

The New Zealand Health Monitor

Updated strategic plan

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MANATŪ HAUORA

Foreword

In 2001 Public Health Intelligence, the epidemiology group of the Ministry of Health, was given the responsibility of managing the Ministry's national population health survey programme, the New Zealand Health Monitor (NZHM). As the first step in establishing this integrated programme of health surveys and record linkage studies, we produced a discussion document in 2002, *The New Zealand Health Monitor: A 10-year cycle of health-related surveys*, which outlined a suggested 10-year strategy.

Public Health Intelligence has subsequently managed several surveys, including (and most importantly) the 2002/03 New Zealand Health Survey. Results from this survey were published in *A Portrait of Health: Key results of the 2002/03 New Zealand Health Survey*. Also published were results from the analysis of data from the first health survey conducted in the Chatham Islands (*Chatham Islands Focus*). The first national Children's Nutrition Survey was carried out in 2002 and the results presented in *NZ Food: NZ Children*. Health behaviour surveys on the use of alcohol and illicit drugs were fielded in 2004 and the results are expected in late 2005.

With four years' experience of successfully managing the NZHM, it is opportune to revise and update the original strategy. This second edition outlines a detailed strategic plan for the future of the NZHM. The cornerstone surveys in the programme are the New Zealand Health Survey, held every three years, and the New Zealand Nutrition Surveys (alternately covering adults and children) every five years. The first national Mental Health and Wellbeing Study, *Te Rau Hinengaro*, was fielded in 2002 and is currently being analysed. A series of annual tobacco-use surveys will commence in late 2005. Other health behaviour surveys, covering topics such as alcohol and drug use, and sexual and reproductive health, will also form part of the NZHM and be repeated at regular intervals. In addition to planning the surveys, Public Health Intelligence will lead the analyses of NZHM data.

The NZHM makes a valuable contribution to the health sector. Information from the various surveys has already been used extensively to provide evidence for policy development and decision-making. A good example is the estimates of body mass index distribution in adults and children, which have informed the development of the Ministry's Healthy Eating: Healthy Action policy. A related example is the use of data from the surveys to produce estimates of the burden of disease of nutrition-related risk factors. Many other examples could be cited.

We welcome your comments about this revised strategic plan for the New Zealand Health Monitor. Any comments can be sent either to Sarah Gerritsen, Advisor (Surveys), Public Health Intelligence, or to me.



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1 Introduction

Information is needed to make evidence-informed decisions at all levels of the health system, from the clinical encounter, to District Health Board (DHB) service planning, to Ministry of Health policy advice. The WAVE project (Ministry of Health 2001) has provided a strategic direction for *service-based* (or patient-based) information systems. These information systems focus on inputs (resources provided or consumed) and throughputs (volumes and times), especially at the local level, but can provide little information about non-users (such as unmet needs and access barriers) or outcomes (except for clinical outcomes at the individual patient level).

By contrast, the New Zealand Health Monitor (NZHM) – an integrated programme of surveys and cohort studies – is a *population-based*, outcomes-focused information system which has the capacity to address precisely these gaps in health information. Together, the two information systems (WAVE and the NZHM) can potentially provide a complete picture of health and health services, and so enable a managed health system at all levels – local, regional and national.

The NZHM is informed by the principles of the New Zealand Health Strategy (Minister of Health 2000) and aims to guide actions intended to realise the goals set out in the Strategy. The NZHM monitors the health status of the population and the main groups within the population, with a particular focus on the personal and social determinants of health, including access to and utilisation of health services, and can therefore contribute to the evaluation of health policy, programmes and services.

The NZHM recognises the Government's commitment, as outlined in the New Zealand Public Health and Disability Act 2000 and He Korowai Oranga Māori Health Strategy (2002), to the special relationship between iwi and the Crown under the Treaty of Waitangi. Accordingly, the NZHM aims to produce estimates with the same precision for Māori as for non-Māori (equal explanatory power) (Te Rōpū Rangahau Hauora a Eru Pōmare 2002).

Mandate for the NZHM

Section 3(c) of the Health Act 1956 requires the Ministry to collect and report information necessary for maintaining and improving the health of the population. The need for population-based health and nutrition surveys to meet this legislative requirement has long been recognised. However, it was not until May 2001 that the Ministry of Health formally delegated responsibility for this to Public Health Intelligence, with the mandate to design and manage such an integrated survey programme – the New Zealand Health Monitor – and set up a dedicated multi-year funding stream for this purpose.

Public Health Intelligence, a business unit within the Public Health Directorate of the Ministry of Health, manages the day-to-day operations of the NZHM, and develops the research objectives and vehicles for the NZHM. The fielding of component surveys is outsourced to specialised survey providers, following which we analyse and disseminate the data, often in collaboration with academic researchers. Governance of the NZHM is provided by a stakeholders group, which includes representatives from all Ministry of Health directorates and DHB representatives. Expert advisory groups may be formed for each survey, as appropriate.

History of major national health surveys in New Zealand

Unlike many similar economically developed countries, New Zealand lacked regularly repeated national population health surveys until relatively recently. Instead, New Zealand's surveys tended to be ad hoc, irregular and uncoordinated. The first such survey was an adult nutrition survey, the 1977 National Diet Survey (Birkbeck 1979). This was followed by the 1989 Life in New Zealand Survey (Hillary Commission 1991), which also included measures of physical activity, and the 1997 National Nutrition Survey (Ministry of Health 1999). The first national Children's Nutrition Survey was carried out in 2002 (Ministry of Health 2003).

The first general health survey was the 1992/93 Household Health Survey (Statistics NZ and Ministry of Health 1993), followed by the 1996/97 New Zealand Health Survey (Ministry of Health 1999). The 1996/97 New Zealand Health Survey was repeated, with modifications, in 2002/03 (Ministry of Health 2004b). A national mental health survey, Te Rau Hinengaro – New Zealand Mental Health and Wellbeing Study, sponsored by the Ministry of Health and managed by the Health Research Council, was fielded in 2002 (data are currently being analysed).

In 1996/97 Statistics New Zealand conducted the first national disability survey (Household Disability Survey and companion Disability Survey of Residential Facilities), co-sponsored by the Ministry of Health. The Disability Survey is a post-censal survey and was repeated following the 2001 Census. Statistics New Zealand intends to repeat this survey in 2006 and following every census or second census thereafter.

Smoking data have been collected in alternate censuses, and in annual surveys of adults since 1983 and of fourth formers since 1997 (Ministry of Health 2005). However, Statistics New Zealand has signalled its intention to discontinue the smoking questions in the census after 2006. Data on other drugs, including alcohol, have been collected through telephone surveys carried out by the University of Auckland on several occasions, most recently in 1998 and 2001 (the National Drug Surveys). In 2003/04 the Ministry of Health, with the Centre for Social and Health Outcomes Research and Evaluation (SHORE), conducted two health behaviour surveys which collected data on illicit drug and alcohol use, respectively (results are expected by the end of 2005).

In 2001 the University of Auckland carried out a country-wide school-based survey of adolescent health (Youth 2000: New Zealand Youth). The University, in partnership with the Ministry of Health and others, proposes to repeat this survey in 2006 and every census year thereafter. In 1995 the University of Waikato conducted a social survey that included a major women's health component (New Zealand Women: Family, Education and Employment). In 2000 the Ministry of Social Policy commissioned a survey, Living Standards of Older New Zealanders, which included a major health component. Since 1998 the Hillary Commission (now SPARC) has conducted a regular national survey, the New Zealand Sport and Physical Activity Survey (SPARC 2002).

In addition to these national surveys, a number of regional or local health surveys have been conducted over the past several decades, most notably the 1982, 1986–88 and 1993–94 Auckland Heart Health Studies, which were part of the WHO Multinational Monitoring of trends and determinants in Cardiovascular disease project (MONICA – Jackson et al 1995). More recently, another major study of Aucklanders focusing on cardiovascular health and diabetes and their risk factors has been completed, with over 4000 participants aged 35 to 74 years (P Metcalf, personal communication 24 June 2005). Results from this research should be available by the end of 2005.

History of major cohort studies in New Zealand

Two major birth cohort studies have been operating in New Zealand for several decades, and continue to provide much valuable information: the Dunedin Multi-disciplinary Health and Development Study (for the latest results, see Poulton et al 2005) and the Christchurch Health and Development Study (see Fergusson et al 2005). The former is the longest-running cohort study in New Zealand, following approximately 1000 babies born in Dunedin in 1972 and 1973, and it now includes an offspring study. The Christchurch study has been monitoring the health and development of approximately 1200 children since their birth in 1977.

The Ministry of Social Development is currently designing a new longitudinal study to follow a nationally representative birth cohort of 4000 to 5000 children in order to provide further insight into the critical factors that influence child development.

The New Zealand Census – Mortality Study (NZCMS), a joint venture of the Wellington School of Medicine and Health Sciences of Otago University and Public Health Intelligence of the Ministry of Health, is a series of cohort studies of the entire population that involves anonymous and probabilistic linkage of census and mortality records (Ministry of Health 2002a). This research is the principal instrument by which the Ministry of Health monitors social inequalities in health and provides further understanding of the various determinants of health.

Public Health Intelligence is also currently developing a Birth Linkage Study, which will routinely link antenatal, birth, delivery and post-natal records to child health records.

Why an integrated health monitor?

As the appetite for evidence-informed decision-making in the health sector has increased, so too has the need to better co-ordinate and regularise New Zealand's investment in health information, especially that collected through population-based health surveys and major cohort studies. Also, an integrated health monitor will enhance harmonisation with the survey programmes, methods and standards of other developed countries and international agencies, especially the World Health Organization's World Health Survey and STEPS risk factor survey (WHO 2003, 2005).

Beyond enabling international benchmarking, the advantages of an integrated survey programme over the ad hoc arrangements that had previously existed include the following.

- The survey programme becomes institutionalised, which enhances public acceptance and knowledge of the surveys, and also contributes to the sustainability of funding and high response rates while simultaneously reducing transaction costs.
- The integrity of the time series is better preserved by ensuring repeated data collection using consistent definitions and instruments, while still allowing flexibility and responsiveness to emergent information needs.
- Opportunities are enhanced for systematic record linkage (thereby expanding the analyses possible) and for improving the timeliness of the estimates.
- Diverse information needs of all users are met more readily (eg, by accumulating samples for DHBs over time), and balanced coverage across all information domains can be ensured.
- Efficiency gains are made by reducing duplication (as well as gaps) in content across component surveys, as well as by greater use of data integration (both survey to survey, and survey to non-survey).

Accordingly, in May 2001 the Ministry of Health established the New Zealand Health Monitor (NZHM), a multi-round integrated programme of household health surveys and cohort studies with a 10-year cycle. Now, four years after the Monitor was established, it is time to update the strategic plan for the NZHM based on the experience gained since then.

This strategic plan for the NZHM will be of interest to the many stakeholders who utilise NZHM data: the Minister of Health, policy-makers in the Ministry of Health, other government departments, people working in the health sector, Māori organisations and iwi authorities, non-government organisations and community groups, academic institutions, researchers, students and the general public.

2 Objectives of the NZHM

Aim

The broad aim of the NZHM is to provide relevant, reliable and timely information (that cannot be collected more efficiently through other means) for the health sector in order to:

- develop and evaluate evidence-informed policies and strategies
- plan and allocate resources to services (or programmes)
- manage the sector strategically.

Objectives

The specific objectives of the NZHM are to routinely and regularly collect, analyse, interpret and disseminate information (collected through population-based surveys and cohort studies) relating to two central questions:

- How healthy are we?
- How healthy is the health system?

How healthy are we?

This question is answered by:

- monitoring trends in the social determinants of health, risk and protective behaviours, and physiological and psychological states
- monitoring physical and mental health, as well as illness trends, through a combination of self-report and objective tests
- monitoring Māori health, and health inequalities between population groups.

NZHM information is used to interpret and explain, rather than merely describe, trends and subgroup contrasts in health and risks to health. In this way it can help the sector to evaluate the effectiveness of policies and programmes or services, and to identify the need for corrective action, as appropriate. NZHM output is intended to inform projections or forecasts, which in turn are fed into the policy or planning cycle (eg, of the Ministry of Health and DHBs).

How healthy is the health system?

This question is answered by:

- monitoring the use and non-use of health services (especially primary health care)
- monitoring the responsiveness of the health system (including respect for persons and client orientation)
- monitoring inequalities between population groups in both the coverage and responsiveness of programmes and services, including issues of cultural safety.

NZHM information can be used to understand gaps in service coverage, barriers to access and unmet need. This understanding can in turn be fed into policy and service planning and evaluation.

The monitoring role of the NZHM

As stated in these objectives, the NZHM primarily has a monitoring function. Monitoring involves the regular and ongoing collection, analysis and reporting of information, and this term is considered to be synonymous with (but preferred to) 'surveillance'. Monitoring is essentially descriptive, answering the 'what?' question. Insights are typically derived by comparing observed with expected or target levels of variables of interest, contrasts between population groups or geographic areas, or time trends.

Monitoring is distinct from research and evaluation. Research involves generating new knowledge and is essentially analytical, answering the 'why?' question. Some applied research may utilise NZHM data, but that is not its primary role. Evaluation involves assessing the effectiveness, cost-effectiveness, acceptability and impact of specific interventions, policies and programmes. It answers the 'what works?' question, and may involve a range of study designs and methods, often including qualitative techniques. Despite overlaps, both research and evaluation (in its formal sense) are considered to be outside the scope of the NZHM.

Users and uses

NZHM monitoring information should be of value to a variety of stakeholders concerned with evidence-informed policy, services and programmes. The main stakeholders are given in Table 1.

Table 1: Users and uses of the New Zealand Health Monitor

Stakeholder	Purpose
Government: <ul style="list-style-type: none"> • the Minister of Health • policy-makers • other government departments 	Monitoring health outcomes and inequalities, development and evaluation of health strategies (eg, chronic disease, inequalities, population subgroups), setting health goals and targets, purchasing services, health promotion, monitoring health service use
Health sector: <ul style="list-style-type: none"> • DHBs, PHOs, PHUs • practitioners 	Monitoring health outcomes and inequalities, monitoring and evaluation of health service performance and programmes (eg, health education, health promotion), patient advice and education
Māori organisations and iwi authorities	Policy setting, programme development and evaluation, health promotion
Non-government organisations and community groups	Policy setting, programme development and evaluation, health promotion
Academic institutions: <ul style="list-style-type: none"> • researchers • teachers • students 	Teaching, research direction, data for research
General public	Education, information

Notes: DHB = District Health Board; PHO = primary health organisation; PHU = public health unit

3 Content of the NZHM

Is the New Zealand population healthier today than it was three years ago? Is inequality in health outcomes between Māori and non-Māori widening? Is the absolute five-year risk of a major cardiovascular event (heart attack or stroke) decreasing in advantaged communities but increasing in deprived areas? What explains these trends? How quickly is the national diet changing? Are children becoming more inactive? What are the impacts of trends for body fat mass and its distribution on health? Is the health system becoming more responsive to the needs of Māori? How much effect does smoking have on health outcomes?

These and many similar questions can be answered only through well-designed, competently fielded and correctly analysed health surveys.

What scope of information does the NZHM collect?

Surveys are relatively slow, expensive and intrusive. The NZHM aims to collect only those data that:

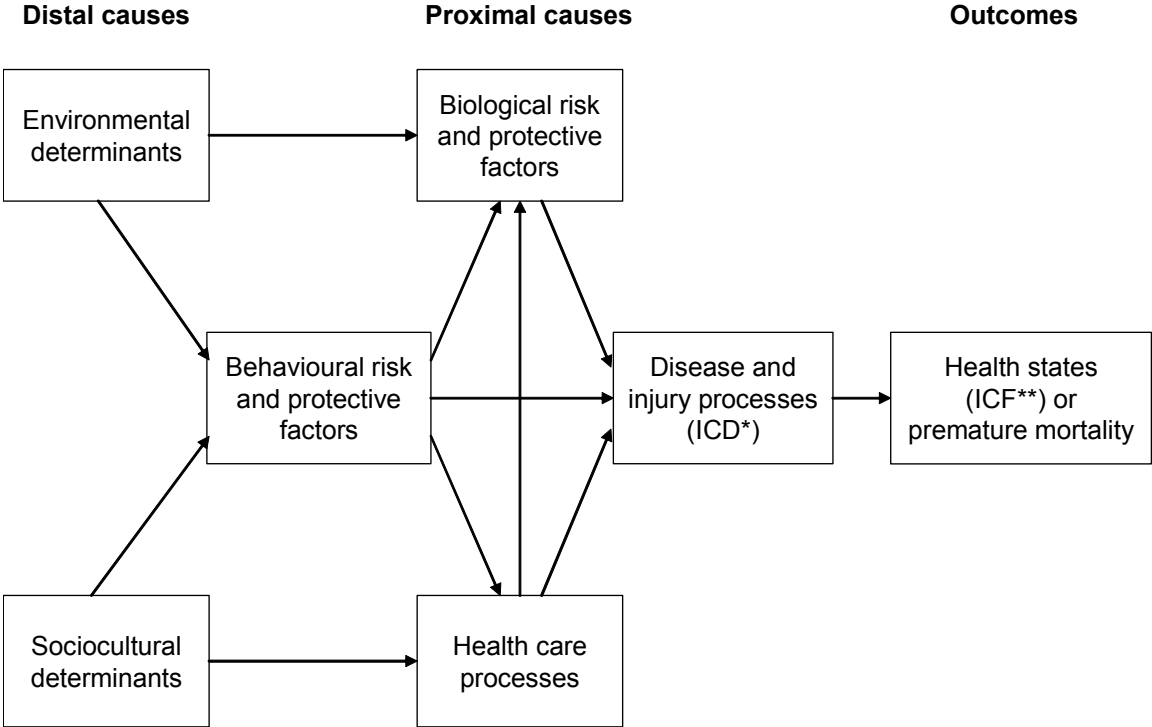
- cannot be collected more effectively and efficiently by other means (ie, through administrative databases or epidemiological studies)
- are needed to inform decisions made by the Ministry of Health or DHBs
- are population based.

Note that information about fundamental biological processes (eg, the risk of developing diabetes due to obesity), or about the effectiveness of clinical treatments, is better derived from research studies of patients or other special groups, and not necessarily restricted to New Zealand.

A logical data structure underpins the inclusion or exclusion of variables. That is, variables for which data are collected are not selected on an ad hoc basis, but are related to an underlying conceptual model of health (Figure 1) and to the Ministry of Health's Managing for Outcomes model (Figure 2). These models identify the critical causal pathways and health outcomes the Ministry believes it can effectively influence. The use of such models or frameworks enables relationships between variables to be explored, and gives the information explanatory rather than merely descriptive power.

The NZHM does not focus on a set of predetermined indicators. Rather, it attempts to collect and analyse data on all variables meeting the criteria listed above. Variables that have been (or may be) selected as 'indicators' for national policies, in particular the New Zealand Health Strategy, He Korowai Oranga, and the Primary Health Care Strategy, will be accorded priority.

Figure 1: Model of health and its causes

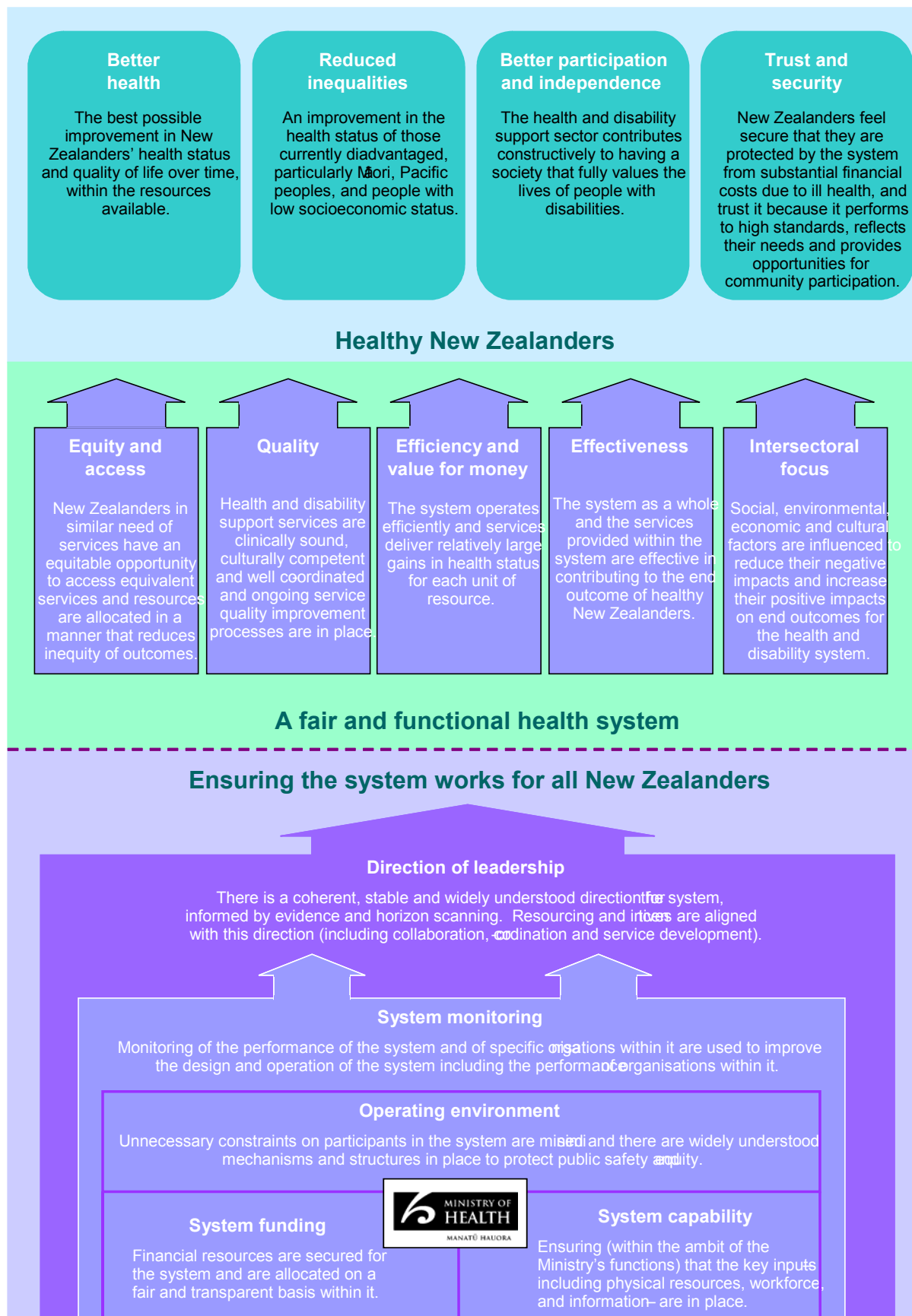


Notes:

* The World Health Organization’s International Classification of Disease (ICD)

** The World Health Organization’s International Classification of Functioning, Disability and Health (ICF)

Figure 2: Ministry of Health’s Managing for Outcomes model



Source: Ministry of Health 2005c.

Information domains

Based on widely used models of health and health systems (see Figures 1 and 2 above), and a review of health information systems in other developed countries, we conclude that health surveys are able to tap three major health information domains:

- health outcomes (health status, disease states)
- causes of these outcomes (social and environmental determinants, risk and protective factors)
- health services (access, utilisation, need, coverage, quality, responsiveness, cost).

Health outcomes

Standard classifications of health outcomes have been developed by the World Health Organization (WHO), to which New Zealand is a signatory, including the International Classification of Functioning, Disability and Health (ICF) and the International Classification of Diseases, now in its 10th revision (ICD–10).

Based on these classifications, four sub-domains may be distinguished:

- subjective (self-rated) health
- functional limitation
- chronic conditions
- injuries.

Subjective health

A variety of scales are available to tap the construct of subjective health, depending on the purpose of the survey/study. As a minimum, the global single-item self-rated health question should be included: 'In general, how would you say that your health is – excellent, very good, good, fair, or poor?'

Functional limitation

The ICF, approved by the WHO in May 2001, recognises 21 key dimensions of health (Box 1). Well-known health status instruments such as the SF-36 (Medical Outcomes Trust) and the HUI3 (Feeny et al 1996) capture some but not all of these dimensions. However, the WHO is currently developing an instrument with wider coverage (WHO 2005). The NZHM aims to collect data on most if not all of these key dimensions. In addition, although these dimensions are intended to cover all age groups, additional scales covering growth and development will be needed for monitoring child health.

Box 1: Key dimensions of health recognised by the ICF

Health dimensions

- vision
- sleep
- communication
- skin and disfigurement
- pain
- excretion
- energy/vitality
- speech
- fertility
- affect
- digestion
- dexterity
- hearing
- sexual functioning
- cognition
- breathing
- mobility

Health-related dimensions

- self-care
- interpersonal relations
- usual activities
- social functioning

Chronic conditions

Estimates of prevalence (and incidence and remission) of chronic physical and mental conditions are becoming increasingly critical as the population becomes proportionately older, and as treatment options for these conditions improve and diversify.

Which chronic conditions from the ICD codes to include in the survey programme depends on the epidemiological picture and policy options. For example, inclusion of just three conditions – urinary incontinence, stroke and dementia – alongside social support (ie, living alone) allows prediction of need for residential care places. Mental illness assessment requires special survey instruments such as the Composite International Diagnostic Interview, or CIDI (WHO World Mental Health 2005).

The chronic conditions in the 2002/03 New Zealand Health Survey included heart disease, stroke, diabetes, asthma, chronic obstructive pulmonary disease, arthritis, spinal disorders, osteoporosis, cancer, and other long-term conditions nominated by the respondents (prominent among which were migraine, stomach conditions including ulcers, bowel problems including irritable bowel syndrome, and serious mental illnesses).

Injuries

Serious injuries result in death or hospitalisation, both of which can be monitored through administrative databases. In comparison, minor injuries are usually treated in primary health care settings, and are therefore more difficult to monitor. Intersectoral work on injury surveillance (by Statistics New Zealand, Accident Compensation Corporation, Ministry of Health, and injury research centres) is currently in process and should ultimately meet most of the requirements for injury data.

Causes of health outcomes

There is no standard classification of health causes. However, the following represent a practical approach:

- socioeconomic, cultural and demographic determinants
- behavioural risk and protective factors
- biological risk and protective factors.

Socioeconomic, cultural and demographic determinants

Basic demographic characteristics – such as age, birth cohort, gender, natality and sexual orientation – are important determinants of health. Socioeconomic, political and cultural forces are recognised as the ultimate determinants of health in most models. Variables of interest to the NZHM include: educational attainment, occupation, labour market status, income, ownership of assets, material living standards, living arrangements, ethnicity, English-language competence, acculturation (migrants only), strength of cultural engagement, experience of racism, social support / connectedness, housing status and quality, mobility, degree of deprivation of neighbourhood of residence, and rurality.

Behavioural risk and protective factors

Health-related behaviours (risk and protective) are important mediators of social inequalities in health outcomes. Variables collected may include:

- nutrition: dietary pattern, food and nutrient intakes, food preferences, food preparation methods, adult weight gain and weight cycling, consumption of dietary supplements and functional foods, household food security
- physical activity: active recreation, incidental activity, energy expenditure, and sedentary behaviours
- drug use: tobacco, alcohol, illicit drugs, prescription drugs
- sleep: pattern, duration
- stress: in life, at work, job control and satisfaction
- gambling
- injury risk and protective behaviours: driving under the influence, speeding, use of protective equipment (eg, seatbelts, cycle helmets)
- violence (including child, partner, elder abuse and other forms of family violence)
- sexual and reproductive behaviours: partner relations, contraception, sexually transmitted infections, fertility
- uptake of clinical preventive services (eg, relevant cancer screening, immunisations).

Some behaviours require special survey methods (eg, sexual behaviours, violence), while others overlap with health service utilisation (eg, cancer screening, immunisation, contraception).

Stage of change (Prochaska et al 1992) is a key variable for designing, targeting and evaluating health promotion programmes. Barriers to, and facilitators of, change (ie, the psychosocial correlates of expressed behaviours) also need to be monitored.

Biological risk and protective factors

A vast array of biochemical tests is available if blood samples can be collected (especially fasting samples). However, much can also be learned from less invasive assays of urine and saliva, as well as from simpler (and cheaper) anthropometric and physiological examinations (eg, taking waist and height measurements, and blood pressure readings).

A similarly wide range of validated tests is available for psychological states, including:

- memory and cognition (eg, attention, problem-solving)
- self-esteem
- mastery (sense of control)
- optimism
- coping style.

Health services

There is no standard classification of health services. The focus of the NZHM is on primary rather than secondary services, because other data sources are available for the latter. The dimensions of particular relevance for the NZHM are:

- coverage
- responsiveness
- cost.

Coverage

Coverage includes access, utilisation and need. A key objective for the NZHM will be to contrast high, average, low and non-users of health services, especially disease prevention services. Reasons for both use and non-use should be sought in relation to perceived need. Patterns of use are important: who was consulted, the care pathway and referral (the 'patient journey'), and whether there is a regular care provider. Particular attention should be paid to informal and alternative services and remedies, as well as self-medication and use (or non-use) of over-the-counter drugs and prescription medicines.

Through careful questioning about use and non-use of services in relation to perceived need, social support and service availability, information can be derived as to effective service coverage, access (including informational, financial, geographic, temporal, physical and cultural dimensions), and unmet need. An as yet largely untapped dimension is carer/family burden.

Responsiveness

Suitable scales for assessing health system responsiveness – the ‘people-centredness’ of the health system – have been developed by the WHO (Murray and Frenk 2000).

Two subscales are recognised:

- respect for persons – autonomy, dignity and confidentiality
- client orientation – promptness of attention, the quality of amenities, access to social support networks during care, choice of provider and clarity of communication.

Continuity of care may be added as an additional domain of responsiveness.

Responsiveness reflects survey respondents’ personal experience of the health system and is based on self-report. Subjective perceptions of the state of the health system in general or satisfaction with care received are not included (patient satisfaction and related data are available from other sources outside the NZHM).

Cost

Most data relating to health and disability expenditure are collected through administrative resource allocation and billing systems. The Household Economic Survey (Statistics New Zealand) also collects some data regarding household expenditure on ‘medical consumption’. By contrast, the NZHM may only focus on two dimensions of cost:

- private health insurance (needed to understand service use patterns)
- out-of-pocket expenses (as these relate to financial barriers to access).

Instruments for data collection

Questionnaires

Much of the data necessary for the information domains listed above can be collected through survey questionnaires, whether interviewer or self-administered. Indeed, some topics – those relating to attitudes, perceptions and expectations (eg, perceived discrimination, stage of change) – can only be captured in this way.

A wide array of validated questionnaires with good psychometric properties (ie, high validity, reliability and responsiveness) are available for many of the domains discussed above (see McDowell and Newell 1996; Bowling 1997). Examples of the instruments that may be used in NZHM questionnaires are listed in Box 2 below.

Box 2: Key instruments that may be included in the NZHM

SF–36 – General health status measure

A 36-item questionnaire that measures eight dimensions of self-reported health status: physical functioning, role limitations due to physical problems, bodily pain, general health, vitality (energy), social functioning, role limitations due to emotional problems and mental health. There is a further unscaled item asking respondents about health change over the past year. The SF–36 is used throughout the world to compare self-reported physical and mental health status.

WHO Long Form – International measure of general health status

A longer questionnaire consisting of 20 health domains, some of which overlap with the SF–36 domains, based on the International Classification of Functioning, Disability and Health (ICF).

NZPAQ Short Form – New Zealand Physical Activity Questionnaire

A seven-item questionnaire covering four topics: walking, moderate physical activity, vigorous physical activity and frequency of activity. An optional question on state of change may be asked. This was developed by Sport and Recreation New Zealand (SRARC) and the Ministry of Health, with input from Statistics New Zealand.

K–10 – The Kessler Psychological Distress Scale

A 10-item questionnaire on non-specific psychological distress to ascertain the level of anxiety and depressive symptoms a person may have experienced in the most recent four-week period. It is also used in population surveys in Australia and the USA.

24-hour dietary recall

A quantitative measure of food and beverage consumption over the previous 24 hours. Food and beverages from the 24-hour recall are matched to food composition data from the New Zealand Food Composition Database to calculate nutrient intakes.

Food Frequency Questionnaire (FFQ)

A questionnaire used to collect information on the usual frequency of consumption of foods and beverages within a given time frame (eg, past two to three months or past year).

ELSI Short Form – Economic Living Standards Index

A 25-item questionnaire developed by the Ministry of Social Development to measure material living standards, based on a person's consumption, personal possessions, social participation and self-ratings of economic wellbeing. ELSI may be used in addition to income, education and occupation to determine socioeconomic position.

Tests

Tests are included in the NZHM to complement self-report data, for four purposes:

- to capture domains that are not accessible to self-report (eg, blood cholesterol levels) or for which self-report is subject to bias (eg, body weight and height)
- to provide a quality check on self-report data, or to help calibrate self-report responses (see below)
- to develop predictive equations (eg, for absolute cardiovascular risk, the local version of the Framingham equation)
- to establish norms for the population.

Tests commonly included in national health and nutrition surveys in developed countries are summarised below (Box 3). Many other tests are also available; those in Box 3 are not intended to be exhaustive, and the NZHM may include other tests depending on the specific objectives of a particular survey. Decisions on which tests to include in the NZHM will ultimately be based on several considerations, including lack of alternative data sources and the need to continue the time series, as well as the practicality, acceptability and cost of the test (assessed through pilot surveys).

Box 3: Tests that may be included in the NZHM

Biological tests

Assessment of *nutritional status* depends heavily on biochemical tests (mainly blood). Among the micronutrient deficiencies of greatest current concern are iron, zinc, selenium, iodine and vitamin D. Other micronutrients of interest include vitamin B₁₂ (older adults) and folate.

Blood lipids and lipoproteins (total cholesterol, HDL cholesterol, LDL cholesterol, triglycerides) are essential for estimating *cardiovascular risk*, along with tests for (pre)diabetic states (including glucose and insulin levels, and glycosylated haemoglobin). Note that some of these tests require fasting blood samples, which may not be practical.

Tests for consumption of drugs and exposure to toxins may also be worthwhile. Key *biomarkers* include cotinine (exposure to tobacco, can be assayed in saliva or urine rather than blood), and lead and mercury levels in children and pregnant women.

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Box 3 continues

Physiological tests

Tests of *vision and hearing* provide valuable confirmatory evidence for self-report data, and are particularly useful for calibrating such data.

Blood pressure measurement is essential for estimating cardiovascular risk and peripheral vascular disease.

Spirometry (obtained using a peak-flow meter) is useful for assessing general population lung function relative to predicted values for population subgroups, and is also an important tool for assessing lung diseases such as asthma, cystic fibrosis and chronic obstructive pulmonary disease.

Physical fitness is an important independent risk factor for cardiovascular disease and a predictor of future mortality risk. Tests range from simple timed pulse recovery to more sophisticated ergocycle and treadmill tests.

Tests of *physical functioning* are particularly important for assessing the health of older people. Such tests include hand grip strength, joint flexion, functional reach test, step test, sit ups, push ups, timed up-and-go tests, and the 5-metre walk speed test.

Anthropometry

Widely used anthropometric measurements include height and weight (to calculate BMI), waist and hip circumference, and skinfolds (at various sites).

Calibration of self-report data

High questionnaire validity and reliability are sometimes insufficient to permit meaningful comparison between population groups or time periods, because variation in health norms or expectations affects respondents' choice of response categories (Salomon et al 2001). For example, Māori and non-Māori may report different difficulty with hearing because of different expectations. As a consequence, the true inequality between the ethnic groups could be disguised (or even reversed) when the survey results are analysed. Or to take another example, the health of New Zealanders may appear to deteriorate over time – not because the true level of health is actually declining, but merely because expectations of what it means to be healthy are increasing (the 'problem of the rising norm').

The solution to this problem of changing expectations (technically referred to as 'response category cutpoint shifting') is to calibrate self-report data using a statistical model, the hierarchical ordered probit (HOPIT). Data for the HOPIT model may be acquired in two ways:

- objective tests
- vignettes.

Objective tests

For some scales (eg, vision, hearing) practical objective tests are readily available. This allows self-reported results for these scales to be calibrated easily by administering the tests to a subsample of survey respondents alongside the self-report questionnaires. Alternatively, the scales could simply be dropped from the questionnaire in favour of the test.

Vignettes

For other scales (eg, pain, affect) there are no practical objective tests available. The only method currently available for calibrating these self-reported responses is to include vignettes in a subsample. Vignettes are standardised descriptions of specific levels on a scale, which are rated by respondents using the same set of response categories they used to rate their own level on the same scale.

Since the vignette has fixed the level of health (on the particular scale), variation in the average response of different population subgroups (or time periods) is attributable entirely to variation in cutpoints (ie, in respondents' expectations for health). Given this additional data, the HOPIT statistical model allows the responses of each subgroup of respondents (defined, for example, by age, gender, class, ethnicity and time period) to be adjusted up or down so as to achieve response equivalence. Scores will now reflect differences in level of health, free from contamination by differences in expectations for health.

Vignettes have been developed and empirically tested for a wide range of scales, including analysis of reliability, framing and ordering effects. Despite the inevitable increase in respondent burden and opportunity cost, vignettes and objective tests may be included, where possible and necessary, in NZHM surveys.

4 Target Populations

The target population for the NZHM is generally the usually resident, civilian population living in permanent private dwellings in New Zealand. However, specific population groups are targeted for inclusion in the NZHM so that inequalities in health can be monitored. The New Zealand population is usually divided by spatial/regional areas and by demographic characteristics.

Common demographic characteristics of interest to the NZHM are:

- age
- gender
- ethnicity
- socioeconomic position
- special populations.

Age

The NZHM attempts to cover all of the life-cycle groups:

- 0–14 years (children)
- 15–24 years (young people)
- 25–44 years (young adults)
- 45–64 years (middle-aged)
- 65+ years (older people).

Different life-cycle stages present different challenges. Two examples of these difficulties are that data collected about children and some older people are commonly collected by proxy from the caregiver; and many young adults are highly mobile and are therefore difficult to include and follow up. Increased sampling of certain age groups (usually older people) is considered in the NZHM when this is necessary to ensure accurate estimates.

Gender

Data are disaggregated by gender to provide insight into the different health experiences and outcomes of males and females. The NZHM attempts to provide gender-consistent interviewers in all face-to-face and telephone surveys when requested.

Ethnicity

New Zealand's population consists of people who identify themselves with a variety of ethnic groups, most commonly classified by the NZHM (following Statistics New Zealand's classification) as: Māori, European, Pacific, Asian and Other.

The NZHM recognises that Māori have a special status as the indigenous people of New Zealand, and that the Crown has specific obligations toward Māori under the Treaty of Waitangi. This relationship between Māori and the New Zealand Government is underpinned by the principles of partnership, participation and protection (derived from the Royal Commission on Social Policy 1988):

- *partnership*: working with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health services
- *participation*: involving Māori at all levels of the health service, in decision-making, planning, development and delivery of services, where appropriate
- *protection*: working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.

In recognising these Treaty principles, the NZHM is committed to the premise that estimates produced for health purposes should have at least the same precision for Māori as for non-Māori. This principle is called *equal explanatory power* (Te Rōpū Rangahau Hauora a Eru Pōmare 2002). Māori are recognised as a population in themselves, not merely a ‘sub-group’ of the New Zealand population. In practice, this requires appropriate sampling strategies and data collection processes in NZHM surveys, in an effort to obtain the same statistical power for Māori as for the rest of the New Zealand population.

The NZHM recognises that there is also a need for more information on the health status, risks to health and patterns of health service use of ethnic groups other than Māori and non-Māori, and is committed to exploring possible ways to address this need. Options may include small population estimation techniques and innovative survey designs. For example, a survey could be conducted only in Auckland, which would not allow for extrapolation to the whole population but would be sufficient to gather information on sub-populations that are well represented in Auckland (Pacific and Asian peoples). Another possible solution is to pool data across survey waves for specific ethnic groups to increase statistical power. A third possibility is to make greater use of screening in the survey sampling design.

Socioeconomic position

The NZHM collects data on socioeconomic indicators because these are key determinants of health. There are two ways to measure socioeconomic position:

- using the New Zealand Deprivation Index (NZDep) – a small-area-based index of deprivation which measures the level of deprivation of each meshblock, or census area unit, according to the following census variables: income, transport (access to car), living space, home ownership, employment status, qualifications, support (sole-parent families), access to telephone (Crampton et al 2004)
- compiling individual data on occupation, educational attainment, income, and living standards/deprivation.

The NZHM uses both of these measures, and also collects data on many of the intermediary pathways linking socioeconomic position to health, including material living standards, labour market status (employment), and housing status (tenure, housing quality and crowding).

Special populations

Most NZHM surveys include in the frame the usually resident, civilian population living in permanent private dwellings. The NZHM also attempts to sample people from outside this population and integrate their data with that of the 'general population'. Special populations of particular interest to the NZHM include:

- people with disabilities
- people living in residential care settings
- refugees and migrants
- patients with a particular illness.

The NZHM is concerned with collecting information from the population, not from providers, and therefore much of the information needed by the Ministry of Health and DHBs concerning providers must be obtained from other sources (often administrative databases). The focus of the NZHS is *serial monitoring* of population health, risks to health, and health service utilisation patterns of the population.

5 Design of the NZHM

Design principles

Nine principles guide the design of the NZHM surveys:

- an integrated framework
- well-defined and measurable objectives
- effective and efficient use of survey frames
- accuracy and precision
- maximising responses and minimising respondent load
- quality control
- ethics and confidentiality
- data access
- record linkage/data integration.

Integrated framework

The NZHM offers an integrated framework for key health statistics. Although the NZHM conducts a number of surveys and cohort studies, these should not be seen as a series of independent surveys and studies but as a means of collecting information that forms a picture of the health of the New Zealand population.

As a signatory to the Protocols of Official Statistics (Statistics NZ 1998), the Ministry of Health employs best-practice survey techniques to produce high-quality data through the NZHM. Standard frameworks and classifications with validated questions are utilised, where possible, to allow for the integration of NZHM data with data from other sources, such as administration databases and other national surveys.

Survey objectives

All surveys and studies conducted under the NZHM have clearly specified objectives that are well defined and answerable in measurable terms. A survey or study is only conducted if data are unavailable or existing data are inadequate.

Frames

The survey frame identifies the units of the survey population (eg, persons, households, etc), so it is an important component of a survey. It determines how well a target population is covered, and affects the data collection method.

Frame imperfections such as coverage errors and out-of-date characteristics are likely to bias or diminish the reliability of the survey estimates and to increase data collection costs. Coverage errors occur due to omissions, erroneous inclusions, duplications and/or misclassifications of the units in the survey frame. These characteristics are considered, along with cost and practicality, when evaluating the options.

The NZHM attempts to make effective and efficient use of both area frames (eg, census meshblocks) and list frames (eg, electoral roll). To achieve this, multiple frames may be employed.

Accuracy and precision

Each NZHM survey is designed to meet the survey objectives using good survey design practices. Emphasis is placed on the accuracy and precision of the survey, rather than the sample size. Two types of error are possible in an estimate based on a sample survey: *sampling error* and *non-sampling error*.

Sampling error occurs because estimates from a survey are based on information relating to a sample of the population rather than a full population. That is, the information obtained may differ from that produced if the whole population had been surveyed.

Non-sampling errors occur because of insufficient coverage of respondents, inadequacies and imperfections in answers provided by respondents, and errors made when coding and processing data. Non-sampling errors may occur in any enumeration regardless of whether it is a sample or the full population. Efforts are made to reduce non-sampling errors by carefully designing and testing the survey, questionnaire and processes, and ensuring detailed quality control of procedures and data.

National surveys have historically been considered of little relevance to small domains because sample size considerations limit the ability to derive robust sub-national estimates. These domains may be geographic, or based on a combination of factors such as age, sex and ethnicity. In particular, there is a need for reliable, timely and detailed information for smaller regions, such as DHBs, and for Māori, Pacific and Asian peoples. Boosting the sample size to provide robust sub-national population information is not an adequate solution, due to the high cost of running a survey and respondent load. Rather than just focusing on reporting information about the whole population, emphasis is placed on researching, developing and implementing appropriate statistical techniques to provide robust small-domain estimates.

Maximising response and minimising respondent load

High participation rates are critical to the success of the NZHM. While some respondents welcome the opportunity to participate, or recognise the importance of providing data, others perceive surveys to be an intrusion. Carefully designed methodology and processes are employed to ensure that the load placed on respondents is minimised, while maximising participation.

Quality control

Quality control of data and processes is an integral component. Quality assurance is achieved using best-practice techniques, comprehensive testing, ongoing performance monitoring, peer review, standard classifications and concepts, and training of interviewers and other staff.

Ethics and confidentiality

All NZHM vehicles must meet strict ethical standards. These standards are explained in detail in chapter 4. Evidence shows that the majority of respondents are willing to participate again in the NZHM.

Data access

A guiding principle of Public Health Intelligence is to make data as widely available as is practical, subject to protecting respondent confidentiality and assuring data quality. There is a range of products and formats available to cater for a wide user audience. These products are explained further in chapter 6.

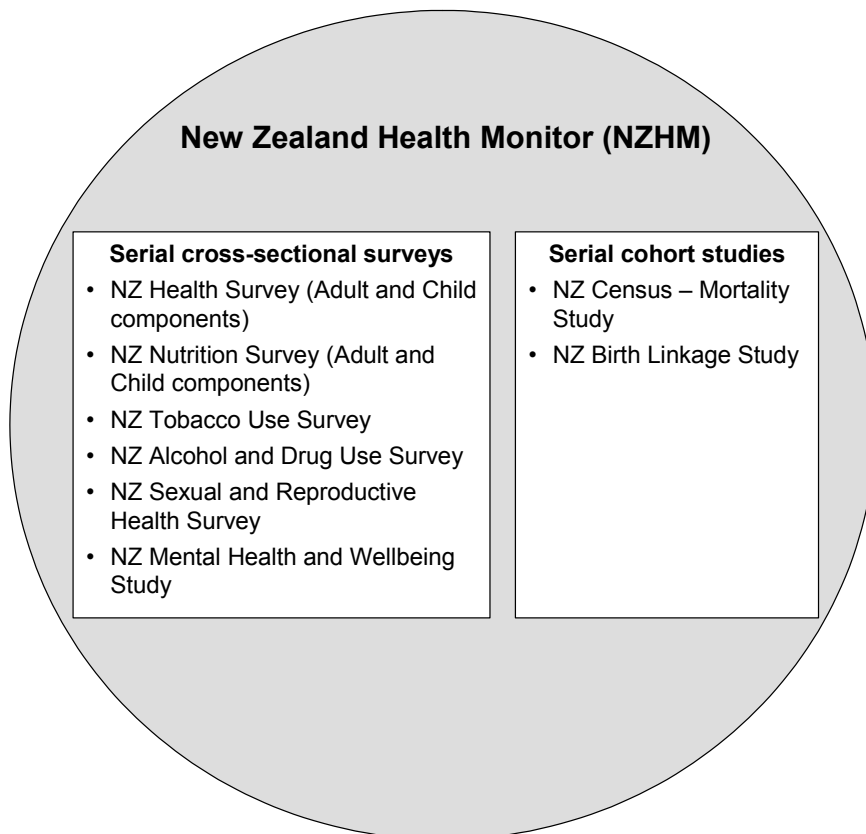
Record linkage (data integration)

Increased use of administrative data is being investigated to improve the accuracy of data collection and to reduce respondent load by minimising the amount of additional data collected from respondents through surveys. Integrating survey and administrative data collections (such as hospital records, cancer registrations and death certificates) can provide unique and valuable new information. Record linkage has the potential to provide a 'snapshot' of the situation at a specific point in time, as well as a 'longitudinal' perspective, observing the same person over a longer period of time. Where practical, the NZHM invites participants in surveys to consent to active and/or passive follow-up.

Vehicles of the New Zealand Health Monitor

There are two main types of vehicles for collecting information in the NZHM: serial cross-sectional surveys and serial cohort studies (often referred to as record linkage studies) (see Figure 3).

Figure 3: Vehicles of the New Zealand Health Monitor



Note that participants in cross-sectional surveys may be asked to consent to active follow-up, and/or passive linkage of hospitalisation or other health-related records to their survey questionnaires, thereby transforming the baseline survey into an ongoing cohort study.

Surveys

Following is a short description of each survey in the NZHM. (See Appendix 1 for a table of the indicative dates for fieldwork of the NZHM surveys 2002–2012, and Appendix 2 for a summary of the NZHM surveys).

New Zealand Health Survey

The New Zealand Health Survey (NZHS) is a general health survey and forms the foundation of the NZHM. Data are currently collected approximately every three years from a representative sample of New Zealand households. The most recent NZHS in 2002/03 only sampled adult New Zealanders; however, it is expected that children will be included in future NZ Health Surveys.

The target population is the total usually resident civilian population residing in permanent private dwellings. Some NZHS waves will also include the population living in residential facilities. The sample size is determined by the survey objectives, but is generally between 7500 and 12,000 adults (with the child sample yet to be determined). Booster samples for specific age groups and ethnicities may be utilised.

Data are collected face-to-face via trained interviewers in the respondents' homes. The NZHS is primarily a health interview survey, but also includes a small health examination component. The examination component currently comprises only anthropometric measurements (height, weight and waist circumference), but may potentially include blood pressure measurements and a range of other tests appropriate to specific age groups.

The content of the NZHS child component is under development. The NZHS adult component currently contains five modules, collecting data on:

- sociodemographic characteristics
- biological and behavioural risk factors
- chronic diseases
- health status
- health service utilisation.

The NZHS includes the potential for a longitudinal (follow-up) component. This may involve passive follow-up (see section on record linkage studies) or active follow-up via interview (typically once only, one to two years post-baseline survey). Participants' consent is gained for follow-up at the conclusion of each interview.

New Zealand Nutrition Survey

The New Zealand Nutrition Survey comprises separate adult and child surveys: the New Zealand Adult Nutrition Survey and the New Zealand Child Nutrition Survey. These surveys collect data on food and nutrient intake (including dietary supplements), factors influencing dietary intake (eg, food preparation practices and household food security), nutritional status, and nutrition-related health status, using a combination of interviews and examinations.

Both nutrition surveys include an interviewer-administered 24-hour dietary recall and qualitative food frequency questionnaire, health questionnaires, as well as an examination component. The examination component includes anthropometric measurements, blood pressure measurement and sometimes bioimpedance. Blood and urine samples are collected for a range of biochemical tests.

For adults, data are collected via trained interviewers in the respondent's home and/or an examination centre. The mode of survey administration is CAPI (computer-assisted face-to-face interviewing), possibly with an additional self-administered questionnaire. The target population for the Adult Nutrition Survey is the usually resident civilian population residing in permanent private dwellings. The target population for the Child Nutrition Survey in 2002 was school children aged 5–14 years, but this may be extended in future years to include 15-year-olds and the 0–4 years age group. Booster samples for specific age groups and ethnicities may be utilised.

Data are generally collected over a 12-month period every five years (alternating between the adult and child components). The sample size is determined according to the survey objectives, but is generally 5000 people for the adult and 4000 for the child survey. Nutrition surveys also include the potential for a longitudinal (follow-up) dimension passively or actively, as discussed earlier.

New Zealand Tobacco Use Survey

The New Zealand Tobacco Use Survey will collect detailed information about tobacco use and the psychosocial correlates of smoking behaviours, beginning in 2005. Data will be collected over a three-month period, two out of every three years (with the New Zealand Health Survey supplying prevalence data for the 'third' year). Data are aggregated across waves as required to achieve adequate statistical power for population sub-groups. The target population is the total usually resident civilian population aged 15–64 years residing in permanent private dwellings. The sample size is generally around 4000 to 6000 people.

The Tobacco Use Survey includes the potential for a longitudinal dimension, most likely active follow-up after approximately 12–24 months to enable the monitoring of trends in smoking dynamics (ie, initiation, quitting and relapsing rates).

New Zealand Alcohol and Drug Use Survey

The Alcohol and Drug Use Survey collects detailed information about alcohol and illicit drug use among New Zealanders aged 15–64 years. Data are collected over a three-month period, every two years. This was originally two separate surveys, with information collected in 2003 on illicit drug use and in 2004 on alcohol use. In future these two surveys will be combined. The sample size is likely to be around 4000 to 6000 people.

New Zealand Sexual and Reproductive Health Survey

Plans to field the first serial Sexual and Reproductive Health Survey in 2006 are currently in progress. The survey will collect detailed information about the health-related risk and protective behaviours associated with sexual and reproductive health. It is designed to be repeated every 10 years. At the time of publication specific details of this survey were yet to be decided.

New Zealand Mental Health and Wellbeing Study

The New Zealand Mental Health and Wellbeing Study, Te Rau Hinengaro, is designed to estimate the prevalence, severity, impairment and treatment of major mental health disorders. This survey is linked to one that has been fielded in many other countries in collaboration with the World Health Organization. The questionnaire used is a New Zealand adapted version of the WHO Composite International Diagnostic Interview, a fully structured lay-administered psychiatric diagnostic interview.

Te Rau Hinengaro is a CAPI (computer assisted face-to-face interview) administered survey. Its target population is the total usually resident adult population (16 years and older) residing in permanent private dwellings. In 2002/03 a sample of 13,000 people was selected, with two over-proportional samples for Māori and Pacific peoples. Data were collected over a 12-month period. The intention is to repeat Te Rau Hinengaro every 10 years.

Record linkage studies

There are two types of serial cohort studies (record linkage studies) in the NZHM: NZHM survey linkages and New Zealand Census linkages.

NZHM survey linkage studies

Records can be linked not only horizontally (data collected at the same time in different data sources) but also longitudinally (data relating to the same person collected at different times), through both passive and active follow-up. Longitudinal data can provide a dynamic rather than merely static picture of health, allowing causal relationships to be explored. For example, horizontal and longitudinal record linkage may shed light on what causes differential utilisation of health services, adjusted for need across ethnic groups – including both individual (eg, socioeconomic position) and service (eg, access) characteristics.

Integrating survey data collections with administrative data sources such as hospital records, disease registrations and death certificates can provide unique and valuable new information. All NZHM survey participants are informed that the information they supply may be anonymously linked to subsequent health events (hospitalisation, cancer registration, diabetes registration, death) using probabilistic linkage to the National Health Index.

In addition to this passive record linkage, consent is obtained in the NZHS surveys to recontact the respondent, typically by telephone one to two years after the survey. This active cohort follow-up can provide longitudinal data on changes in an individual's health state, risk profile, and service utilisation patterns not available from any other source.

Census linkage studies

The New Zealand Census – Mortality Study (NZCMS) is a study of the relationship between socioeconomic factors and mortality in New Zealand, based on the probabilistic linkage of anonymised census records from Statistics New Zealand with mortality records from the New Zealand Health Information Service. The NZCMS is a joint project of the Wellington School of Medicine and Health Sciences (University of Otago), Public Health Intelligence (Ministry of Health) and Statistics New Zealand. This ongoing record linkage process allows reliable comparison of mortality rates (all-cause and by-cause) for Māori, Pacific and European/Other New Zealanders, which has in the past been problematic due to inaccurate recording of ethnicity on death registrations.

The main purpose of the NZCMS is, however, the ongoing analysis and monitoring of trends in socioeconomic mortality gradients. The study design is ideal for this in view of the rich socioeconomic data collected in the census. The NZCMS also allows analyses of trends in socioeconomic mortality gradients, as each cohort (followed up for three years after each census) is treated in exactly the same way.

Birth linkage studies

Public Health Intelligence is currently developing methods for the anonymised linkage of antenatal care, delivery, birth and postnatal records. This would provide longitudinal information on antenatal exposure and reproductive outcomes. Two examples of this might be 1) the impact of mothers smoking during pregnancy on birth weight and 2) the effect of complications during delivery on child development.

Ethical issues

The NZHM surveys and record linkage studies operate under strict ethical standards and are subject to the approval of research ethics committees, where appropriate. The main principles adhered to by the NZHM are:

- respect for persons
- informed consent
- privacy and confidentiality
- minimisation of harm
- cultural and social responsibility.

Respect for persons

Respect for persons involves recognition of the personal dignity, beliefs (including cultural and religious beliefs), privacy and autonomy of individuals. Individuals have the right to decide whether or not they wish to participate in the NZHM, and they need not give reasons for refusing to participate. Individuals have the right to withdraw from the research at any time.

Field researchers involved in NZHM surveys (both telephone and face-to-face surveys) carry identification with them, including a reference telephone number, so that participants can call to establish the field worker's legitimacy if they wish.

Informed consent

Informed consent consists of three basic components:

- adequate information is provided to enable an informed judgement to be made
- information provided is in a form and manner that will enable it to be understood by each individual
- the consent is voluntary (participation free from manipulation, coercion, inducement or any other undue influence).

Public Health Intelligence requires that the survey provider attempt to match the language, ethnicity and gender of an eligible respondent with corresponding characteristics of the survey interviewer, when requested. Where appropriate, interpreters are available for potential participants whose first language is not English, and translations of the consent forms may be supplied.

The consent of the primary caregiver is obtained when interviewing people under the age of 15 years. If the interviewer has any concerns about the maturity or ability of a 15-year-old to participate in NZHM surveys, then the primary caregiver's informed consent is requested in addition to the 15-year-old's consent.

Additional consent is always obtained for the collection and analysis of blood and any other bodily substance, and samples are not used for purposes other than those for which consent was originally given. (Please see the section on cultural and social responsibility below, for more information on blood samples.)

Privacy and confidentiality

Any information collected in the NZHM surveys that could be used to identify individuals is treated as confidential. Interviewers sign a confidentiality agreement before survey work begins, stating that they are prohibited by law from disclosing any information to anyone except authorised staff, and that they agree to abide by the Assurance of Confidentiality.

The names and addresses of people and households collected in the surveys are not stored with the responses. No information is released that would enable an individual or a household to be identified.

Unit record data are stored in a secure area and are accessible on a restricted 'need to know' basis only. All applications by academics or researchers to access unit record files are assessed according to predefined criteria (see chapter 6 for more information on this). If successful, applicants are required to sign an agreement to ensure no breach of confidentiality occurs in regard to the storage of, access to and use of the data and their outputs. Generally, only confidentialised unit record files are released.

Record linkage, even if based on anonymous probabilistic matching, raises privacy concerns. Public Health Intelligence works through privacy issues with the Privacy Commissioner and with key Māori representatives (such as kaitiaki groups).

Minimisation of harm

Public Health Intelligence attempts to minimise the risk of harm for all participants in the NZHM. The safety of participants is of utmost concern, and so only appropriately qualified staff are employed, and they are given detailed training and adequate supervision.

The results of any testing of blood or urine samples are returned to the participants with an explanatory letter as soon as possible after collection and analysis. When potential health problems are discovered through testing in the NZHM, the participant or caregiver is advised to see a general practitioner and, if necessary, is assisted to do so.

NZHM research involves the smallest number of human participants and the smallest number of tests on these participants needed to ensure scientifically valid estimates. Unavoidable risks, such as inconvenience and discomfort to the participant, are always balanced against the possible benefits to the participants from their involvement.

Minimisation of harm to Māori research participants is enhanced by the inclusion of Māori as partners and advisors in the design, implementation, management and analysis of NZHM research. Representatives of other groups, such as Pacific and Asian peoples, consumers of mental health services, etc, are also routinely invited to work with Public Health Intelligence to minimise the chance of harm to specific participants of the NZHM.

Cultural and social responsibility

New Zealand's cultural diversity results in a range of views on the relative weight of individual and collective values. The NZHM attempts to not only be sensitive to individual research participant's rights and interests, but also respect the social and cultural sensitivity of each particular population group in New Zealand. Where NZHM research may have an impact on a specific community or population group, we consult with those groups likely to be affected and makes every attempt to accommodate their recommendations, where possible.

An example of this is the consultation conducted by Public Health Intelligence with laboratory specialists, Māori and Pacific groups in 2003 on the topic of blood samples. This consultation has led to the following protocols being adopted regarding the collection of biological samples in the health examination component of NZHM surveys.

Biological samples

- Participants remain the owners of any biological sample provided for the NZHM. Researchers and analysts are the guardians of those samples.
- All NZHM staff acknowledge and respect that for many people blood is regarded as precious and sacred/tapu because it carries genealogical information/whakapapa and/or religious significance.
- Voluntary, informed consent is gained in a culturally appropriate manner for the collection, storage, analysis and return or discarding of any biological samples.

- Participants are given the opportunity to offer a prayer or blessing before their biological samples are taken for storage and analysis.
- Biological samples are stored in a safe, clean, secure place that is specifically allocated for this purpose. Samples will not be sent overseas. A blessing/karakia is performed for the place of storage to ensure spiritual safety.
- Participants choose one of three options at the time of collection regarding the use of their samples: 1) the samples are not used for any tests or research other than that specified; 2) left-over samples can be used for other tests or research when the participant is informed about the purposes of the research and specific consent is obtained; or 3) left-over samples can be used for other research purposes and there is no need to inform the participant or obtain further consent.
- Participants choose one of the following options at the time of collection regarding how they wish their samples to be discarded once testing is completed: the sample may be returned to them, buried (returned to the land), or destroyed in the laboratory.

Research and development programme

A critical component for the long-term success of the NZHM is the research and development programme. The key objectives of the programme are to ensure we use best-practice techniques to achieve quality, timeliness and cost efficiencies, while minimising respondent burden.

Current specific research areas are:

- maximising the use of administrative data – to reduce respondent load, provide unique and valuable new information, and improve accuracy
- small-domain estimation for small geographical areas and small ethnic groups
- the methodology for collecting robust estimates for Māori, Pacific and Asian people (efficient and cost-effective while maximising accuracy and precision, and achieving equal explanatory power for Māori)
- initiatives to improve response rates
- evaluation of sample frames and the use of multiple frames
- multi-mode data collection (eg, the use of both telephone and face-to-face data collection).

Public Health Intelligence is keen to collaborate with other organisations and researchers with similar interests, and has already established partnerships with technical experts in some of the above fields.

6 Analysis and Dissemination of NZHM Data

Public Health Intelligence has the responsibility for conducting analyses and organising the dissemination of NZHM data. Sometimes analyses may be done in collaboration with research centres that specialise in a particular field. A range of products is available from Public Health Intelligence that enable access to NZHM data and analyses, including hard-copy and electronic reports, fact sheets, journal articles, data cubes, summary tables, and data sets. (Refer to www.moh.govt.nz/phi for a detailed list of available products.)

Key results of NZHM surveys are published approximately six months after Public Health Intelligence receives the final, clean data set from the contracted collecting agencies. Subsequent releases may include a DHB-level release, if possible.

Confidentialised unit record files (CURFs) are also available once the key results of a survey or study have been released. Access to CURFs is granted subject to the usual safeguards for privacy and confidentiality and any other legal requirements, especially those relating to integrated data sets. Researchers who are granted access to CURFs sign a Data Access Agreement that contains the following key points:

- the data are only used for the named research project
- the data are securely stored, and only available to researchers of the named research project
- there is no transfer of data to a third party
- no attempts are made to data-match or identify the participants
- the data set is destroyed on completion of the named research project.

Public Health Intelligence aims to maximise access to and use of its data both within and beyond the Ministry of Health and DHBs, while ensuring responsible use of NZHM data. We are committed to capacity building to ensure that academic, independent and community-based organisations benefit from the data collected in the NZHM.

Data collected by the NZHM are the property of the Ministry of Health. However, if surveys are carried out jointly with Statistics New Zealand, data sets are also held by Statistics New Zealand, as required under the Statistics Act 1975. Where universities or other contractors collect data, the contract clearly defines data set access and publication rights. Provision for sharing intellectual property rights with Māori is made (a number of the surveys already have special provision for Māori with regard to intellectual property rights).

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Appendix 1: Fieldwork Dates for NZHM Surveys 2002–2012

Time periods are indicative. Surveys will generally take place during the time period indicated. However, they will not necessarily take the whole time period to complete.

NZHM surveys	Previous survey	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
NZ Health Survey (NZHS)	1996/97											
NZ Adult Nutrition Survey (ANS)	1996/97											
NZ Child Nutrition Survey (CNS)												
NZ Tobacco Use Survey (TUS)*												
NZ Alcohol and Drug Use Survey (ADUS)												
NZ Sexual and Reproductive Health Survey (SRHS)												
NZ Mental Health and Wellbeing Study (<i>Te Rau Hinengaro</i>)												

Key:

 The NZ Alcohol and Drug Survey was originally two separate surveys, 2003 (Drug Use) and 2004 (Alcohol). In future they will be combined.

 Every third year smoking prevalence data are collected in the NZ Health Survey.

* Tobacco Use Survey data collection waves are aggregated as required to provide population sub-group estimates.

Appendix 2: Summary Table of NZHM Surveys 2002–2012

NZHM survey	Topic/data areas	Frame (target population)	Sample	Mode	Frequency
New Zealand Health Survey	Chronic diseases, biological and behavioural risk factors, reported health status, health service utilisation, sociodemographics.	All New Zealanders	Approximately 7500 to 12,000	Face to face, computer-assisted (CAPI) questionnaire plus anthropometric measurements in respondent's home.	Every three years (next 2006/07)
New Zealand Adult Nutrition Survey	Food and nutrient intake, factors influencing dietary intake, nutritional status and nutrition-related status.	New Zealand adults (15 years+)	Approximately 5000	24-hour dietary recall and food frequency questionnaire (FFQ), self-administered questionnaire, plus examination, in respondent's home.	Every 10 years (next 2007/08)
New Zealand Child Nutrition Survey	Food and nutrient intake, factors influencing dietary intake, nutritional status and nutrition-related status.	New Zealand children (5–14 years)	Approximately 4000	24-hour dietary recall and FFQ, caregiver-administered questionnaire in home, and examination component at school.	Every 10 years (next 2012)
New Zealand Tobacco Use Survey	Tobacco use and the psychosocial correlates of smoking behaviours. Prevalence and consumption data available from the NZ Health Survey in third year.	New Zealand adults (15–64 years)	Approximately 4000 to 6000	Face-to-face CAPI questionnaire in respondent's home.	Two out of every three years (2005, 2006, 2008, 2009 etc)
New Zealand Alcohol and Drug Use Survey	Alcohol and illicit drug use, and the behaviours associated with alcohol and drug use.	New Zealand adults (15–64 years)	Approximately 6000 to 8000	Computer-assisted telephone interview (CATI).	Approximately every three years (next 2007)
New Zealand Sexual and Reproductive Health Survey	Health-related risk and protective behaviours associated with sexual and reproductive health.	New Zealand adults (16–64 years)	To be decided	To be decided.	Approximately every five years (next 2006)
New Zealand Mental Health and Wellbeing Study (Te Rau Hinengaro)	Prevalence, severity, impairment and treatment of major mental health disorders.	New Zealand adults (16 years+)	Approximately 13,000	Face-to-face CAPI questionnaire in respondent's home.	Approximately every 10 years (next 2012)