Child Health

Information Strategy

MINISTRY OF
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MANATŪ HAUORA

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Executive Summary

The Child Health Information Strategy (CHIS) is an overarching plan to guide the development, collection and use of information about the health of children and young people. Development of the CHIS is one of the six future directions identified in the Child Health Strategy (Ministry of Health 1998a) that are intended to guide the development and delivery of child health services over the next 10 years. The primary goal of the CHIS is to achieve better health for children in New Zealand by making clinically useful, appropriate, up-to-date, and accurate health information available at every contact between a child and a health professional.

Better child health information is central to improving services and outcomes for children in our diversified health sector. Information collected in line with the strategy will enable authorised child health care providers (for example, general practice teams, well child providers and hospital clinicians) to more easily share relevant information about a child with each other and to identify and follow up children who do not access routine health care such as immunisations and well child checks.

To achieve these child health objectives, the CHIS supports the development of an infrastructure, including consistent data-collection standards, appropriate data-sharing protocols, and provider education and development. Information systems developed on the basis of the strategy will build on existing systems, knowledge and current practice (where appropriate) to develop interlinking information systems incrementally by utilising up-to-date information technology.

There are three components of the CHIS:

1. The first part of the CHIS comprises a hierarchy of registers of children. All New Zealanders have a unique National Health Index (NHI) number, and information gathered from different providers can therefore be linked to the same person. These registers may comprise General Practice patient management systems or Primary Health Organisation registers, District Health Board district level registers, or a national register of children and the associated clinical data collected at each level. District and national child health registers need to track movement of children between providers or districts and provide denominator information for monitoring service coverage.
2. The second part of the CHIS is the information technology infrastructure, which securely carries information between local provider systems and regional and national registers. This requires the development of common data dictionaries, rules for privacy, security and access and systems for linkage to disparate databases such as the National Minimum Dataset and the Medical Warning System. The business rules for data management on the network are being finalised by the Ministry of Health WAVE project (Ministry of Health 2001).

3. The third part of the CHIS is the requirement to develop local and regional service initiatives, which ensure that children who are missing out on well child and other services are contacted and offered services in a culturally and clinically appropriate way. The implementation of the CHIS requires local providers to begin to work collaboratively towards common health goals, and an innovative contracting environment to facilitate that collaboration. Primary Health Organisations (PHOs) will be an important vehicle for collaborative service provision.

It is anticipated that the information systems required to implement the CHIS will be incrementally introduced, starting with the National Immunisation Register (NIR), and that each step can improve the availability of up-to-date and accurate information at every contact between a child and health services. It will enable identification, recall and follow-up of children who are missing out on universal and targeted health services. The implementation of information systems in accordance with the strategy will improve targeting by identifying children and communities with increased need. It will also improve monitoring of well child services, and provide population level information for planning (both nationally and locally), and for provider, parent and public education and research.

Introduction

Our children's health status

The health status of New Zealand children is poor in comparison with other OECD countries (Ministry of Health 1998b). There are large disparities, with tamariki Māori, Pacific children, children with high health and disability needs, and children from low-income families experiencing significantly poorer health outcomes. New Zealand has high infant death and youth suicide rates, our immunisation coverage (from what we can tell from limited data) is static or decreasing, levels of hospitalisation for asthma and respiratory problems are unacceptably high, and unintentional injury and poisoning rates are high.

A significant amount of public health funding is directed towards improving the health of New Zealand children. Much of this focuses on health promotion, prevention and early detection, such as home visiting, well child checks, immunisation, Family Start and Strengthening Families initiatives. Despite this, we are unable to confidently identify and provide appropriate services to children with higher need, or effectively evaluate programme outcomes, because of a lack of information about our children's health.

Our health system is complex. Most children and families use a number of health providers, and the current systems for sharing information between providers do not work well and are limited in scope. Well-managed child health information, based around a core of modern information technology, is capable of dramatically improving the communication and co-ordination between providers. It also has the potential to improve public access to information about how to keep well, and could improve the management of certain diseases through making information available to health professionals and the public.

Programmes must also be in place to ensure that the information gained from an information system is put to use through appropriate services for hard-to-reach children and families – those for whom the health system is relatively inaccessible or incomprehensible. In most cases those services already exist, albeit in a somewhat unco-ordinated way throughout New Zealand. These information systems must protect people's privacy and yet ensure that information about the health of populations is available to health service providers, planners, researchers and policy makers.

However, information systems can do nothing on their own to improve child health. Child health providers, policy makers, parents and academics must use better information wisely to ensure that New Zealand children and their families get the right services at the right time to protect, promote and enhance health and development. It will take commitment from all these groups to ensure that the relevant information is collected, shared appropriately and safely analysed, reported and acted on.

Why we need better child health information

A great deal of information about the health of individual children is collected through existing processes and information systems. These vary from simple paper-based patient records, to sophisticated information-gathering systems that can communicate with other providers. However, most existing systems have major shortcomings, including:

- There are no national or district level registers of children that could enable information sharing and monitoring of service coverage.
- There is poor data standardisation and compatibility and the ability to link with other systems is variable.
- The information collected has limited application beyond the individual child and provider.
- Clinical information cannot generally be shared between providers for the patient's benefit.
- Valuable data is not available for prevention, research and education.

Most general practices are now using computerised patient management systems with adequate registration and recall systems. Virtually all primary care providers are computerised for registration, recall and payment, and all transactions are now identified with an NHI. A number of child primary health care providers such as the Plunket Society and some Māori, Pacific and community providers have developed in-house registers with recall systems and sophisticated reporting procedures. Some providers have simple client registers that work off paper-based records and have no way to communicate electronically with other providers. It is important that these existing systems and providers are brought within an overall umbrella strategy. Without a national strategy we risk a proliferation of possibly expensive and ineffective systems, potentially lacking standardisation, co-ordination and funder and provider support. We would be making investments in expensive IT systems for minimal health gain.

Principles, Goals and Objectives of the Child Health Information Strategy

The following set of principles underpins the development and implementation of the CHIS.

- The strategy will support Crown obligations under the Treaty of Waitangi.
- The strategy will enable and encourage local flexibility in an environment of national consistency.
- The strategy will ensure that standards facilitate sharing and comparison of information.
- The child health community – including Māori, Pacific peoples and parents – will be consulted during implementation of child health information systems.
- Legal and ethical requirements for privacy will be fully considered and respected.
- Sustainability will be an important criterion for every CHIS-based initiative.
- There will be effective local and national governance processes in place for all systems.

The primary goal of the CHIS is:

- to achieve better health for children in New Zealand by making clinically useful, appropriate, up-to-date, and accurate health information available at every contact between a child and a health professional.

The key objectives of the CHIS are to:

- support the development of district level and national level child registers which can link together provider registers and Patient Management systems
- support the development of the infrastructure for safe and secure messaging and Web-based information networks for child health data
- ensure that the public, health professionals and health management see child health information systems as safe, user-friendly and useful
- make it easy for health professionals to act on better additional child health information
- ensure that the public have better access to health information, including the information held about themselves and their children
- identify children, families and communities with increased need or who are missing out on universal preventive services
- make sure that non-identifiable information is available for policy and planning and for research.

What is the Child Health Information Strategy?

Overview

The Child Health Information Strategy (CHIS) is an overarching plan to guide the development, collection and use of information about the health of New Zealand children. The fundamental purpose of the strategy is to improve the health of our children by making clinically useful, appropriate, up-to-date, and accurate health information available at every contact between a child and a health professional.

The CHIS describes three key components for successful child health information programmes.

Part one:
Registers and clinical information collection

The first part of the CHIS comprises the development of registers of children and the clinical information collected about a child and caregiver as they contact the health system. These registers may be developed at both local and national levels and will be based on a defined population. This is required in order to ensure that all children are identified and that services have been offered to every child. It also ensures that we have accurate denominator information so that trends in coverage (e.g. immunisation level) can be measured. The child is initially registered at the first contact between a parent and child and a health service provider – such as a midwife or GP/obstetrician, Plunket, an iwi or Pacific well child provider, a hospital or a general practice team.

The initial contact at birth and subsequent contacts generate both clinical and demographic data, such as the fact that an immunisation was given or a vision-screening test done on a certain individual, their family name, address, ethnicity, date of birth, NHI number, and so on. Most of the information gathered in a consultation between the health professional and the parent(s) or child/young person stays with the patient/client and the health professional. This information is almost always recorded electronically on the provider's patient management system or in paper-based clinical notes, and the relevant aspects are hopefully recorded in the Tamariki Ora / Well child book. There are many situations in which some of this information needs to be shared with other providers who will also be working with that child and family.

There are two levels at which child health registers need to work. The first of these levels is the provider-based patient/client register and recall system. Providers must know who their patients/clients are and what health interventions have been provided to them. Most well child events have a well-defined schedule that enables a simple patient management provided with system or similar to identify children who have not been provided with a service and generate a list of these children. There are also important health events that are not part of preventive or screening schedules and the individual provider also records these in the patient or client notes.

The second level of CHIS registers includes regional and/or national databases. For appropriate information sharing to take place, the separate provider-based registers must be linked into registers such as KidsLink to enable information sharing at a district level. A single centralised child health register must also be in place to ensure cross-district information transfer and the capability of national level reports for immunisation coverage.

Future development of child health information systems.

Initially, child health information systems will allow providers better access to records and/or results of immunisation, well child screening and surveillance (such as vision and hearing screening) and early intervention/preventive activities such as vitamin K administration. As the system develops it will be important to include relevant clinical detail about a child's health such as growth and developmental milestones or intercurrent illnesses, which is the information that is currently collected in the Tamariki Ora/Well child book. The ultimate stage of the CHIS development envisages the development of 'disease state management' capability. This adds to the system the ability to interpret clinical observations such as growth data and produce charts or alerts, which could assist with the management of children with chronic conditions such as asthma or diabetes. This would simplify multidisciplinary management of complex health conditions and enable the patient and their team of health professionals to have ready access to up-to-date medical data.

Part two:
Sharing the information

The second part of the CHIS is the development of the electronic network that links child health providers together into local groups or nodes, and to the district level and central child health registers.

The network needs to allow certain information about an individual to be shared (with the permission of the patient/client/parent) in a secure fashion between health providers. Providers will always retain a full set of the information that the parent or child has given to them or which they have discovered through physical examination or laboratory tests. This information stays on the provider's own system as clinical notes. A restricted subset of this information can be shared with other parties. When an event which needs to be shared occurs at the clinical level, it is essential that the information can be shared with other relevant health providers so that the best possible information is available to the health professional caring for the child at all times. In most situations this information sharing needs involve no additional action by the health professional involved. It should be automatic. However a look-up facility for the relevant information needs to be available to providers such as children's wards, ED departments and other locations which may need to provide occasional health care to the child and family.

The other important function of the network is the opportunity to support the measurement of the uptake of services for defined populations, and to link health interventions to desired outcomes.

Child health providers currently undertake a large number of preventive and early intervention activities, which are expected to lead to better outcomes for children and their families. These include immunisation, neonatal metabolic screening, administration of vitamin K, vision and hearing screening, and well child checks. Without accurate information about who has received which service, providers and planners are not only prevented from knowing who has slipped through the net and not received the services they are entitled to, but also have no idea about the effectiveness of the services which are provided.

Part three:
Closing the loop

The third part of the CHIS is about making a difference for those children who are hard to reach or who do not take full advantage of the well child service. This aspect also deals with the follow-up of children who move frequently. Under the current system many of these children are missing out on services that could significantly improve their health and well-being. Local, regional and national information systems must support the tracking and follow-up of children needing well child services. However, just because a child is registered and being tracked through the health system does not mean they will get the services they need. Individual episodes of acute care may be noted, but if no one takes responsibility for ensuring that the parents are made aware of the importance of preventive care and immunisation, and works to mitigate the barriers of poverty and ignorance, there can be no progress in improving the health status of the populations of children who need the most care.

Ensuring children get the services they need means that service agreements with providers need to ensure accountability for service delivery, developing collaborative working arrangements between providers and community groups, fostering innovative solutions for accessing children and families in priority populations, and delivering services in ways that get around the barriers of poverty and ignorance. Child health information systems are an integral part of this process because they can identify these children. Finding them and delivering the services is the difficult part. Sometimes the child may have moved house or may have gone to live with another family member. This is when the collaborative local provider network is required to act. Community providers such as Pacific and Māori networks are often more likely to know where Māori and Pacific children are living and may be able to put an appropriate health worker in contact with the family to facilitate the service or perform it themselves. At this stage the new provider can take the opportunity to bring the child up to date with outstanding well child services and ensure that a suitable new local well child provider and GP is contacted who will take on the ongoing accountability for the child's care.

The development of effective information systems is therefore crucially dependent not only on the ability, but also on the willingness, of providers to share information with each other and work co-operatively towards a common shared goal or achievement of health gain. One of the lessons we have learnt from previous pilots of information systems is that if provider goodwill and a willingness to work together are not present, the programme will not deliver any positive benefits, or may fail to function altogether. Where information programmes such as KidZnet in Hamilton/Rotorua, the Family Health Team in Dunedin and the integrated care programmes in south and west Auckland have been implemented, there is a shared commitment from different providers to work together to achieve these goals for the children and families in their communities.

Achieving a robust child health information infrastructure requires that policy and planning regarding privacy and governance rules and provider development is done well in advance of implementing an information technology solution. These activities need to be done at national (Ministry of Health), regional (District Health Boards), and local (PHO and provider) levels.

How Does the CHIS Link to the Child Health Strategy?

The Child Health Strategy (Ministry of Health 1998a) identified six future directions for improving the health of New Zealand children. These are:

- The Child Health Information Strategy.
- A greater focus on health promotion, prevention and early intervention.
- Better co-ordination.
- Child health workforce development.
- Improve child health evaluation and research.
- Leadership in child health.

The development and implementation of the Child Health Information Strategy has implications for the other five future directions listed in the Child Health Strategy, as shown below.

A greater focus on health promotion, prevention and early intervention

Development of information systems in accordance with CHIS will allow the individuals, communities and/or population most in need of health care to be clearly identified so that services can be more effectively targeted to areas of higher need. Where there are conflicting demands on resources, services can be prioritised more effectively. Good information will inform decisions about the nature and extent of services required to meet need, and the effectiveness of interventions. Although there are limitations to any measurement or evaluation tool, better information systems will maximise opportunities to identify where interventions are needed and the value of various programmes.

At an individual level, children missing out on services can be identified and followed up to ensure they are getting the preventive health care they need. Treatment decisions can be based on a full understanding of the individual child's medical history and the family's behaviour.

Immunisation is a key preventive health activity. New Zealand rates are not as high as we want them to be, and being able to identify both populations and individuals missing out will assist in targeting increased services to some areas and in following up specific individuals.

Better access by professionals, providers and parents to relevant regional and national information about health promotion and preventive programmes could assist individuals and agencies identify what has worked well, what does not work, and how to design better research and evaluation programmes.

Education, communication, peer review and recognition of good practice can initiate and reinforce provider behaviour change. Consultation with relevant groups, including professionals, families and communities, can also lead to change in provider behaviour.

Better information systems could also lead to the improvement of the quality and flow of information to parents and families, helping them to make sound choices about what will benefit their health or that of their children and, ultimately, reduce demand on health services.

Some parents do not see the value of routine preventive programmes such as well child screening and surveillanace. Demonstrating that such programmes reduce avoidable disability will help providers and parents to make better-informed choices about participation.

Better co-ordination

Lack of co-ordination is a significant barrier to improving child health services and disability support services. The existing services have gaps and duplications, and communication between providers could be improved. A number of initiatives have aimed at improving the co-ordination of services at the individual, community and population levels. Integrated care projects are a clear example. Some of these have developed, or are developing, information systems that allow for information sharing between providers. Not only are information systems an integral part of the development of co-ordination initiatives, but they also provide opportunities for other groups of providers to learn about how to work together. The development of PHOs provides a new opportunity for better co-ordination across a number of professions and organisations.

Where the responsible health professional identifies a child missing out on an immunisation, and that child's family does not respond to reminders, a community-based health worker can provide a home visit and support the family to make an informed choice about having their child immunised.

Implementation of improved information systems will allow for the identification of children missing out on health services or moving between providers in order to ensure that providers are identified to follow up and meet their needs. It may also allow funders more accurately to identify communities where co-ordination between providers and between primary and secondary services is not good, and thus encourage service development in these communities.

In parts of New Zealand where efforts have been made to improve communication and co-ordination of services to children between the primary and the secondary services, asthma admission rates have fallen significantly. This could more easily be replicated nationwide if better information was available to providers.

Electronic information sharing provides a valuable tool for encouraging behaviour change, because it makes improved service delivery easier to accomplish. The strategy will also encourage better record-keeping and facilitate learning.

Child health workforce development

Many areas of New Zealand have families who find it hard to access secondary services. An information system accessed by most child health professionals in New Zealand could facilitate sharing of clinical care between primary and secondary health practitioners. When linked with developing initiatives such as telemedicine this could permit better services to be offered to these families and also facilitate the in-service training of rural practitioners through shared care of a child with a secondary or tertiary paediatrician.

A doctor or nurse practitioner in a remote rural practice will readily be able to access up-to-date guidelines for clinical practice. They will also be able to electronically share an up-to-date record of a shared patient's clinical information with other primary care providers and secondary or tertiary specialists for regular review or acute care episodes. Eventually the system will assist the rural practitioner in appropriate disease management.

The information system could also allow for the sharing of ideas and initiatives, and provide access to a range of information related to professional development and best practice. Standards and guidelines can be made easily accessible and available when they are needed for a specific purpose.

Injuries are the most significant cause of hospitalisation and death in children and young people over one year of age. Knowledge of preventive strategies and programmes needs to be widely shared. The establishment of a comprehensive national information system will improve the access of many community-based providers to relevant information.

Improve child health evaluation and research

The Child Health Programme Review (Ministry of Health 1998b) identified the lack of New Zealand service evaluation as a significant problem in establishing which interventions will bring about the best health gain in various areas of child health. Many child health interventions – both preventive and therapeutic – have not been well evaluated either here or overseas. Access to existing evaluations will assist in planning treatment and services. The collection of data on process and outcomes will contribute hugely to our ability to evaluate our programmes.

Most of the current child health screening and preventive programmes have never been formally evaluated or monitored. A child health information system, which integrates well child events and subsequent hospital admissions or mortality, could assist with ongoing evaluation of the effectiveness of these programmes.

In setting priorities for allocating the research funds available, the strategy will be valuable in identifying an appropriate response to areas of child health that are currently causing concern. Being able to identify and access current national data and international research projects and results will help in the planning of further research projects.

The successful functioning of the Child and Youth Mortality Review Committee requires up-to-date information about a child's contacts with the health sector. The CHIS can assist this committee to track the services (or lack of services) easily in situations where a child has died.

Unless funders and providers have information about better alternatives, they tend to go on using the traditional approaches to prevention or treatment.

Leadership in child health

The development of the Child Health Information Strategy demonstrates leadership on the part of the Government and the Ministry of Health. The child health sector has a particularly committed workforce, and initiatives that support and enable them in their various roles help to motivate improved service delivery and behaviour change.

The strategy and the systems it supports provide opportunities for providers and the workforce to demonstrate leadership. Identification of need or of individuals and groups who are not participating in appropriate health services is not in itself going to improve health outcomes. Individuals and organisations must take responsibility for seeking solutions to problems. Such action is often initiated at a national level, but can also happen at a local or individual provider level.

Individual health professionals and organisations have taken the lead in the implementation of provider integration and information-sharing initiatives. These initiatives have formed the nucleus of the KidsLink implementation.

Leadership in child health is about shared responsibility for setting good examples and motivating others to change behaviour. Some individuals and organisations are in a position to exert more influence, and these individuals and organisations carry special responsibilities.

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