	35.5%
41-50	3.2%	0.0%
Ethnicity		
New Zealand European	61.3%	61.3%
Māori	9.7%	16.1%
NZ European/ Māori	3.2%	9.7%
New Zealander	19.4%	9.7%
Other	6.4%	3.2%
No. of children responsible for		
0	35.5%	54.8%
1	41.9%	29.0%
2	19.4%	6.5%
3	3.2%	9.7%

The antenatal interviews consisted of four parts. First was a simple demographic questionnaire. Second, was a series of open-ended questions about infant immunisation information they had been given and what might impact on their decision-making about immunisation (see Appendix B for the antenatal interview schedule). Third the Short Test of Functional Health Literacy in Adults (STOFHLA)¹¹⁴ was administered, taking about 10-12 minutes. This test assessed the health literacy and numeracy level of interview participants. This test was chosen for its brevity and because it has both high reliability and high construct validity and has been used in a wide variety of international health literacy studies¹¹⁵. One of the initial aims was to compare the results of high health literacy individuals against those with low levels. However, our sample makeup resulted in only one participant with inadequate health literacy, therefore, this analysis could not be conducted. Fourth, the intervention group received the visual flip chart presentation of immunisation information, heard the accompanying spoken information and were given a fridge magnet; the control group did not receive the fridge magnet and did not see the flip chart, but listened to the accompanying talk. Importantly, both groups received their immunisation information in a face-to-face encounter during the interview sessions.

While many of the antenatal interviews took place at midwives' clinics, some were conducted at the participants' workplaces. Only one participant refused permission for the interview to be taped; her responses were hand-written by the interviewer. All participants gave permission for their immunisation records to be accessed through the National Immunisation Register and all participants agreed to participate in a second interview. The interviews took place in a rolling process over three months, undertaken as participants were recruited. Transcription of the interviews was on-going.

All participants received a choice of a \$10 petrol or supermarket voucher as a token of appreciation for their participation and all stated that they wished to receive a summary of the research findings at the end of the project.

4.3.2 Antenatal interview results

The transcripts were analysed again through a grounded analysis inductive approach. Five macro-themes were found within the antenatal interview data. These were:

- sources of immunisation information;
- judgements about the quality of that information;
- impact factors (sources or issues that respondents felt had been particularly influential on their immunisation decision);
- information needs;
- preferred sources of information.

One planned part of the analysis was unable to be undertaken. This was a comparison between recall of the immunisation information and immunisation uptake rates between participants with adequate health literacy and those with inadequate health literacy (as defined by the STOFHLA). The sample of interviewees all had adequate health literacy skills, except for one participant. Therefore, comparisons were unable to be undertaken. Possible reasons for this include: 1) participants were volunteers who took part in the study knowing a reading activity was part of the interview process. This may have ensured those with low literacy levels in general did not choose to participate; 2) the STOFHLA is a screening tool that has not been validated with New Zealand audiences and may not have been sensitive enough to pick up on differences between participants in this study.

4.3.2.1 Sources of information

Overall, interviewees reported receiving information from a variety of sources. As a disclaimer, these reported sources are based on self-recall and may not include all sources from which information is found. Also, receipt of information does not imply quality of information or engagement with that information. Participants who had received a brochure or seen something in the media, often they had paid it little attention or had a low opinion of the quality of that information.

Interestingly, 34 interviewees (55%) initially reported they had not received any immunisation information either in written form or via a discussion. Often, however, as the interview proceeded, these same people recalled they had seen something in the media or received a brochure. Nevertheless, there remained the initial feeling that 'nobody' had specifically informed them about immunisation.

The most commonly reported source of information was brochures (39 respondents), however, comments suggested these brochures were sometimes not read: *"You get pamphlets and stuff, but I'm not much of a reader"*; *"A little photocopied pamphlet type thing that's just shoved into a pack"*. Brochures were generally distributed through midwives *"My midwife has just briefly given me some*

information to read, but I've not really gone through it". One participant commented that they had been given a pamphlet by their midwife who asked them to read it and to bring any questions back to her at the next meeting. Similar sources of information about the immunisation schedule mentioned by interviewees included the WellChild book and posters in doctor's surgeries and antenatal classes.

Stories in the media were the second most commonly reported source of information for interviewees (38 respondents). This included television, radio and articles in magazines. Participants were split on the usefulness of this information with some seeming uncertain about immunisations, for example, *"I saw a programme on, I think it was on the Oprah Winfrey show, where the kids were immunised as you do against all these things and their kids got ADD from it" and others who were not "I remember watching something about parents and immunisations causing autism, but I don't believe that, so I don't really take any notice".*

Family members (29 respondents) and friends or peers (18 respondents) were named as influential sources of immunisation information. One interviewee noted *"My mum chose not to immunise me straight away, like a couple of months down the track I think, so that sort of makes me wonder, you know 'oh, what should I do? What would be better?'. Another respondent stated "I talked to Mum about it and she's all for it". Talking with friends and peers can also influence decisions, for example: "From the people we know who have been immunised, they've got really hardy immune systems, so we're going to go with it"; "I find that sometimes when you talk to people about things like that you get so many different opinions that you start to doubt your own and why you think it's a good idea".*

Some participants had had the opportunity to discuss immunisation with their Doctor (15 respondents) and/ or Practice Nurse (10 respondents). Others had received information from sources such as the internet, antenatal classes and naturopaths.

4.3.2.2 Information quality judgements

Fifty-one of the 62 participants reflected on the quality of the immunisation information they had received to-date. Figure 1 outlines the proportions of participants who felt their information needs were or were not satisfied.

One reason for dissatisfaction included that it was difficult to find 'both sides' of the immunisation issue i.e., information on the benefits of vaccination versus the risks: *"I would have liked some more information around what the immunisation actually does to the body and what the actual results of any studies were, in terms of how effective they are and how many follow-ups they need...you get a little bit of information around 'oh, they might get a bit of a rash, they might get a bit of a fever, but it's like really lightly skimmed over, the side effects of things"; "I wasn't happy with the information that I was given and tried further to find information myself, but could not find anything".*

Other dissatisfaction comments claimed that immunisation pamphlets received were *"biased, because it was coming from the people that recommend you do the immunisations, so there was no real solid information in it".*

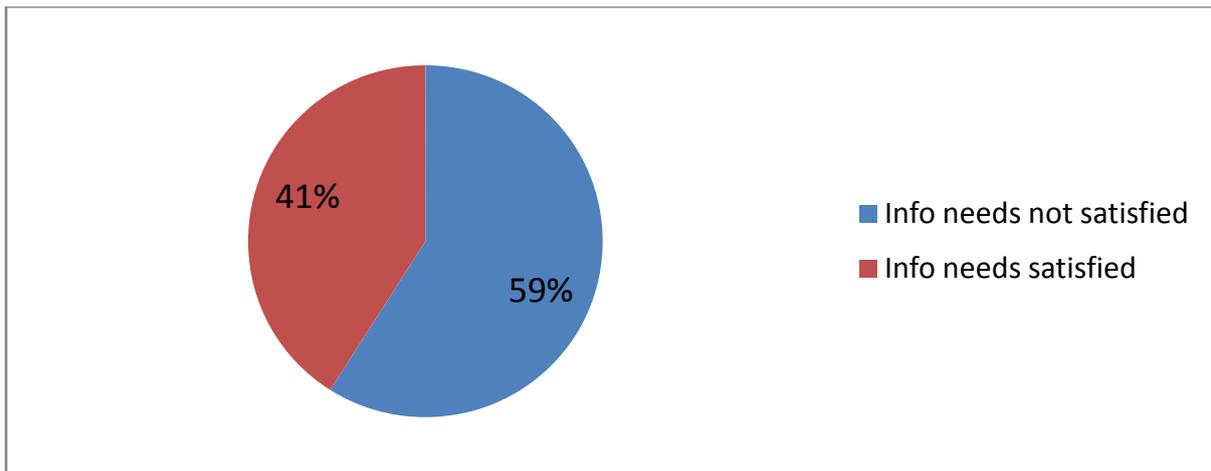


Figure 1. Quality judgements of received immunisation information by antenatal interviewees

Respondents who indicated satisfaction with the immunisation information they had received, felt that they had been adequately forewarned about possible reactions and how to respond and had been given the opportunity to discuss any questions or concerns. Some typical comments included: *“It was good to...read about [it], just explaining what exactly they do and which ones they’ll do at what time”*; *“There was Plunket and I had a Māori health organisation as well come and see me about immunisations. So I had the doctors, the nurses and those two organisations...I thought it was good. I really didn’t have any [questions or concerns] because they filled me in that well”*; *“I think that once you get people away from the focus of what they’ve seen on the news and what they’ve said in the paper and focus them on the actual factors of what the right facts are, then I think that makes a huge difference”*.

4.3.2.3 Impact factors

When asked about the factors influencing any immunisation decision made or thoughts around immunisation, many respondents stated feelings of uncertainty about immunisation (24 interviewees) and fear of complications from the vaccine (19 interviewees). Despite these fears and uncertainties however, 30 participants recounted that their personal experiences of immunisation would likely lead to them immunising their child in the future, for example, *“I was fine, my sister was fine, my niece was fine, so I thought ‘nah, he’ll be fine”*. There was also the perception that ‘everyone does it’, endorsed by 19 participants, for example: *“Everyone was doing it so that was the only reason I’m doing it”*; *“It’s just something you do. I think in New Zealand you don’t question it, you take the kids in anyway”*.

Other impacting factors on immunisation thoughts and decisions included:

- family influences (10 respondents): *“My mother-in-law who thinks it definitely needs to be done and if you’re a week late, well, ‘When are you going to get it done?’”*;
- perceptions of lack of autonomy in decision-making (seven participants): *“I just didn’t feel right about it. There was a huge big push for it...it just didn’t sit with me that one and I just kind of felt that it was a huge big, it was more like a scaremongering thing”*;

- the need for their child to mix with other children safely: *“I still don’t like us relying on every other child being vaccinated...I mean he is going to Montessori at like 2 and a half, he’ll be going there soon. I think it’s more to be safe than sorry”*;
- fear of the pain of vaccination: *“It’s not a nice thing to take your little baby along and they cry you know and that side of it is horrible”*;
- guilt if the child were to contract the disease at a later time: *“If she got meningitis and I could have had her immunised, I wouldn’t be able to live with myself, so she was immunised for that”*.

4.3.2.4 Information needs

Table 5 outlines the types of information participants stated they would like in immunisation communication resources, which were very similar to the focus groups. As can be seen by the highest ranked information need, respondents generally wanted more information. However, there were specific types of information they were interested in and it was important that information was accessible in terms of language and layout.

Table 5. Information needs of antenatal interview participants

Rank	Information Need	No. of respondents	No. of comments
1	More information	18	21
2	Balanced information	13	15
3	Accessible information	8	9
4	Information about reactions	7	7
5	Information about purpose of vaccination	7	8
6	Information about the appointment	5	6
7	Information about vaccine content	5	6
8	Timing of communication	4	7
9	Other including websites	3	3

The second most highly ranked information need was for balanced information. Participants did not ask for information that compared anti-immunisation material against pro-immunisation material. Instead, they were focused on the statistical risk of reactions from the vaccinations, against the statistical benefits of receiving the vaccinations. For example, one respondent said *I think it would be good to have actual information around how many babies actually are at risk of getting these diseases and what the risks of having them are, so that you can make a more informed choice because some of it seems a bit scare tactic to me”*.

Comments about accessibility of information largely related to the technical language used: *“Some of the words are hard to read...long words. I don’t understand some of them...I take the pamphlets home and...my partner probably won’t know what it is either”*. Also, comments were made about making resources more visual: *“There is maybe not a lot of the visual stuff...pictures of the different types of diseases and things, you don’t sort of get any of that at the moment which would be quite useful”*. Respondents also commented on the amount of information received during the antenatal period saying *“You get given so much you don’t really know where to start”*.

Specific information requirements were information about potential reactions, the purpose of vaccination, the contents of vaccines and the process at the vaccination appointment. With reference to the latter, two participants mentioned that resources that tell caregivers that *“It’s not as bad as you think...they cry for about 15 seconds and then you...give them a cuddle and it’s fine”* would be useful. Comments about the timing of immunisation communication, suggested that earlier in pregnancy might be useful, as closer to the birth, the focus of the mother-to-be is on the birth itself.

4.3.2.5 Preferred sources of information

Twenty-five respondents preferred receiving immunisation information through discussions with a health professional and a further 11 preferred discussions in conjunction with later Internet use. Twelve participants preferred using the Internet as their only information source. Other sources, mentioned by a few participants, included family, friends and people who were not obviously pro-immunisation.

Interestingly, only four respondents preferred written information such as brochures.

4.4 Phase two: Postnatal interviews

4.4.1 Method

The follow-up interviews began as the interview participants from the antenatal interviews reached eight weeks post-birth. However, while all the interviewees had agreed to a second interview, one woman was unable to be contacted, giving a total of 61 interviews in the second round (31 women from the control group, 30 women in the intervention group). All but one of the second interviews was conducted over the phone (with one conducted face-to-face).

The purpose of the postnatal interviews (see Appendix C for the postnatal interview schedule) was to:

- Explore the decision made about (and influencing factors on) the six-week immunisation;
- Determine the type of information received since the antenatal interview;
- Determine what was recalled about that information;
- Determine what was understood from that information;
- Evaluate the quality and usefulness of the flipchart and fridge magnet.

4.4.2 Postnatal interview results

The transcripts were analysed through a grounded analysis inductive approach. Nine macro-themes were found within the postnatal interview data. These were:

- sources of immunisation information received since the antenatal interview (excluding the intervention);
- judgements about the quality of that information;

- impact factors (sources or issues that respondents felt had been particularly influential on their immunisation decision);
- information needs;
- preferred sources of information;
- recall of intervention information from the antenatal interview;
- evaluation of the fridge magnet;
- text messaging preferences;
- recommendations for timing.

4.4.2.1 Sources of information since the antenatal interview

It is important to note again that this data set is based on participant recall of information received. Indications of little recall of resources should not be taken as evidence that no information was provided to the participant. Also, participants were asked to reflect on immunisation information they had received since the last interview apart from the intervention.

Sixteen interviewees (26%) stated they had not had an opportunity for a specific conversation about immunisation with anyone since the antenatal interview. Promisingly, this was down from thirty-four participants who had not had this opportunity as yet in the antenatal interviews. Some of these sixteen people said they had received brochures, immunisation schedules, or had attended an immunisation appointment and received brief information at it. However, if they signalled to the interviewer that they did not feel they had specifically been informed by talking to anyone about the issue and having an opportunity to ask questions, this was recorded as 'no discussion'.

The impact of health professionals as sources of information has risen with midwives moving from third in the antenatal interviews to first in the postnatal interviews, Plunket Nurses moving from sixth to second and Practice Nurses moving from eleventh to third. This may reflect increasing points of contact with the health system during birth and post-natal phases and contact with Practice Nurses at the first immunisation appointment.

In terms of written resources, brochures were still a primary source of communication received (mentioned by 29 respondents). Interactions with family (16 respondents), peers (13 respondents) and information from posters (14 respondents) were also mentioned. The impact of messages through the media (dropping from second to tenth), antenatal classes, naturopath consultations and other sources were mentioned by only a few participants.

4.4.2.2 Information quality judgements

Approximately half (28) of the participants felt that the information they had received (excluding the intervention) was helpful, while 26 respondents felt that it consisted of only 'token' information. Of interest, when the participants were split by control and intervention groups, the control group participants were more likely to find the received information helpful, whereas the intervention participants were more likely to find it unhelpful or 'token'. In terms of the types of information each group found helpful, many of the control group respondents found helpful information gained from talking with Practice Nurses at the first immunisation appointment, whereas intervention

group interviewees were more likely to find helpful information in brochures (such as the Bounty Pack) or articles in parenting magazines.

Overall, five respondents stated that the information they had received was completely inadequate. Approximately a quarter of interviewees claimed that the only information they had received was an immunisation schedule. Nobody reported receiving anti-immunisation information from any source. Finally, approximately a quarter of respondents claimed they experienced 'information overload' usually containing very similar information, which caused them to 'tune out'. One participant commented: *"What I felt is when baby was born at the hospital, I got given hundreds of papers, some pamphlets and I am amazed how much [the Ministry of Health] print. It's amazing...but it's too much...all of them, they have sort of the same information...so I found it was loads of information and I was wondering why [the Ministry of Health] have different programmes because they all target sort of the same thing. It's hard to understand a wad of things"*.

4.4.2.3 Impact factors

In the antenatal interviews, there was a lot of uncertainty and fear about side effects of vaccinations. However, in the postnatal period, while concern about safety of the vaccines was still the most mentioned impact factor (16 respondents, eight in each group), interestingly, the number of people expressing uncertainty about aspects of immunisation had dropped to one control group member. Safety concerns included: *"Still concerned about baby having the combinations and too many too soon"*; *"You do worry...I think it's just...not foreign, but it's something going into them"*; *"Just all the results like the increase of autism and asthma and all these other things"*.

Six participants mentioned autonomy as an influence on immunisation decision-making saying *"I'm all for it, but don't be too quick to make a decision. Like, really think it through"*. Personal experience was the third most frequently mentioned impact factor, but at five respondents was largely down on the 30 respondents who mentioned it in the antenatal interviews.

A new theme that emerged as important for five respondents was the concern to ensure that children in general were protected, with most alluding to the 'herd immunity' argument. Other influencing factors mentioned were: everyone does it and the pain of the injections (four participants); and family influence and the desire for their child to mix with other children (two respondents).

4.4.2.4 Information needs

The need for more information in general as put forward by 18 respondents in the antenatal interviews, has now dropped to two participants (both in the control group). Similarly, however, a need for balanced information is ranked first in information needs in the postnatal interviews (compared to second in the antenatal interviews), although the total number of people mentioning it has dropped from 13/62 (21%) to 8/61 (13%). Balanced information is also of more importance to the intervention group (6 respondents) than to the control group (2 respondents). One intervention participant commented on a family member/ friend who had decided to immunise: *"The main piece of information that she was really after was how many, what is the risk in a million, the chance in a*

million of my baby contracting that disease in the first place. And the other thing she wanted to know is what is the risk of my baby getting complications from the vaccine...once she got that, I think she actually decided to go and get them, so there was actually quite a big turnaround...".

The control group seemed more concerned about potential reactions and appointment advice (10 respondents versus two in the intervention group). A few people remained interested in the purpose of vaccination and vaccine contents.

4.4.2.5 Preferred sources of information

The preferred sources of information were very similar to the antenatal interview results. Thirty-one participants preferred receiving immunisation information through a discussion with a health professional (compared to 25 interviewees in the antenatal period). A further nine participants preferred a discussion in conjunction with later Internet use. Only six respondents preferred using the Internet only which was half the amount since the antenatal interviews. Other sources included family members and, for two participants, alternative therapy practitioners.

Three respondents stated they preferred written information such as brochures (similar to the number in the antenatal period).

4.4.2.6 Recall of intervention information from the antenatal interview

Qualitatively, the amount of recall participants had of the intervention was assessed. The intervention for the control group was the spoken information only, while for the intervention group, it consisted of the spoken information in conjunction with visual presentation of the flipchart and a fridge magnet to take away. The numbers presented in Table 6 below should not be interpreted as statistically valid, but at a qualitative level, some differences were evident.

Table 6. Qualitative recall levels of the intervention resources by control and intervention group

Amount of Recall	Control Group (No. of Respondents)	Intervention Group (No. of Respondents)
Little or no recall	13	5
Moderate recall	11	14
Confident recall	7	11

As can be seen in Table 6, the control group were more likely than the intervention group to have little to no recall (one or no items of information) of the spoken information even with prompting. Both groups had a similar level of moderate recall however (one or two clearly recalled pieces of information). The intervention participants were more likely than the control group to confidently recall three or more items of information without prompting. The disease pictures were particularly memorable and several people indicated that these had specifically influenced their decision-making.

One comment from a moderate-recall intervention participant on the flipchart was: *"That pretty much did it for me. Knowing what could happen to them if you didn't get them immunised. Because I*

was kind of like half against it and half for it. But when you see what can happen to them you just feel like if you didn't get them immunised and something did happen, then it would be your fault..."

A confident-recall intervention participant commented: *"I thought it was quite good in the sense that it had the pictures...It was you know visually seeing the pictures, seeing the words and also hearing you speak them, you know elaborate. It just gave a bit more rounded picture for immunisation rather than being given, you know, 'here is a pamphlet'...I would have wanted more information about...the illnesses that you are trying to prevent with the immunisations, but I did find that because it showed pictures like the unwell children, pictures of the measles and stuff, so it was a nice glimpse of everything and then it gave a little bit of food for thought so then if people wanted to investigate it further they could"*.

4.4.2.7 Evaluation of the fridge magnet

Of the 30 respondents who had received a fridge magnet, 22 (73%) had put the magnet up on display in their home, 21 on the fridge and one on a notice board. Of these 22, nearly half (10) had personalised the magnet in some way, five with their child's name and immunisation dates only and five also personalising it with a photo. When interviewees were asked for ideas for improvement, almost all said it was fine as it was. One participant, however, suggested less information be included on the magnet. Conversely, another respondent suggested more information be included (specifically about potential reactions after the vaccination).

Of the eight people who had not displayed the magnet at home, five said they could not remember where they had put it, two had fridges unsuitable for magnets and one said it was too big to go on the fridge. One of these participants suggested that an option for distribution would be to have two forms: a magnet, or reminder stickers for a calendar.

Some typical participant comments about the fridge magnet were:

"I've had that on my fridge...it's really good to have that as a constant reminder".

"It's just there, so if I do forget it, it's right in front of me just every day, so it gives me an idea of when the vaccination is coming up and when to book them".

"I think it's good because it stands out on the fridge and I get told I've got too much on our fridge, but it's quite colourful".

"I just have it on the fridge so it reminds me to do it because I put her Plunket book away and everything".

"It's easy to read. I mean, I don't think you really could make it any better personally".

4.4.2.8 Text messaging preferences

Overwhelmingly, all respondents (except one) felt that text message reminders about immunisation appointments were a good idea. However, they also stated that a written appointment letter was still important as well. Some respondents suggested people should be able to nominate their preferred method of reminder (such as email or text or both).

4.4.2.9 Recommendations for timing of delivery of the resources

Generally, interviewees agreed that two discussions about immunisation were important, with most suggesting an antenatal and postnatal discussion. For the antenatal discussion, it was generally felt that if it was held too early in pregnancy, people may not be engaged with postnatal issues or may forget the information by the time the immunisation is due. Too late in the antenatal period, however and it was felt that attention would be focused entirely on the birth. Therefore, approximately 28-30 weeks was considered the optimum time for the antenatal discussion.

For the postnatal discussion, approximately 3-4 weeks post-birth was considered optimum. Directly after the birth, respondents felt that they would be too tired and overwhelmed to consider the information. Additionally, they also wanted a couple of weeks to think about the information prior to the six-week immunisation date.

4.5 Immunisation uptake rates

4.5.1 Method

The Whanganui-based research facilitator/ interviewer and a project team member from the Whanganui Regional PHO were tasked with checking the National Immunisation Register (NIR) database. A roll-out process was used with the database checked at several points over eight months as interviewees gave birth to their children and the associated immunisation dates passed. Every interviewee was tracked using the child's NHI number and immunisation uptake recorded for the six week and the three month immunisation. Additionally interviewees were asked in their postnatal interview if they had immunised at six weeks and whether they intended to immunise at three months.

4.5.2 Results

Figure 2 shows the results from the postnatal interviews. Twenty-six participants in the control and intervention groups respectively had immunised their child at six weeks. The remaining four intervention participants intended to immunise, as did two of the control group participants. However, three control group respondents had declined to immunise their child at six weeks.

When respondents were asked how likely they were to immunise at three months, all the intervention participants stated they were 'highly likely' to do so. The majority of the control group also said they were 'highly likely' to immunise. Two were undecided and one said their child would not be immunised at all.

Subsequent checking of the NIR database showed that of the 62 participants, all had fully immunised their children up to three months, with the exception of three control group participants who had missed both immunisation times.

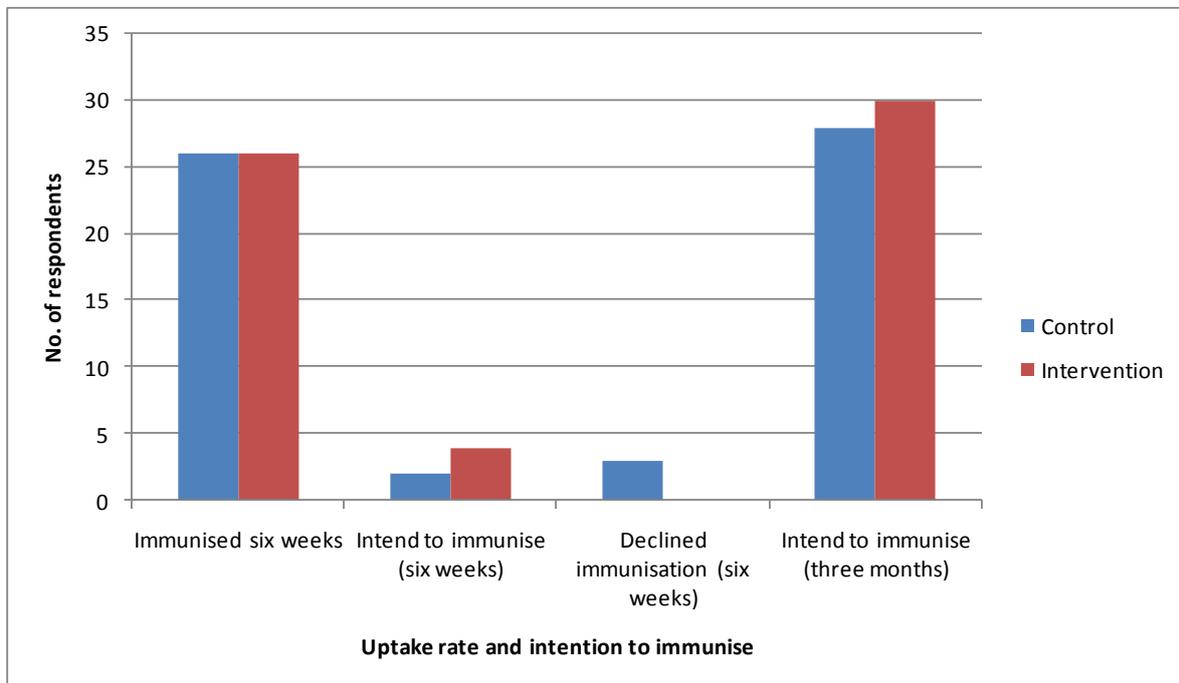


Figure 2. Immunisation uptake rate at six weeks and likelihood of immunising at three months

Any differences perceived between the two groups cannot be ascribed any statistical significance given the pilot nature of the sample and the qualitative nature of the study. However, these results give some indications for future research with larger samples.

4.6 Feedback to health professional groups and participants

Result dissemination meetings were held with Whanganui Hospital midwives (as well as the Whanganui regional New Zealand College of Midwives meeting), the Whanganui District Health Board Immunisation Steering Committee, Paediatric Nurses, Practice Nurses and Plunket Nurses. Dissemination meetings were also held for staff and focus group participants from each of the project team members' organisations and interview participants. The purpose of these meetings was not only to feed back the results, but also to invite discussion and refinement suggestions.

All the groups expressed enthusiasm for the resources, with the health professionals stating that they would find the flipchart useful to stimulate discussion around immunisation. The midwives and Plunket Nurses in particular noted that a simply worded "casual" resource such as the flipchart encouraged actual discussion between the professional and the client as it invoked confidence in the health professional. This confidence was due to having a resource with clear answers to the most commonly asked questions about immunisation, combined with information on where to go for more information if the client wished to know more detail. These groups expressed that they would use such a resource, were it to be made available.

Suggestions for further refinement of the flip chart included:

- More explanation of what each of the diseases were for the health professional to discuss with the client
- Reworking of the 'What are vaccines?' page as cartoons could be viewed as patronising and were out-of-sync with the rest of the pages using photographs
- A space at the back for the health professional to note any recent changes to the schedule and local contact details for further information if applicable
- Inclusion of pages that cover the risks of vaccination versus the risks of the disease
- More discussion points included for the NIR outline so parents are aware of their rights
- More incorporation of different ethnicities in the photographs
- A cardboard base is needed

The fridge magnet was also met with enthusiasm by the health professional groups. Suggestions for further refinement included:

- The 'any questions' and 'urgent advice' box to be made more prominent
- The space for the baby's photo to be removed as clients were unlikely to use it

Subsequently, additional pages for the flipchart and modifications to both resources have been completed.

5. DISCUSSION AND RECOMMENDATIONS

5.1 Summary of purpose

The purpose of this study was to develop communication resources to better communicate infant immunisation information to mothers, fathers, caregivers and other extended family members. The development of these resources was directed by engagement with immunisation end-users and health, family support and education professionals. Following a pilot trial of these resources (a flipchart and a fridge magnet) with 62 women in their third trimester, the resources were evaluated by health professionals and end-users as useful, engaging, meeting a community-identified need and of use to health professionals tasked with infant immunisation communication. In this section, we summarise the key findings of this study, followed by a series of recommendations for immunisation communication resource development, delivery and future research.

5.2 Information needs

The end-user focus groups used to develop the resources and the subsequent pilot trial interviews showed some striking similarities in expressed information needs. Overall, these showed:

- Little knowledge of infant immunisation, including purpose, process and schedule.
- Feelings of uncertainty and fear around perceived side-effects and risks of immunisation arising partly from media and other stories about links with neurological disorders.
- Difficulties of finding trusted, accessible information about risks of immunisation.
- A need for ‘balanced’ information, outlining risks and benefits of vaccination.
- A desire for resources with bright colourful photographs and simple wording.
- Most participants wanted information as part of a discussion; only 4 of 62 antenatal interviewees (dropping to three in the postnatal interviews) preferred written information.
- Participants found Ministry of Health information booklets and pamphlets “too wordy” even though these sources fulfilled their information needs.
- In the antenatal period, most respondents wanted “more information”. By the postnatal period this had dropped markedly from the most frequently mentioned need to just two respondents.
- About three-quarters of the sample reported having the opportunity for a specific discussion or chat about immunisation with a health professional by the postnatal interview.
- Further comments revealed this may sometimes have been restricted to receiving written information.
- Concern about safety of the vaccines was still the highest ranked influencing factor on thoughts about immunisation in the postnatal interviews, suggesting that all information needs are not being met.

5.3 Preferences for information delivery

A common preference for information delivery was seen throughout the focus groups and antenatal and postnatal interviews.

- Those who had an opportunity in the antenatal period to discuss concerns and ask questions of a health professional felt more satisfied with the information received (with some stating they felt more confident about a decision to immunise).
- The majority felt an interaction with a trusted health professional, who did not push a pro-immunisation perspective, was the best way to receive immunisation information.
- Respondents were prepared to view images and read short key flipchart messages, but the verbal delivery and the relationship with the health professional were also important in remembering and trusting the information.
- Control group participants, who only received spoken information, were more likely to remember little to none of the information, but often recalled that there were no pictures to illustrate what the interviewer was saying.
- Intervention participants, who received both spoken information and the visual flipchart presentation, were more likely to remember three or more items of information without prompting.

We conclude, therefore, use of the flipchart as part of a discussion, rather than a structured verbal presentation, could encourage enhanced recall on these figures.

As this project was based on an assumption that immunisation is to be encouraged, it was heartening that most participants stated that they intended to or did immunise their child. This decision was not necessarily the result of an explicit decision-making process, but often the outcome of personal experience with prior vaccinations for other family members, or the perception that ‘everyone does it’. It could therefore be argued that more information delivery and better communication around immunisation is not needed. However, the focus groups and interviews indicated that different means of communicating immunisation information will be needed as people become more resistant to an authoritarian approach. For instance, some older focus group participants said that although their children had been immunised, if they were faced with the decision today they would be more likely to question health professionals telling them they should immunise.

5.4 Disease pictures in the resources

As outlined above, focus group participants and health professionals agreed that resources should be brightly coloured, have simply worded key messages and use images fitting the written and spoken text. An interesting conundrum in the literature and in our discussions with health professionals, was the decision to use pictures of the diseases in the resources. Our focus group participants were fairly unanimous in stating they wanted to see the diseases vaccines help protect against. A reason for this was the need to know why the vaccines were important. Knowledge of the disease was scant particularly for younger parents and caregivers, given that most were too young to have seen outbreaks of such diseases as polio. However, the research team was also aware the use of disease pictures has been minimised in health communication resources due to the perception that it is ‘scaremongering’. Focus groups discussed this and yet participants were strong on the necessity of including them. The ‘scaremongering’ aspect of disease pictures may reflect the context in which they are portrayed. We surmise that when disease pictures (as well as the remainder of the key immunisation information) are presented in a factual way, without implying

the client 'should' immunise or that the disease 'will' occur without immunisation, the autonomy of the client is respected and such pictures may not be viewed as scaremongering.

5.5 Recommendations

Based on the above results and discussion, we have put together a list of key recommendations for immunisation resource development in terms of design, resource delivery and future research into immunisation communication practices.

5.5.1 Recommendations for resource development (integrated into the flipchart and magnet)

1. That bright colours and simple language are used;
2. That the choice to immunise or not is emphasised as sitting with the caregiver;
3. That short key messages are used as opposed to paragraphs or detailed information;
4. That key information includes:
 - normal responses to the vaccine;
 - reactions to be concerned about;
 - what to do in the case of an adverse reaction;
 - nature of the diseases;
 - key dates;
 - the purpose of vaccination;
 - vaccine contents;
 - the process of vaccination (before, during and after the appointment);
 - risks and benefits of vaccination (including proportions of the population);
 - websites and 0800 phone numbers to access further detailed information if required.
5. That photographs of real people rather than cartoon-like illustrations are used, including photographs of healthy babies, parents and grandparents of different ethnicities to relate to differing target audiences;
6. That photographs of the diseases and an associated factual explanation be included in immunisation communication (however, in the disease images, only a portion of the body should be shown);
7. That a reminder of immunisation dates that is easily accessible and visual is needed (such as a fridge magnet).

5.5.2 Recommendations for further resource development

2. That key information includes:
 - the statement that vaccines are not 100% effective;
 - the statement that vaccines are not 100% safe, but serious reactions are very rare;
 - a statement acknowledging the presence of anti-immunisation material;
3. That photographs of breastfeeding mothers be included in the flipchart;
4. That stories addressing anxieties and uncertainties from real parents etc. be included;
5. That the four-year immunisation be noted on the infant schedule used in the present study resources to act as a reminder that pre-school immunisations continue until four years;

6. That 'alternatives' to immunisation such as homeopathy be addressed in a factual, comparative way;
7. That different language versions be made available (particularly Te Reo);
8. That options for future proofing of the current project resources be considered, for example, such as stickers for schedule changes, reprinting of certain pages etc.;
9. That references, in this project's resources, to other current more detailed immunisation resources from the Ministry of Health and IMAC be made more prominent so as to link and layer the sources of information;

5.5.3 Recommendations for the delivery of resources

1. That information be given as part of a discussion between the health professional and client;
2. That a flipchart tool is preferred as a means to stimulate discussion and to give confidence to the health professional in answering key questions;
3. That immunisation information sessions should only cover the key basic information (technical and more detailed information in other sources should be addressed via providing avenues to find that information if required);
4. That information must be presented in a factual way which is not authoritarian in tone, nor implies that immunisation is the 'correct choice';
5. That information is presented twice. Once in the antenatal period, approximately 28-30 weeks and again in the postnatal period, approximately 3-4 weeks post-birth;
6. That the flipchart be distributed in electronic format for use on health professional laptops;
7. That the flipchart be produced in a larger form for group discussions, such as in antenatal classes;
8. That there is potential for the fridge magnet to be given to parents by the Practice Nurse at the first immunisation appointment (allowing the Practice Nurse to insert all the due dates);
9. That, for ease of delivery, the flipchart would benefit from a cardboard base.

5.5.4 Recommendations for future immunisation communication work

1. That the flipchart and fridge magnet resources developed through this study be trialed further in terms of the delivery and further development recommendations above;
2. That consideration be given to funding grassroots communication campaigns, where messages and materials are designed by the target audiences;
3. That communication approaches include informing and training health professionals as to people's information needs and expectations of them, anxieties and uncertainties, such that they feel comfortable to facilitate the balanced conversations and Q&A sessions that people desire;
4. That anxiety about complications and pain be addressed using guidelines from the risk communication literature, such as ways to reframe the risk;
5. That the growing anxiety about the numbers of immunisations required be addressed with communication that follows the risk communication guidelines;
6. That communication approaches consider how to leverage the important influence of family members, particularly maternal grandmothers;

7. That attention be paid to detailed segmentation (not only by culture and age but also by attitude towards immunisation and attitude towards authority) of the targeted audiences, with separate communications designed for each segment;
8. That each communication for each audience segment identify the four to five most important messages for that audience and limit communication to those messages;
9. That the theoretical literature on persuasion and risk communication could prove helpful in the above task of strengthening attitudes;
10. That official information both offline and online is more informative than it is authoritarian;
11. That GPs and GP representative groups be consulted with, with a view to developing some standardised immunisation communication approaches (or refining the current resources) that meet patients' increasing needs for consultation and dialogue;
12. That midwives and midwife representative groups be consulted with, with a view to developing some standardised immunisation communication approaches (or refining the current resources) for use during pregnancy;
13. That the importance of relationships with health providers is recognised as a factor in immunisation rates and that ways to establish and sustain such relationships is investigated.

6. REFERENCES

1. Petousis-Harris H, Turner N, Kerse N. New Zealand mothers' knowledge of and attitudes towards immunisation. *N Z Fam Physician*. 2002; 29(4): 240-246.
2. Wroe AL, Turner N, Salkovskis PM. Understanding and predicting parental decisions about early childhood immunizations. *Health Psychol*. 2004; 23(1): 33-41.
3. Watson PB, Yarwood J, Chenery K. Meningococcal B: Tell me everything you know and everything you don't know. New Zealanders' decision making regarding an immunisation programme. *N Z Med J* [Internet]. 2007 [cited 2009 May 20]; 120(1263): 8 p. Available from <http://www.nzma.org.nz/journal/120-1263/2751/>
4. Sligo F, Comrie M, Olsson S, Culligan N, Tilley E. *Barriers to adult literacy: A discussion paper*. Wellington and Palmerston North, NZ: Department of Communication and Journalism, Massey University; 2005. 69 p. Adult Literacy and Employment in Wanganui Series, Report 0501, ISSN 1176-9807.
5. Tilley E, Sligo F, Shearer F, Comrie M, Murray N, Franklin J, Vaccarino F, Watson B. *Voices: First-hand experiences of adult literacy learning and employment in Wanganui*. Wellington and Palmerston North, NZ: Department of Communication and Journalism, Massey University; 2006. 108 p. Adult Literacy and Employment in Wanganui Series, Report 0605, ISSN 1176-9807.
6. Sligo F, Watson B, Murray N, Comrie M, Vaccarino F, Tilley E. *Lifelong literacy: Issues of strategy*. Wellington and Palmerston North, NZ: Department of Communication and Journalism, Massey University; 2007. 50 p. Adult Literacy and Employment in Wanganui Series, Report 0701, ISSN 1176-9807.
7. Ministry of Health. *The National Childhood Immunisation Coverage Survey 2005*. Wellington: New Zealand Ministry of Health; 2007. 82 p. Public Health Intelligence Occasional Bulletin No. 39.
8. Ministry of Health. *Immunisation coverage at milestone age 24 months: reporting period, 12 month period ending March 2010* [Internet]. 2010 [updated 2010 Mar; cited 2010 Apr 22]. Available from: <http://www.moh.govt.nz/moh.nsf/indexmh/immunisation-coverage-data>
9. UNICEF. *The child care transition, Innocenti Report Card 8, 2008* [Internet]. 2008 [updated 2008; cited 2009 Jun 29]. Available from: <http://www.unicef-irc.org/publications/507#document>
10. World Health Organization. *WHO vaccine-preventable diseases monitoring system, 2008 global summary* [Internet]. 2008 [updated 2008; cited 2009 Sep 21]. Available from: http://whqlibdoc.who.int/hq/2008/WHO_IVB_2008_eng.pdf
11. Centre for Disease Control and Prevention. *Statistics and surveillance: 2008 table data* [Internet]. 2008 [updated 2008; cited 2009 Jun 29]. Available from: http://www.cdc.gov/vaccines/stats-surv/nis/data/tables_2008.htm#overall
12. NHS Information Centre. *NHS immunisation statistics England 2008-09* [Internet]. 2009 [updated 2009 Sep 3; cited 2009 Oct 1]. Available from: <http://www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles/immunisation/nhs-immunisation-statistics-england-2008-09>

13. Medicare Australia. *Australian Childhood Immunisation Register (ACIR) statistics* [Internet]. 2009 [updated 2009 Sep 30; cited 2009 Oct 1]. Available from: <http://www.medicareaustralia.gov.au/provider/patients/acir/statistics.jsp>
14. Ministry of Health. *Immunisation coverage at milestone age 24 months: Reporting period, 1 January 2009 to 1 April 2009* [Internet]. 2009 [updated 2009 Jun 30; cited 2009 Sep 15]. Available from: <http://www.moh.govt.nz/moh.nsf/indexmh/immunisation-coverage-data>
15. Schensul JJ. Building community research partnerships in the struggle against AIDS. *Health Educ Behav.* 1999; 26(2):266-283.
16. Buckeridge DL, Mason R, Robertson A, Frank J, Glazier R, Purdon L, Amrhein CG, Chaudhuri N, Fuller-Thomson E, Gozdyra P, Hulchanski D, Moldofsky B, Thompson M, Wright R. Making health data maps: A case study of a community/university research collaboration. *Soc Sci Med.* 2002; 55: 1189–1206.
17. Boydell KM, Volpe T. A qualitative examination of the implementation of a community-academic coalition. *J Community Psychol.* 2004; 32(4): 357-374.
18. Harper GW, Bangi AK, Contreras R, Pedraza A, Tolliver M, Vess L. Diverse phases of collaboration: working together to improve community-based HIV interventions for adolescents. *Am J Community Psychol.* 2004; 33(3/4): 193-204.
19. Roussos ST, Fawcett SB. A review of collaborative partnerships as a strategy for improving community health. *Annu Rev Public Health.* 2000; 21: 369–402.
20. Bishop R. *Collaborative research stories: Whakawhanaungatanga*. Palmerston North: Dunmore Press; 1996.
21. Gibbs M. Toward a strategy for undertaking cross-cultural collaborative research. *Soc Nat Resour.* 2001; 14: 673-687.
22. Ministry of Health. *Request for proposal: immunisation audience research*. Wellington: Ministry of Health; 2010.
23. Ministry of Health. *Immunisation coverage at milestone age 12 months: Reporting period, 1 April 2008 to 1 April 2009* [Internet]. 2009 [updated 2009 Apr 1; cited 2009 May 19]. Available from: <http://www.moh.govt.nz/moh.nsf/indexmh/immunisation-coverage-data>
24. Grant CC, Petousis-Harris H, Turner N, Goodyear-Smith F, Kerse N, Jones R, York D, Desmond N, Stewart J. *Practice and health professional determinants of immunisation coverage*. In press 2009.
25. Ministry of Health. (2003). *Immunisation in New Zealand: Strategic directions 2003–2006*. Wellington: National Immunisation Programme, Ministry of Health; 2003. 27 p.
26. Petousis-Harris H, Goodyear-Smith F, Turner N, Soe B. Family physician perspectives on barriers to childhood immunisation. *Vaccine.* 2004; 22(17-18): 2340-2344.
27. Petousis-Harris H, Goodyear-Smith F, Turner N, Soe B. Family practice nurse views on barriers to immunising children. *Vaccine.* 2005; 23(21): 2725-2730.
28. Hamilton M, Corwin P, Gower S, Rogers S. Why do parents choose not to immunise their children? *N Z Med J.* 2004; 117(1189): 6 p.
29. McLeod D, Bowie RD, Kljakovic M. The cost of childhood immunisation in general practice. *N Z Med J.* 1998; 111(189): 73–6.
30. Wroe AL, Turner N, Owens RG. Evaluation of a decision-making aid for parents regarding childhood immunizations. *Health Psychol.* 2005; 24(6): 539-547.
31. Petousis-Harris H, Goodyear-Smith F, Godinet S, Turner N. Barriers to childhood immunisation among New Zealand mothers. *N Z Fam Physician.* 2002; 29(6): 396-401.

32. Petousis-Harris H, Turner N, Kerse N. New Zealand mothers' knowledge of and attitudes towards immunisation. *N Z Fam Physician*. 2002; 29(4): 240-246.
33. Jelleyman T, Ure A. Attitudes to immunisation: a survey of health professionals in the Rotorua District. *The New Zealand Medical Journal*. 2004; 117(1189): 12 p.
34. Petousis-Harris H, Goodyear-Smith F, Ram S, Turner N. The New Zealand national immunisation hotline – what are callers seeking? *Vaccine*. 2005; 23(42): 5038-5044.
35. Bond L, Nolan T, Pattison P, Carlin J. Vaccine preventable diseases and immunisations: a qualitative study of mothers' perceptions of severity, susceptibility, benefits and barriers. *Aust N Z J Public Health*. 1998; 22(4): 441-446.
36. Wroe AL, Bhan A, Salkovskis P, Bedford H. Feeling bad about immunising our children. *Vaccine*. 2005; 23(12): 1428-1433.
37. Petousis-Harris H, Boyd E, Turner N. Immunisation education in the antenatal period. *N Z Fam Physician*. 2004a; 31(5): 303-306.
38. Leask J, Chapman S, Hawe P, Burgess M. What maintains parental support for vaccination when challenged by anti-vaccination messages? A qualitative study. *Vaccine*. 2006; 24(49-50): 7238-7245.
39. Moran N, Shickle D, Richardson E. European citizens' opinions on immunisation *Vaccine*. 2008; 26(3): 411-418.
40. Goodyear-Smith F, Grant C, Petousis-Harris H, Turner N. Immunization champions: characteristics of general practitioners associated with better immunization delivery. *Hum Vaccin*. 2009; 5(6): 403-411.
41. Paterson J, Percival T, Butler S, Williams M. Maternal and demographic factors associated with non-immunisation of Pacific infants living in New Zealand. *N Z Med J*. 2004; 117(1199): 8 p.
42. Paterson J, Schluter P, Percival T, Carter S. Immunisation of a cohort Pacific children living in New Zealand over the first 2 years of life. *Vaccine*. 2006; 24: 4883-4889.
43. Turner NM, York DG, Grant CC, Goodyear-Smith F, Petousis-Harris HA. *Successful systems: characteristics of general practices influencing immunisation coverage and timeliness*. In press 2009.
44. National Vaccine Advisory Committee. Strategies to sustain success in childhood immunizations. *JAMA*. 1999; 282(4): 363-370.
45. Turner N. Concerns of health providers and parents affect immunisation coverage. *N Z Med J*. 2004. 117(1189): 3p.
46. Turner N, Baker M, Carr J, Mansoor O. Improving immunisation coverage: what needs to be done? *New Zealand Public Health Report*. 2000; 7(3/4): 11-14.
47. Turner N, Grant C, Goodyear-Smith F, Petousis-Harris H. Seize the moments: missed opportunities to immunize at the family practice level. *Fam Pract Advance Access* [Internet]. 2009 [cited 2009 Sep 14]; May 28: 4 p. Available from: <http://www.6minutes.com.au/common/contentmanagement/6min/vault/pdf/immsops.pdf>
48. Samad L, Butler N, Peckham C, Bedford H, Millennium Cohort Study Child Health Group. Incomplete immunisation uptake in infancy: maternal reasons. *Vaccine*. 2006; 24(47-48): 6823-6829.
49. O'Hallahan J, Lennon D, Oster P, Lane R, Reid S, Mulholland K, Stewart J, Penney L, Percival T, Martin D. From secondary prevention to primary prevention: a unique strategy that gives hope to a country ravaged by meningococcal disease. *Vaccine*. 2005; 23: 2197-2201.
50. Grant C. Immunisation and the importance of good timing. *N Z Med J*. 2004; 117(1199): 4 p.

51. Guyer B, Hughart N, Holt E, Ross A, Stanton B, Keane V, Bonner N, Dwyer DM, Cwi JS. Immunization coverage and its relationship to preventive health care visits among inner-city children in Baltimore. *Pediatrics*. 1994;.94(1): 53–58.
52. Hull BP, McIntyre PB, Sayer GP. Factors associated with low uptake of measles and pertussis vaccines: an ecologic study based on the Australian Childhood Immunisation Register. *Aust N Z J of Public Health*. 2001; 25(5): 405–410.
53. Grant CC, Roberts M, Scragg R, Stewart J, Lennon D, Kivell D, Ford R, Menzies R. Delayed immunization and risk of pertussis in infants: unmatched case-control study. *Br Med J*. 2003; 326(7394): 852-853.
54. Bailie RS, Si D, Dowden MC, Selvey CE, Kennedy C, Cox R, O'Donoghue L, Liddle H, Connors CM, Thompson S, Burke H, Brown A. A systems approach to improving timeliness of Immunisation. *Vaccine*. 2009; 27(27): 3669-3674.
55. Grant C, Scragg R. Delayed immunisation of infants as a risk factor for pertussis. Paper presented at: *Pediatric Academic Societies Meeting*; 2000; Boston Massachusetts.
56. Hull BP, McIntyre PB. Timeliness of childhood immunisation in Australia. *Vaccine*. 2006; 24: 4403-4408.
57. Gellin BG, Maibach EW, Marcuse EK. Do parents understand immunizations? A national telephone survey. *Pediatrics*, 2000; 106(5): 1097-1102.
58. New Zealand Government, Business New Zealand, New Zealand Council of Trade Unions, Industry Training Federation *New Zealand Skills Strategy 2008 Discussion Paper*. Wellington: New Zealand Government; 2008.
59. Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. *Communicating With Special Populations*. 2002; 34(5): 383-389.
60. Nielsen-Bohlman L, Panzer AM, Kindig, DA. *Health literacy: A prescription to end confusion*. Washington, DC: The National Academies Press; 2004.
61. Kickbusch I. Health literacy: Addressing the health and education divide. *Health Promot Int*. 2001; 16(3): 289-297.
62. Ratzan SC, Parker RM. Introduction. In: *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. NLM Pub. No. CBM 2000-1. 2000; Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services.
63. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 2^{1st} century. *Health Promot Int*. 2000; 15(3): 259-267.
64. Kerka S. Health literacy beyond basic skills: *ERIC Digest* [Internet] 2003. Available from: <http://www.ericdigests.org/2004-1/health.htm>
65. Weiss BD, Hart G, McGee DL, D'Estelle S. Health status of illiterate adults: relation between literacy and health status among persons with low literacy skills. *J Am Board Fam Pract*. 1992; 5(3): 257-264.
66. Baker DW, Parker RM, Williams MV, Clark WS, Nurss J. The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health*. 1997; 87(6): 1027-1030.
67. Howard DH. The relationship between health literacy and medical costs. In Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health literacy: a prescription to end confusion*. 2004; Washington, DC: The National Academies Press.

68. Weiss BD, Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *J Am Board Fam Pract.* 2004; 17(1): 44-47.
69. Ratzan SC. Health literacy: communication for the public good. *Health Promot Int.* 2001; 16(2): 207-214.
70. Wilson FL, Brown DL, Stephens-Ferris M. Can easy-to-read immunization information increase knowledge in urban low-income mothers? *J Pediatr Nurs.* 2006; 21(1): 4-12.
71. Nutbeam D, Kickbusch I. Advancing health literacy: a global challenge for the 21st century. *Health Promot Int.* 2000; 15(3): 183-184.
72. Nutbeam D. The challenge to provide 'evidence' in health promotion. *Health Promot Int.* 1999; 14(2): 99-101.
73. Gordon JC. Beyond knowledge: guidelines for effective health promotion messages. *Journal of Extension* [Internet]. 2002 [cited 2009 Sep 9]; 40(6) December. Available from: <http://www.joe.org/joe/2002december/a7.php>
74. McCray AT. Promoting health literacy. *J Am Med Inform Assoc.* 2005; 12(2): 152-163.
75. Nutbeam D. Evaluating health promotion – progress, problems and solutions. *Health Promot Int.* 1998; 13: 27-43.
76. Jacobson TA, Thomas DM, Morton FJ, Offutt G, Shevlin J, Ray S. Use of a low-literacy patient education resource to enhance pneumococcal vaccination rates: a randomized controlled trial. *J Am Med Assoc.* 1999; 282(7): 646-650.
77. Houts PS, Doak CC, Doak LG, Loscalzo MJ. The role of pictures in improving health communication: a review of research on attention, comprehension, recall and adherence. *Patient Educ Couns.* 2006; 61(2): 173-190.
78. Doak CC, Doak LG, Root JH. *Teaching patients with low literacy skills.* 2nd ed. Philadelphia: J.B. Lippincott; 1996.
79. Katz MG, Kripalani S, Weiss BD. Use of pictorial aids in medication instructions: a review of the literature. *Am J Health Syst Pharm.* 2006; 63(23): 2391-2397.
80. National Cancer Institute. *Clear and simple: developing effective print materials for low-literate readers* [Internet]. 1995 [updated 2003 Feb 27; cited 2009 Jul 28]. Available from: <http://www.cancer.gov/cancerinformation/clearandsimple>
81. Morrow DG, Hier CM, Menard WE, Leirer VO. Icons improve older and younger adults' comprehension of medication information. *J Gerontol B Psychology and Social Sciences.* 1998; 53B(4): 240-254.
82. Davis TC, Fredrickson DD, Arnold C, Murphy PW, Herbst M, Bocchini Jr JA. A polio immunization pamphlet with increased appeal and simplified language does not improve comprehension to an acceptable level. *Patient Educ Couns.* 1998; 33(1): 25-37.
83. Weiner J, Aguirre A, Ravenell K, Kovath K, McDevit L, Murphy J, Asch DA, Shea JA. Designing an illustrated patient satisfaction instrument for low-literacy populations. *Am J Manag Care.* 2004; 10(11): 853-860.
84. Davis TC, Bocchini Jr JA, Fredrickson D, Arnold C, Mayeaux EJ, Murphy PW, Jackson RH, Hanna N, Paterson M. Parent comprehension of polio vaccine information pamphlets. *Pediatrics.* 1996; 97(6): 804-10.
85. Austin PE, Matlack R, Dunn KA, Kesler C, Brown CK. Discharge instructions: do illustrations help our patients understand them? *Ann Emerg Med.* 1995; 25(3): 317-320.
86. Delp C, Jones J. Communicating information to patients: the use of cartoon illustrations to improve comprehension of instructions. *Acad Emerg Med.* 1996; 3(3): 264-270.

87. Plimpton S, Root J. Materials and strategies that work in low literacy health communication. *Public Health Reports* [Internet]. 1994 [cited 2009 Apr 21]; 109(1): 86-92. Available from <http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1402246&blobtype=pdf>
88. Hill LH. Using visual concept mapping to communicate medical information to patients with low health literacy: a preliminary study. In: Cañas AJ, Novak JD, editors. *Proceeds of the 2nd international conference on concept mapping - concept maps: theory, methodology, technology*; 2006; San José, Costa Rica.
89. Moll JM. Doctor-patient communication in rheumatology: studies of visual and verbal perception using educational booklets and other graphic material. *Annals of the Rheumatic Diseases*. 1986; 45(3): 198-209.
90. Houts PS, Bachrach R, Witmer JT, Tringali CA, Bucher JA, Localio RA. Using pictographs to enhance recall of spoken medical instructions. *Patient Educ Couns*. 1998; 35(2): 83-88.
91. Houts PS, Witmer JT, Egeth HE, Loscalzo MJ, Zabora JR. Using pictographs to enhance recall of spoken medical instructions II. *Patient Educ Couns*. 2001; 43(3): 231-242.
92. Dowse R, Ehlers MS. Medicine labels incorporating pictograms: do they influence understanding and adherence? *Patient Educ Couns*. 2005; 58(1): 63-70.
93. Moll JM, Wright V, Jeffrey MR, Goode JD, Humberstone PM. The cartoon in doctor-patient communication. Further study of the arthritis and rheumatism council handbook on gout. *Annals of the Rheumatic Diseases*. 1977; 36(3): 225-231.
94. Eagle L, Hawkins J, Styles E, Reid J. Breaking through the invisible barrier of low functional literacy: implications for health communication. *Stud Commun Sci*. 2006; 5(2): 29-55.
95. Ngoh LN, Shepherd MD. Design, development and evaluation of visual aids for communicating prescription drug instructions to nonliterate patients in rural Cameroon. *Patient Educ Couns*. 1997; 30(3): 245-261.
96. Coulter A, Ellins J. Effectiveness of strategies for informing, educating and involving patients. *Br Med J*. 2007; 335(7609): 24-27.
97. Weiss BD. Outside the clinician-patient relationship: a call to action for health literacy. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health literacy: a prescription to end confusion*. 2004; Washington, DC: The National Academies Press.
98. Dowse R, Ehlers MS. The evaluation of pharmaceutical pictograms in a low-literate South African population. *Patient Educ Couns*. 2001; 45(2): 87-99.
99. Dowse R, Ehlers MS. Pictograms for conveying medicine instructions: comprehension in various South African language groups *S Afr J Sci* [Internet]. 2004 [cited 2009 Apr 21]; 100 (November/December, Rhodes Centenary): 687-693. Available from: http://eprints.ru.ac.za/137/01/sajsci_v100_n11_a35%5B1%5D.pdf
100. Mansoor LE, Dowse R. Effect of pictograms on readability of patient information materials. *Ann Pharmacother*. 2003; 37: 1003-1009.
101. Hameen-Anttila K, Kemppainen K, Enlund H, Bush PJ, Marja A. Do pictograms improve children's understanding of medicine leaflet information? *Patient Educ Couns*. 2004; 55(3): 371-378.
102. Evers DB. Teaching mothers about childhood immunizations. *Am J Matern Child Nurs*. 2001; 26(5): 253-256.
103. Dunn RA, Shenouda PE, Martin DR, Schultz AJ. Videotape increases parent knowledge about poliovirus vaccines and choices of polio vaccination schedules. *Pediatrics* [Internet]. 1998

- [cited 2009 Aug 12]: 102(2): e26. Available from: <http://pediatrics.aappublications.org/cgi/content/full/102/2/e26> Retrieved 12/08/2009.
104. Leiner M, Handal G, Williams D. Patient communication: a multidisciplinary approach using animated cartoons. *Health Educ Res.* 2004; 19(5): 591-595.
 105. Neumann WL. *Social research methods: qualitative and quantitative approaches.* 3rd ed. Boston: Allyn and Bacon; 1997.
 106. Quaghebeur K, Masschelein J, Nguyen HH. Paradox of participation: giving or taking part? *Journal of Community & Applied Psychology.* 2004; 14: 154-165.
 107. Ravn JE. Cross-system knowledge chains: the team dynamics of knowledge development. *Systemic Practice and Action Research.* 2004; 7(3): 161-175.
 108. Glaser B. *Emergence vs. forcing basics of grounded theory analysis.* Mill Valley, CA: Sociology Press; 1992.
 109. Ministry of Health. *Childhood immunisation.* Wellington, New Zealand: Ministry of Health; 2006.
 110. Ministry of Health. *Immunise your children* [DVD Code HE1915 and Pamphlet,]. Wellington: Ministry of Health; 2008. 1 DVD: 31 min., sound, colour; 1 Pamphlet.
 111. Immunisation Advisory Centre. *In the loop: a guide to immunisation.* Auckland: Immunisation Advisory Centre; 2009.
 112. Bloch A. Doing social surveys. In: Clive Seale, editor. *Researching society and culture.* 2nd ed. London: Sage; 2004.
 113. Liamputtong P, Ezzy D. *Qualitative research methods.* 2nd ed. Melbourne: Oxford University Press; 2005.
 114. Nurss JR, Parker RM, Williams MV, Baker DW. *STOFHLA: Short Test of Functional Health Literacy in Adults.* North Carolina: Peppercorn Books and Press; 2001.
 115. Harper K, Thompson-Robinson M, Lewis M. Health literacy assessment of patients in rural Florida. *Texas Journal of Rural Health.* 2003; 21(3): 3-8.
 116. Schillinger D. Improving chronic disease care for populations with limited health literacy. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors, *Health literacy: a prescription to end confusion.* 2004; Washington, DC: The National Academies Press.

7. APPENDIX A: FOCUS GROUP SCHEDULE

The manner in which the questions are asked and the wording used will necessarily change dependent on the target audience. These questions are to guide the facilitation process and the facilitator should use these as a guide to the areas that he/she will need to cover.

1. Introduction by the facilitator
 - Welcome and introductions
 - All answers are needed
 - All views and opinions are important to share
 - A variety of views and opinions are expected so do not worry if your opinion is different from others in the group
 - If anyone would like to talk or share some thoughts individually after the group, the facilitator will be available to talk

2. Decision-making around immunisation

These first two questions will allow for a discussion where the remaining questions may be answered without being asked. However, the remaining questions are given here as prompts if discussion does not flow easily.

1. Is/Was immunisation of your child something you have thought about? (Not at all?)
2. How did you make a decision about whether to immunise or not?

Prompt questions:

- What do you think influenced that decision i.e. family, friends, past experience, media, medical information/personnel?
- Who in your whanau will make/made the decision around immunisation?
- When will that decision be made?
- What decision was made?
- Why did you make that decision?
- What barriers did you face in acting out your decision? (i.e. for those that have decided to immunise – transport barriers, opening hours, fear of needles, other life priorities etc).

3. Key messages

1. Take a moment to think of any messages about immunisation you have seen or information you have found. What did you think about the messages/information?
2. Here is some of the information that is generally given to people making immunisation decisions (facilitator to show the two main brochures that people are given). The facilitator may also ask people to pair up if appropriate and discuss the resources in light of the following questions before discussing their thoughts with the whole group. Have you seen these? What do you think is the most important information you would look to obtain from these resources i.e. what do you want to know about immunisation?
3. What are the best ways for you to receive information? E.g. korero, handouts, a mixture of both, internet?

Prompt questions:

- What were some of the slogans that you recall? E.g. “Hep B won’t get me” or the MENZ B slogan (may need to prompt if none are remembered). What were some of the slogans that meant something to you (if any)?

4. Illustrations

The illustrations need to be presented in the form of handouts and a flipchart. The facilitator will give a brief overview of the development of the illustrations explaining how they reflect Wanganui settings and Wanganui people and were based on the words of people with low literacy levels.

1. Here’s an example of the illustrations that we propose to use to discuss immunisation with soon-to-be mothers and their whanau/families. We would like to take some of the key messages that this group and other groups come up with and put them into illustrations to help communicate key immunisation information. What do you think of this idea?
2. Are they easy to understand? Meaningful?
3. What suggestions would you have for improving or changing these?
 - Would you think the illustrations might be more useful in another form? Let their ideas come through first before any prompting e.g. picture hand-out, flip chart, fridge magnet, coaster etc.
 - Is it useful having the Wanganui community in the background, or would you prefer something else? Would you think people like yourselves would relate to pictures of men, women, families, older people, younger people etc?
 - What would you like to see in the pictures e.g. people talking, immunisation taking place, etc?

8. APPENDIX B: ANTENATAL INTERVIEW SCHEDULE

Introduction by Interviewer: “We’re trying to develop materials to make health information easier to understand. *Perhaps give them a quick reminder of the information in the information sheet.* I would like to talk to you today about any thoughts you might have on immunisation. I will also ask you to do some short reading activities. Did you have any questions about anything before we start? Feel free to ask me any questions as we talk if you like”.

The interview will begin with the recording of written consent and demographic data. The consent form is to be read to the participant and any questions answered. The demographic data should be gathered orally and written down by the interviewer.

Some of the sub-questions may be answered in the answer to the first broad question.

1. Has anyone talked to you about immunisation?
 - a. Medical (i.e., doctors or nurses)
 - b. Non-medical (i.e., family or friends)
2. What types of information on immunisation have you seen?
 - a. First see what they recall – What did you think about this information? Was it helpful/not helpful? What (if anything) did you take from it?
 - b. Second, use prompts
 - i. Any ads on TV, newspapers, posters, pamphlets, internet?
 - ii. What did you think about this information? Was it helpful/not helpful? What (if anything) did you take from it?
3. Where do you think you could find information on immunisation?
4. What stage are you at with thinking about immunisation? What are your thoughts on it so far?
 - a. Do you have any concerns? Are there any tensions?
 - i. What are you debating/tossing up?
 - ii. Who have you talked to about those concerns? Who would you talk to? (if anyone).
 - iii. If interviewee has made a decision about immunisation: Why did you make the decision you’ve made?

Finally, I’d like to ask you to do some short reading activities. (Read out the STOFHLA instructions).

Interviewer: “As I mentioned before, we’re trying to develop materials to make health information easier to understand. I am going to briefly share with you some standard information about immunisation. This is only one of the sources of information that are out there and all of the information I share with you is available from your health provider. Some people are getting information in a different way. With you, I would like to talk you through some information (if they are in the control group) or I would like to show you this flipchart as I talk you through some information”.

Flipchart/Flyer or Talk Only.

Thank the participant and remind them that if they have any questions about the study they can contact the people on the Information Sheet.

9. APPENDIX C: POSTNATAL INTERVIEW SCHEDULE

Key: Not shaded = All participants, Shaded = Intervention participants only.

Introduction by Interviewer: “Thanks for talking with me again. As you already know, we’re trying to develop materials to make health information easier to understand. I would like to talk to you today about any thoughts you may have had on immunisation since we last spoke. Did you have any questions about anything before we start? Feel free to ask me any questions as we talk if you like”.

Some of the sub-questions may be answered in the answer to the first broad question.

1. Has anyone talked to you about immunisation since I last spoke with you in [month]?
 - a. Medical (i.e., doctors or nurses)
 - b. Non-medical (i.e., family or friends)
2. Where do you think you could find information on immunisation?
3. What types of information on immunisation have you seen since we last spoke?
 - a. First see what they recall –
 - i. What did you think about this information?
 - ii. Where did you get this information?
 - iii. Was it helpful/not helpful?
 - iv. What (if anything) did you take from it?
 - b. Second, use prompts
 - i. Any ads on TV, newspapers, posters, pamphlets, internet?
 - ii. What did you think about this information?
 - iii. Was it helpful/not helpful?
 - iv. What (if anything) did you take from it?
 - c. (Additional for intervention participants) –
 - i. Do you remember the flipchart I showed you?
 - ii. What did you think of the flipchart you saw last time? (prompt for pictures, words)
 - iii. Was it useful/not useful?
 - iv. Do you recall anything about the information I shared with you?
If yes...
 - v. What (if anything) do you remember from it?
 - vi. What did you think about it (*impact it had on them*)?
 - vii. Do you have any ideas as to how the flipchart could be improved?
 - viii. Do you think it would be useful to produce information in a flipchart in different versions for NZ European, Maori and Pasifika using different languages and images? Why/why not?

Control group only – what do you remember from the oral presentation?

Second use prompts: Do you recall anything about (*if they say yes, ask what they remember about that –discuss these also with the control group so we can assess differences in known information*):

- The immunisation schedule
- The diseases vaccines help protect against

- What happens when your child is vaccinated
- The normal responses to vaccination
- The symptoms you should be concerned about
- Where to get more information if you want it

- d. Do you recall the disease pictures?
 - a. What did you think of them?
 - b. Were they useful/not useful?
- e. [Same questions as (c) for the fridge magnet – intervention people only]
 - i. Do you remember the fridge magnet I gave you?
 - ii. What did you think of the magnet? (prompt for pictures, words)
 - iii. Was it useful/not useful?
 - iv. What (if anything) do you remember from it?
 - v. What did you think about it (*impact it had on them*)?
 - vi. Do you have any ideas as to how it could be improved?
 - vii. Did you put it on your fridge?
 - viii. Do you think it would be useful to produce information in a fridge magnet in different versions for NZ European, Maori and Pasifika using different languages and images? Why/why not?

4. Intervention group only –

- a. Was the flipchart and fridge magnet you saw useful to you in the antenatal period?
- b. What about in the postnatal period?
- c. Do you have a preference for when you would have liked to discuss these things?

5. Have you had your baby immunised?

- a. What impacted on your decision to do so/not do so?
- b. If not, what are your thoughts on it so far?
 - i. Do you have any concerns?
 - ii. What are you debating/tossing up?
 - iii. Who have you talked to about those concerns?
 - iv. Who would you talk to? (if anyone)
 - v. On a scale of 1-5 with 1 being never and 5 being very likely, how likely is it, do you think, that you will immunise at 3 months?

6. One idea that has been mentioned is the use of text messaging to remind people of when their baby's appointment is.

- a. Do you think this is a good idea? Yes/No

7. Is there anything else you would like to say?

Thank the participant and remind them that if they have any questions about the study they can contact the people on the Information Sheet.