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Development and Testing of a Caregiver-proxy Child Health Questionnaire for the New Zealand Health Survey

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Abstract

The New Zealand Ministry of Health has expanded its population health survey, the New Zealand Health Survey (NZHS), to include a questionnaire specifically on child health. The principal aim of the NZHS child questionnaire is to collect health data from parents or caregivers that can be used for monitoring population-level child health status, health service utilisation, and the health risk and protective behaviours that have their origins in childhood. Previously, only data collected through child contact with the health system, for example hospital administration records and disease/injury databases, have been available for monitoring child health in New Zealand. This paper reviews the questionnaire development for the child health component of the 2006/2007 New Zealand Health Survey, including topic selection, question development, cognitive-testing, preliminary sample design, final questionnaire drafting, and dress rehearsal testing.

KEY WORDS: Questionnaire design; health surveys; child health

1. Introduction

1.2 The need for child health data in New Zealand

There is growing concern about child health in New Zealand. Compared to similar Western countries, children in New Zealand have high rates of infectious disease, especially pneumonia, bronchiectasis, skin infections, meningococcal disease, tuberculosis and rheumatic fever, and high rates of injury (D'Souza and Wood 2003). With increasing obesity, Type 2 diabetes may now be appearing in New Zealand children, and there is recognition that many adult health outcomes, such as cardiovascular disease, have their origins in childhood (Ministry of Health 2005a).

Child health problems are not distributed evenly throughout the New Zealand child population. Indigenous Māori infants have nearly twice the death rate of non-Māori, a six times greater risk of death from Sudden Infant Death Syndrome and 20 times the risk of contracting rheumatic fever (Melville 2003). A quarter of New Zealand children are Māori, therefore any attempts to improve child health must include a focus on Māori health.

Like many other countries, New Zealand also has large disparities in health by socio-economic position. Poverty can result in overcrowded houses, poor heating, inadequate nutrition, and stress, which in turn results in poor child health outcomes. In the 2004 *New Zealand Living Standards* research, 13% of parents reported that they had postponed a visit to the doctor for their child because of cost, with two-thirds of these children living in families experiencing severe or significant hardship (Jensen et al. 2006).

Gaps in existing administrative data sources, such as hospital admissions and disease and injury databases, supported the argument that more information about the health of children is needed to inform child health monitoring and policy planning. In May 2005, the Ministry of Health decided to expand its population health survey, the New Zealand Health Survey (NZHS), to collect health data from parents or caregivers on their child's health status, health service utilisation, and the health risk and protective behaviours that have their origins in childhood. Concurrent work also began on a national child health indicator framework to collate these disparate

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sources of information on child health, with the intention that the new NZHS child module could feed into this framework (Craig 2006).

1.2 The New Zealand Health Survey

The New Zealand Health Survey (NZHS) is the main data collection vehicle in a programme of health surveys and cohort studies collectively called the New Zealand Health Monitor. The Health Monitor programme is managed by Public Health Intelligence, the epidemiology group of the Ministry of Health. In addition to the NZHS, this programme also includes national adult and child nutrition surveys, a mental health survey, an annual tobacco survey, an alcohol and drug use survey and an upcoming oral health survey (Ministry of Health 2005b).

Previous New Zealand Health Surveys were conducted in 1992/1993, 1996/1997 and 2002/2003, and there is a commitment from Government to repeat this survey every three years from 2006/2007 (Ministry of Health 2005b). Data collection for the NZHS is conducted face-to-face in respondents' homes with trained interviewers using computer-assisted personal interview (CAPI) software.

Content of the NZHS survey questionnaires has varied over the years, but generally includes modules on chronic health conditions, general health status (measured using SF-36 and other instruments), health service utilisation focusing on primary health care, behavioural risk and protective factors (such as physical activity, tobacco and alcohol use) and sociodemographic information. Since the 2002/2003 NZHS, a short anthropometry section has been included where respondents' height, weight and waist girth are measured by the interviewer.

1.3 Methodology for the 2006/2007 New Zealand Health Survey child module

Some child health data regarding health care service utilisation was collected in the 1996/1997 NZHS by asking additional questions to respondents if they were the parents of a child aged under 15 years. However this methodology yielded only 1019 children in the final sample and consequently a relatively large margin of error on the child data (Ministry of Health 1999).

In an effort to increase the number of children in the final sample, the 2006/2007 NZHS child respondent is randomly selected at the household, rather than the respondent, level and then the primary caregiver of the child is interviewed regardless of whether this person was the adult respondent in the NZHS. Any person aged 15 years and over is eligible to complete the NZHS adult questionnaire. This approach is expected to result in approximately 5,000 children (aged from birth to 14 years) in the final sample from the 12,500 households participating in the NZHS over the 12-month collection period. See the paper *Sampling the Māori Population in the 2006/2007 New Zealand Health Survey* by Clark and Gerritsen in these proceedings for more information on the survey design.

The constraint of having less than 12 months from conception to data collection within which to develop the questionnaire resulted in the use of an efficient approach to questionnaire development. This paper details the four-step process used to develop the child health questionnaire for the 2006/2007 NZHS: developing objectives using theoretical frameworks, clarifying the variables of interest, writing the draft questionnaire and testing the questions. This process could be modified for use in other questionnaire design situations.

2. Developing conceptual frameworks and objectives

2.1 The whole child approach and key settings model

In order to produce child health data that would feed directly into policy making, the developers began by consulting the policy frameworks currently used in New Zealand regarding child health and wellbeing. The whole child approach described in the *New Zealand Agenda for Children* (Ministry of Social Development 2002) provided an appropriate theoretical framework with which to base subsequent decisions regarding content for the questionnaire.

The whole child approach advocates thinking about a child's whole life, as opposed to focusing on isolated issues or problems. This approach emphasises what children need for healthy development, rather than simply reacting to problems as they arise. However children are not seen as "adults in development" but rather value is attached to the

point at which they are at in their life now – ‘being’ as well as ‘becoming’. It stresses the importance of looking across Government at what can be done to support children’s healthy development, instead of looking for single-sector solutions (Ministry of Social Development 2002).

The whole child approach advocates involving children as much as possible in policy decision-making, recognising that children are competent participants in society and a source of valuable information (Ministry of Social Development 2004). The developers considered including an instrument in the NZHS designed to collect information directly from children themselves, in addition to the primary caregivers’ questionnaire. However, child participatory research methodology requires considerable time and expertise to develop, and so it was decided to explore this concept further for possible inclusion in the 2009/2010 NZHS.

Another important aspect of the whole child approach is that although children are citizens in their own right, they cannot be separated from the “key settings” in which they live and grow. In order to understand children, we must understand their environment – their parents, family, friends and peers, school, communities and other important social and cultural settings (Ministry of Social Development 2004). In developing the 2006/2007 NZHS Child questionnaire, the whole child approach and key settings model emphasized the importance of looking at possible multi-level determinants of health, ensuring the complexity of children’s lives was captured.

2.2 New Zealand Child Health Strategy

The Ministry of Health’s Child Health Strategy (1998) also clarified the direction of the NZHS Child questionnaire by identifying four priority population groups for child health policy: Māori children, Pacific children, children with high health and disability support needs, and children from families with multiple social and economic disadvantages. The 2006/2007 NZHS Child questionnaire aims to collect appropriate information to allow for detailed analysis of these priority groups where possible.

3. Defining topics and variables of interest

3.1 Focus on outputs

With a clear theoretical background for guidance, the developers began by listing child health topics of interest and the current data sources available for those topics. For example, cancer was included in the list and it was noted that there is a national cancer registry, as was nutrition, noting that there is a National Children’s Nutrition Survey every 10 years for school aged children. Child specific topics such as breastfeeding and early childhood education attendance were also included in this list.

For those topics where gaps in the current data existed, the developers considered the likely output variables that could be produced if the topic were included in the NZHS, and added these to the topic list. Some topics were retained even when there was an existing data source, where the topic was an important variable for analysis in relation to other variables. For example, the topic of chronic conditions was retained, not for the purpose of producing prevalence estimates but in order to conduct sub-group analysis of the health service utilisation data by children with and without diagnosed chronic conditions.

3.2 Wide consultation on topics

Consultation using the topic list with corresponding output variables was then conducted in August 2005 with government and non-government agencies, policy makers, academics and child health specialists. By consulting on the topics and variables planned for the questionnaire, stakeholders could focus on the possible value and use of data and identify unnecessary topics (where there would be repetition with existing sources of data) as well as missing topics, more easily than if reviewing a draft questionnaire. This also saved considerable time for the developers by providing quick feedback on the decisions and progress to that point.

An example of repetition with an existing source of data was the topic of immunisation. A nationwide immunisation registry was in development at the time, which would be capable of providing nearly 100% coverage of child immunisation; therefore there was no longer any need to monitor immunisation through cross-sectional surveys.

Two examples of topics not included on the list which were raised by policy analysts were disciplinary methods used with children and child exposure to passive smoking especially in cars. These are upcoming NZ policy issues and the analysts lacked the data needed to inform decision making around these topics. These topics were accordingly incorporated into the questionnaire.

4. Compiling the draft questionnaire

4.1 International child health surveys

Once the topic list was finalised, copies of previous child health questionnaires were gathered in order to compile a draft questionnaire using existing validated questions where possible. Priority was given to questions that had been used on similar populations in national-level health surveys. The developers found the following questionnaires particularly helpful: Australian National Health Survey child questionnaire, Western Australian and New South Wales Child Health and Wellbeing Surveys, Health Survey for England child questionnaire, Canadian National Population Health Survey and the US National Survey of Children's Health.

4.2 Child health instruments

A general health status instrument that produced aggregate scores for respondents over a wide range of topics, similar to the SF-36 questionnaire, was considered important for inclusion in the NZHS child questionnaire. The developers wanted to select an instrument that ideally covered the widest age range possible (between birth and 15 years), could be completed in less than 10 minutes, had good psychometric properties (validity, reliability and responsiveness), and covered the domains of physical, mental/emotional and social development of the child. It was preferable that the instrument had been used in other national population-level health survey, and if possible used before in New Zealand.

The following instruments were considered: Ages and Stages Questionnaires (ASQ), AGS Early Screening Profiles (ESP), Child Health and Illness Profile (CHIP-CE and CHIP-AE), Child Health Questionnaire (CHQ-PF28), Functional Disability Inventory (FDI), KIDSCREEN-27/10 Index Health Related Quality of Life Instrument, Paediatric Evaluation of Developmental Status (PEDS), Paediatric Quality of Life Inventory (PedsQL 4.0), SF-10 for Children Health Survey, Strengths and Difficulties Questionnaire (SDQ).

Of these instruments, the PedsQL 4.0 SF and the CHQ-PF28 met the majority of criteria for inclusion in the 2006/07 NZHS Child questionnaire. The PedsQL 4.0 SF could be used with children aged 2 year olds and over, was quick to complete and covered all the health domains. This instrument had straightforward questions which the developers were confident would work well with the diverse New Zealand population. However, the PedsQL 4.0 SF was only newly developed, and consequently had not been widely tested for validity. By comparison, the CHQ-PF28 was widely validated, showing strong psychometric properties. The long-form had been used successfully throughout the world, including in Australia, so comparison data would be available. It took less than 10 minutes to complete and was similar in layout and wording to the SF-36 in the NZHS Adult questionnaire. Although the CHQ-PF28 was only for use with 5 to 18 year olds, a version for under 5 year olds was in development (Landgraf et al 1999).

The developers settled on the inclusion of the CHQ-PF28 in the 2006/07 NZHS Child questionnaire with the intention of adding the new CHQ instrument for under 5 year olds in future NZ Health Surveys.

4.3 Final content of the 2006/2007 New Zealand Health Survey Child Questionnaire

Table 1. Summary of the final content of the 2006/2007 NZHS Child questionnaire

Module 1: Health and development		
Topic	Source of question	Age group
Diagnosed chronic conditions	Based on NZHS Adult question	birth-14 years
Treatment for chronic conditions	Based on NZHS Adult question	birth-14 years
Asthma (5 questions)	International Study of Asthma and Allergies in Children (ISAAC) short form (Asher et al 1999)	5-14 years

Rhinitis (3 questions)	ISAAC short form (Asher et al 1999)	5-14 years
Eczema (3 questions)	ISAAC short form (Asher et al 1999)	5-14 years
Module 1: Health and development continued...		
General health perception	CHQ-PF28 (Landgraf et al 1999)	birth-14 years
Physical limitation (3 questions)	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Limitations caused by emotional difficulties	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Limitations caused by physical health	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Bodily pain	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Behaviour, mental health, self-esteem (10 questions)	CHQ-PF28 (Landgraf et al 1999)	5-14 years
General health perception (4 questions)	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Impact of child's physical health on caregiver	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Impact of child's emotional health on caregiver	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Impact of child's physical health on caregiver's time	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Impact of child's emotional health on caregiver's time	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Impact of child's health on family activities (2 quest)	CHQ-PF28 (Landgraf et al 1999)	5-14 years
Family cohesion	CHQ-PF28 (Landgraf et al 1999)	birth-14 years
Discipline (2 questions)	Based on Maxwell (1993)	birth-14 years
Module 2: Health service utilization		
Topic	Source of question	Age group
Usual primary health care provider (3 questions)	Based on NZHS Adult question	birth-14 years
General Practitioners (8 questions)	1996/97 NZHS	birth-14 years
Primary health care nurses (5 questions)	Based on NZHS Adult question	birth-14 years
Medical specialists (2 questions)	Based on NZHS Adult question	birth-14 years
Oral health care (9 questions)	Based on 2002 Children's Nutrition Survey (Ministry of Health 2003)	1-14 years
Prescription medicines (3 questions)	Based on NZHS Adult question	birth-14 years
Health advice over the phone (2 questions)	Based on NZHS Adult question	birth-14 years
Secondary health care (5 questions)	Based on NZHS Adult question	birth-14 years
Module 3: Risk and protective factors		
Topic	Source of question	Age group
Caregiver's perception of child's weight	Adapted from Australian National Health Survey (ABS 2001).	birth-14 years
Breastfeeding (2 questions)	Australian National Health Survey (ABS 2001)	birth-14 years
Infant nutrition (6 questions)	Australian National Health Survey (ABS 2001)	0-4 years
Nutrition (6 questions)	Adapted from Youth'07.	2-14 years
Activity (5 questions)	Youth'07 (Watson et al 1999) and 2002 Child Nutrition Survey (Ministry of Health 2003)	5-14 years
Module 4: Sociodemographics		
Topic	Source of question	Age group
Gender	Based on NZHS Adult question	birth-14 years
Primary caregiver's relationship to child	Based on Statistics NZ relationship classification	birth-14 years
Date of birth	Statistics NZ Census 2006	birth-14 years
Ethnicity and Māori descent	Statistics NZ Census 2006	birth-14 years
Country of birth and year of arrival if migrant	Statistics NZ Census 2006	birth-14 years
Languages child can speak /languages spoken to child	Based on Stats NZ questions Census 2006	birth-14 years
Receipt of disability or child disability allowance	Statistics NZ Census 2006	birth-14 years
Medical insurance	Based on NZHS Adult question	birth-14 years
Exposure to passive smoke in house and car	Based on NZHS Adult question	birth-14 years
Child household mobility	Youth '07 (Watson et al 2001)	birth-14 years
Shared-care and/or custody arrangements	New	birth-14 years
Early childhood care (4 questions)	New – developed with Ministry of Education	0-4 yrs
Primary caregiver's age on last birthday	Based on NZHS Adult question	birth-14 years
Primary caregiver's highest education	Based on NZHS Adult question	birth-14 years
Primary caregiver's employment and hours per wk	Based on NZHS Adult question	birth-14 years
Household income and composition (4 Qs)	Based on NZHS Adult question	birth-14 years

Tenure/ownership of dwelling	Based on NZHS Adult question	birth-14 years
Number of bedrooms in dwelling	Based on NZHS Adult question	birth-14 years

5. Testing the questions

5.2 Cognitive testing

Cognitive testing of the draft questionnaire was conducted by a contracted research organisation in March 2006 with 11 female parents/caregivers and 9 male parents/caregivers of children ranging in age from 1 week old to 14 years old. The respondents had varying socioeconomic positions and education levels. The overall research objective in undertaking cognitive testing was to ensure the questions were easily understood by respondents and able to produce high quality data (Fowler Jr. 1995).

The cognitive testing focused on three main processes: 1) how the respondents understood and interpreted the questions, 2) how respondents recalled the information required to answer the questions, and 3) the judgments respondents made as to what information to use when formulating their answers.

Interviewers began with a short word association exercise about the topics covered in the questions. This helped the researchers know how respondents understood and interpreted the key words before they were ‘contaminated’ by the research process (i.e. before respondents thought about their answers to the specific questions being tested). For example, the interviewer said “obesity” and the respondent may have answered “fat” or perhaps they may have indicated that they did not know what that word meant. Then the interviewer ran through the questionnaire as though it was the actual interview. Following on from this, the interviewer asked some additional validation questions to measure whether or not respondents reliably provided the same answers to key questions. Next the interviewer prompted discussion about the respondent’s perceived understanding of the information sought by the questions, and a general overview of how they found the questionnaire and show cards. Then there was a detailed discussion about the respondents’ understanding and interpretation of each question. The researcher paid particular attention to those questions the respondent appeared to hesitate on, and/or those questions the respondent did not readily comprehend. Finally, the interviewer asked the respondent about potential improvements to questions (wording, tone, pitch and ordering).

One example of a question that was altered following cognitive testing was a CHQ question regarding family cohesion: “Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family’s ability to get along with one another?” Respondents of Māori and Pacific ethnicity found it difficult to answer this question as their understanding of the word ‘family’ had much wider connotations than the European nuclear family. Māori and Pacific respondents were often trying to judge the ability of their extended family to get along, which could easily include over 200 people. A definition was added to the questionnaire, “By family, I mean your immediate family members that live in this household”, with agreement by the CHQ developers (Landgraf and Ware) that this definition retained the original intent of the question.

Cognitive testing was a valuable tool for ensuring the reliability of proposed questions, both in what was being asked and what was being understood by respondents.

5.3 Dress rehearsal

The 2006/2007 NZHS dress rehearsal was conducted in May 2006 in 16 PSUs (Census meshblocks) geographically spread throughout the country with both urban and rural areas selected. The purpose of the dress rehearsal was to test the instruments, operations and data processes in a ‘live’ field situation (Aday 1996). In total 150 households agreed to participate in the dress rehearsal, which resulted in 51 child interviews.

The dress rehearsal data pointed to several issues. There were a few obvious height and weight mis-measurements which affirmed the importance of interviewer training, resulting in the inclusion of a child demonstration in the interviewer-training video and special points to note when measuring children. The developers also uncovered a routing problem where home-schooled children were asked several questions not applicable to their situation. In

addition, interviewers reported several instances where respondents requested further information or definitions of words, which were then consequently added to the questionnaire.

Quantitative analysis of the dress rehearsal data was undertaken to ensure that there were not too many refusals or don't know responses, that there was a good spread in response categories, and no missing data. Questions which elicited an 'other' response, where the interviewer had to type in the specific answer, were carefully checked to ensure that the predetermined coded list of response categories was appropriate. A small amount of reliability and validity testing was also undertaken where appropriate. Reliability was determined by ensuring that the data was consistent in the responses received, and validity was evaluated using existing hospital administration data to check if the responses were close to the hypothetical 'true measure' of what was being measured.

The dress rehearsal proved that the addition of a child health questionnaire to the main adult survey did not adversely affect response rates due to the increased time the interviewer had to be in the household, as originally hypothesised. In fact there was general consensus from the dress rehearsal interviewers that the addition of a child health questionnaire in many instances had assisted their entry to the household, as people were often more willing to discuss their child's health details than their own and could see the value in the government collecting child health information.

The dress rehearsal established that the questionnaire took an average time of 30 minutes to complete in the field, and not the 20 minutes originally intended. However, this length was considered appropriate by dress rehearsal respondents and there were no respondents who ended the interview prematurely or declined to participate because of the length of the questionnaire.

6. Conclusion

At the time of writing, the 2006/2007 NZHS has been in the field for four months with over 1500 child health interviews completed. Detailed analysis of the first quarter dataset revealed no major errors or concerns, and interviewers continue to report that the questionnaire is well received by respondents and assists with gaining the cooperation of the householder.

This paper has reviewed the streamlined process used to develop and test a new child questionnaire for use in the New Zealand Health Survey, noting the challenges and learnings from designing a questionnaire with limited time and resources. This exercise has shown that a quality questionnaire which minimizes survey-response error can be developed if you: 1) start with clear and concise objectives based on strong theory, 2) use validated questions where possible from similar surveys, 3) focus the consultation on topics and variable of interest rather than questions and 4) test new questions thoroughly.

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