

Privacy Impact Assessment

National Child Protection Alert System

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Privacy Impact Assessment

A. Introduction and Overview

Purpose and definitions

- The purpose of this document is to analyse and discuss the privacy implications of the proposed National Child Protection Alert System.
- The intended audience of this document are the National Child Protection Alert System stakeholders, including the Ministry of Health and those District Health Boards which lodge Child Protection Alerts on the National Medical Warning System.
- This report follows the format suggested in the Privacy Commissioner's publication *Practical Guidance on Undertaking Privacy Impact Assessment: a Privacy Impact Assessment Handbook* ("the Handbook").
- Definitions:
 - Medical Warnings System. "The Medical Warnings System is a value-added service closely aligned with the National Health Index. It is designed to warn healthcare providers of the presence of any known risk factors that may be important when making clinical decisions about patient care".¹
 - Child. This refers to any person 0-16 years of age, that is up to but not including the 17th birthday. It also includes the unborn child.
 - Antenatal Alert. This refers to a Child Protection Alert placed on the clinical record of the mother of an unborn child.

¹ Ministry of Health. (2003). *Medical warning system. Data Dictionary, version 6.1*. Available from URL: www.nzhis.govt.nz/moh.nsf

Policy background

- In the New Zealand Health Strategy, family violence is a priority health issue². The Ministry of Health's *Family Violence Intervention Guidelines; Child and Partner Abuse*³ provide a framework for the health sector to respond to family violence. A key component of this strategy is for healthcare providers to screen all adult women for family violence, by direct questioning. For children, however, there is no validated screening tool. In the absence of such a tool, healthcare providers must identify and respond to child abuse and neglect based on signs and symptoms.
- These guidelines cannot be implemented without significant changes in the attitude and behaviour of many health professionals. Front line health providers recognise that a systems approach is required to achieve these changes. This involves the support of senior management, comprehensive policies, standardised documentation, access to senior staff for consultation, effective systems to share information, community agency collaboration, workforce development and quality improvement activities such as audit and evaluation.
- Since 2000, more than one third of New Zealand District Health Boards (DHB) has developed procedures to draw the clinician's attention to children presenting to hospital when previous child protection concerns have been identified. These child protection alert systems have been established using variable criteria and all but two operate internally.
- The Paediatric Society of New Zealand (PSNZ) is an independent society of health professionals throughout New Zealand, who daily deliver health care services to children. The Society includes almost all practising paediatricians in New Zealand, and also includes paediatric surgeons, general practitioners, paediatric dentists, child health nurses, midwives, allied health professionals (such as dieticians, physiotherapists, occupational therapists, speech language therapists, play specialists and pharmacists), child mental health professionals from several disciplines and social workers. The current membership of the Society is 478.
- The Child Protection Special Interest Group (SIG) is a sub-group of PSNZ members with a special interest in the provision of services to children affected by abuse and neglect. Current membership of the SIG is 121.
- In 2005, the PSNZ issued a position statement endorsing the establishment of a national Child Protection Alert System, and outlining the infrastructure required⁴. Since then, the Privacy and Children's Commissioners, the Ministry of Health, the Chief Operating Officers of DHBNZ, the Ministry of Social Development and the NZ Police have all supported the development of such a system.
- The system infrastructure includes involvement of a specialist multidisciplinary team in each DHB, policies and procedures, workforce development for clinicians and quality improvement activities such as a process and outcome evaluation.

² Ministry of Health. (2000). *The New Zealand health care strategy*. Wellington

³ Fanslow, J. (2002). *Family Violence Intervention Guidelines; Child and partner abuse*. Wellington; Ministry of Health.

⁴ Paediatric Society of New Zealand (2008). *Statement: National Child Protection Alert System within Health*. Wellington.

- The only possible location for lodging the Child Protection Alert System (CPAS) is the National Health Index (NHI) national Medical Warning System (MWS), as it is the only database that is accessed by all DHB.
- The national Medical Warning System (MWS) is attached to the New Zealand Health Information Service (NZHIS) NHI. The advantage of the national system is that when DHB access the NHI database, existing flags on the MWS can be downloaded, alerting the health provider in another DHB to the information.

Ministry of Health Privacy Policies

Access to information on the Medical Warning System is governed by the policy set out in the Current Data Access Policy (NZHIS, October 2002).⁵ This provides that details on releasing identifiable data from the NHI and MWS are regulated by the NZHIS Information Release Policy September 2001. The NZHIS Information Release Policy September 2001 sets out a procedure whereby requests are analysed to determine whether they are requests under the Official Information Act 1982 or under the Privacy Act 1993. The policy then provides a step by step process for determining access requests under each Act in accordance with the law. If information is to be released, the recipient is required to sign a Recipient Undertaking, which sets out the terms and conditions of using the data (where appropriate).

Ministry of Health Corporate Structure

From 1 July 2010 the NHI and MWS will be regulated within the National Collections and Reporting Group, which will be part of the Information Delivery and Operations Directorate.

Medical Warning System Privacy Officer

The Privacy Officer for the Ministry of Health is the Chief Legal Adviser. Under the previous structure, there was also a Privacy Officer for the National Collections. A position in the new structure may take over this responsibility.

⁵ Ministry of Health (2002). *Current Data Access Policy. October 2002*. Available from URL: <http://www.nzhis.govt.nz/moh.nsf/pagesns/75>

B. Description of project and information flows

Problems

- Acts of child abuse are frequently not single events. Many children diagnosed with abuse have previous child protection concerns, and this risk often persists for many years.⁶
- Most cases of serious abuse occur in infants and pre-verbal children, who are unable to tell others. Such abuse is under-diagnosed, in part because signs and symptoms are missed due to a lack of diagnostic suspicion.^{7,8,9}
- Both the Police and CYF maintain national electronic databases, but they are not readily accessible to healthcare providers. Most significantly, a health provider is only likely to try and contact the statutory authorities if he or she already had a high level of concern that a child is at risk.
- Only a minority of children who are seriously injured or die from abuse in New Zealand are known to the Department of Child Youth and Family (CYF)^{10,11}. In contrast, it is almost certain that all are known to at least one healthcare provider.
- Many children identified with care and protection concerns are very mobile – because their caregivers are mobile, or because they are passed from one set of caregivers to another. This often includes moving between multiple DHB, so information should be available nationally.
- Investigations of child abuse deaths in New Zealand consistently highlight how important it is for health services to share information about children at risk, and how often this fails to happen.^{12,13}
- Child abuse and neglect is often accompanied by delayed presentation to a health care provider. It is possible that a caregiver who becomes aware that health care providers are sharing information, may further delay bringing a child for necessary medical care, resulting in a worse health outcome for the child.
- Over the last ten years, seven DHB have developed a process to flag in their health information system the existence of child protection concerns, retrieve the information and act upon it appropriately (a “Child Protection Alert”). However, they have multiple systems and variable criteria.¹⁴
- In five DHB the systems are internal only, reducing the ability to communicate with other DHB CPA systems. These seven DHB provide healthcare services to slightly over half of the nation’s children.

⁶ Kelly P, MacCormick J, Strange R. *Non-accidental head injury in New Zealand: The outcome of referral to statutory authorities*. Child Abuse & Neglect 2009; 33: 393–401

⁷ Jenny C, Hymel K, Ritzen A, Reinert S, Hay T. *Analysis of Missed Cases of Abusive Head Trauma*. JAMA. 1999;281(7):621-26

⁸ Kemp A, Coles L. *The Role of Health Professionals in Preventing Non-Accidental Head Injury*. Child Abuse Review. 2003;12:374 - 83

⁹ Sanders T, al e. *Factors affecting clinical referral of young children with a subdural haemorrhage to child protection agencies*. Child Abuse Review. 2003;12:358-73

¹⁰ Doolan, M. (2004). *Child Death by Homicide: An examination of incidence in New Zealand 1991-2000*. Te Awatea Review, 2 (1), 7-10

¹¹ Kelly P, Farrant B. *Shaken baby syndrome in New Zealand*. J Paediatr Child Health 2008; 44: 99–107.

¹² Office of the Commissioner for Children. (2000). *Final Report of the Investigation into the Death of James Whakaruru*. Wellington

¹³ Office of the Commissioner for Children. (2003). *Report of the Investigation into the Deaths of Saliel Jalessa Aplin & Olympia Marisa Aplin*. Wellington

¹⁴ McLaren, Z. (2004). *Implementing a Child Protection Alert System*. Unpublished paper

- DHB and other healthcare providers have inconsistent practices for adding information to and retrieving information from the national MWS.
- The MWS is an antiquated system, with problems that include:
 - Data integrity. In other Alerts on the MWS, there is no uniformity of data entry. The MWS data dictionary requires the use of ICD codes, but this policy is not followed. An enormous variety of phrases are used to describe the same thing - for example, Latex allergy, allergic to rubber gloves, etc. The integrity of data on the MWS is relatively poorly controlled by the MWS itself.
 - Database maintenance. The MWS database was established in the 1960s, and has not been rigorously maintained. For example, the MWS data dictionary was last revised in 2003. It specifies ICD 9 codes, but elsewhere in the NZHIS the ICD 9 system was replaced by the ICD 10 system some years ago.
 - Access and security of information. For the system to be effective, all health professionals who may care for the child need to be able to access this information, easily. It should not be visible to those with no lawful reason for access to the information. Currently, only NHI users with “update access” can view the MWS. At present, only DHBs, the Centre for Adverse Reactions and Monitoring, and some MOH staff have “update access”. Those in the primary sector have “read only” access. While it was intended that primary providers who are authorised and have a “read-only” connection should be able to view medical warnings, there is a technical issue preventing this. This technical issue is under investigation by the Ministry. However, what priority this work will receive is unknown. In the primary care setting access to the NHI is generally via a particular computer.¹⁵ The Access Agreements require the primary care provider to limit access to that computer to staff whose jobs require them to access the NHI (or MWS in the future).
 - Data quality. As a result of the above issues, many DHB question the quality of MWS data, and do not make it readily available to front-line clinicians.
- Any Alert system (whether used for child protection or any other “known risk factors that may be important when making clinical decisions about patient care”), has inherent limitations that are additional to the quality of the system itself. These include:
 - The absence of an Alert does not mean the absence of risk. Risk factors may exist, but have not led to the creation of an Alert, either because they were noted before an Alert system was established, or because they are unknown to a health provider.
 - An Alert is only an adjunct to a health assessment, and draws the attention of a healthcare provider to potentially relevant health information. It is not a diagnostic tool, and does not remove the

¹⁵ Generally speaking, in the primary care setting a stand-alone front end (NOAH) is installed on a specific PC(s) because access is governed by Digital certificates (which are specific to a user or organization) that must reside on the PC or server which is using the NOAH application.

responsibility of the health provider to conduct a thorough assessment based on all available information.

Solutions

A nationally consistent Child Protection Alert System (CPAS). This is achievable, would enhance information sharing between DHB and has widespread support. The outcome of implementing such a system should be enhanced practice and improved child safety. Such a system can be achieved in a series of logical steps

- Extensive consultation on key ethical, legal and procedural issues has occurred and positions have been agreed. In particular:
 - The minimum threshold for placing a CPA is that a notification to Child, Youth and Family has been made, and a multi-disciplinary team has determined that the CPA is warranted.
 - Caregivers will not automatically be told that a CPA was placed.
 - Alerts will remain in place until the child reaches 17 years of age.
- Use of the MWS for this purpose has been trialled successfully by Hawke's Bay DHB since 2003, and by Auckland DHB since 2009. Infrastructure developed and trialled in these two DHB has informed the working group and the development of a national resource kit.
- A working group has problem-solved key issues and developed a resource kit for DHB to support consistent implementation, including:
 - Systems infrastructure guideline and approval checklist.
 - Template policy on the application, use and removal of CPAS. This includes the process for loading alerts on the MWS and health record department response to alert information requests.
 - Template documentation form(s) to record child protection information relevant to the child protection alert.
 - Terms of Reference for Multidisciplinary Team.
 - Flowchart to guide staff response to CPA.
 - Training slides regarding to incorporate into routine training
 - Process to monitor application / implementation of alert system.
- A structure to support evaluation has been established through the Ministry of Health Violence Intervention Programme. Service specifications require DHB to report on their establishment of a CPAS and engagement with the national process, and this is monitored through contract reports and a formal annual external evaluation process.
- A governance structure has been developed between the Chief Operating Officers of DHB NZ and the National Health Board Business Unit of the Ministry of Health. The following process has been agreed:
 - Each DHB wishing to engage in the system will develop an infrastructure for lodging an internal Child Protection Alert, compliant with the requirements of the national CPAS.
 - Each DHB will then sign a Memorandum of Agreement with the National Health Board Business Unit and Paediatric Society of New Zealand, committing to compliance with the principles and policies of the national CPAS, before any CPA are lodged on the MWS.

- Each DHB which has signed the Memorandum of Agreement, will establish a system to lodge Child Protection Alerts on the MWS, in concordance with that Memorandum and the systems checklist.
 - The CPAS, or the lodging of CPA on the MWS, will begin prospectively within each DHB, on a date determined by that DHB.
- DHB internal systems, established as outlined in the resource toolkit, will be responsible for ongoing staff training to ensure that staff understand the use and limitations of the CPAS. In particular, it is not possible to review all historical cases and place alerts. For this reason, and because of the general problem with any Alert system noted above, children will present with care and protection issues, but with no Alert. Conversely, children may present with an Alert, but no current care and protection concerns. Staff will be trained that if a child has an Alert all subsequent presentations should not be presumed to be a result of abuse.
 - A staged rollout will be used for implementation. The implementation will first involve those DHB with an established internal CPAS who wish to align with the national system. The long-term objective is that all DHB will take part, but only when the necessary infrastructure is established.

Patient information flow

1. Lodging a Child Protection Alert on the MWS (Figure 1)

The quality of the health information supporting the Alert is critical for the integrity of the system. Any CPA placed must be supported by enough health information to inform subsequent clinical decision-making by other health professionals.

A DHB health professional identifies a child protection concern

The health professional follows DHB policy and procedures for identification of child protection concerns. It is determined that notification to CYF is required, and this notification is made. Alternatively, the health professional becomes aware that a child is already under the care or investigation of CYF, and forms the view that a CPA may be appropriate in the circumstances of the case.

Standard child protection practice is that DHB staff inform families that a referral to CYF has been made, and the reasons for that referral. Exceptions apply where it is believed that telling the family about notification will imperil the safety of the child, referrer or any other person. Generally, the family are not further informed that a CPA has been placed, unless they specifically ask about it. If a family ask whether a CPA will be placed, they will be told, unless exceptional circumstances exist¹⁶.

The DHB health professional notifies the DHB Child Protection Coordinator

The health professional who notified CYF, or who has been informed of CYF involvement, sends a copy of the CYF referral to the DHB Child Protection Coordinator (CPC) or other designated person, along with all relevant child protection information they hold.

¹⁶ See analysis on pages 16 (second to last bullet point on page), 19 (Rule 3) and 21 (Rule 6).

The case is discussed by the CPA multi-disciplinary team

Receipt of this information by the CPC or other designated person automatically generates a discussion of the case within the standardised CPA MDT. The referring health professional is invited to participate in this review.

If insufficient information is available to decide if an alert is warranted, the request may be returned to the clinician/CPC for further information.

In the event that the CPA MDT determine an alert is not warranted the rationale will be detailed on the summary sheet.

The criteria for CPA placement are met

The MDT decides whether the criteria for CPA placement are met. These are:

- A child is 0 – 16 years. This includes unborn children, where the alert is placed on the mother's file until birth. (After birth, the case will be reviewed by the CPA multidisciplinary team (MDT). Standard practice will be to remove the Alert from the mother's file at the time of this review, unless the MDT decides there is a strong likelihood that the risk will apply to future pregnancies. If there is a strong likelihood that the risk will persist into any future pregnancy, an Alert will remain on the mother's NHI. This decision will be reviewed at each subsequent pregnancy).

AND

- The child (or, in the case of an unborn child, the mother) has been notified to CYF.

AND

- The potential future risk to the child's health is sufficient that an alert is warranted.

All relevant documentation is completed

If an alert is warranted, all relevant documentation is completed by the CPC or other designated person, including the request for an Alert document and the Alert summary report (the information behind the Alert).

The documentation is forwarded to the DHB Clinical Records Department

The CPC or other designated person forwards the appropriate forms to the Clinical Records Department so that the alert can be placed on the child's health record – or, in the case of a pregnant woman where high risk has been identified, on the woman's health record.

DHB Clinical Records staff set up electronic CPA on internal systems.

Designated Clinical Records staff lodge an Alert following standardised procedure. The wording is exactly the same, whether the CPA is placed on the file of the child or, in the case of an unborn child, on the file of the mother.

Designated Clinical Records staff files copies of the Alert and Alert Summary Report (the information behind the Alert) on the electronic and or paper files in accordance with the DHB alert policy.

DHB Clinical Records staff lodge the CPA on the MWS

Designated Clinical Records staff enters the CPA onto the MWS. The alert entry on the system reads as follows: "Child Protection Concerns: contact XDHB".

Review of Antenatal Alerts

The DHB CPA MDT reviews Antenatal Alerts after the baby is born, and decides whether the alert should be transferred to the newborn baby's file. This review will occur as soon as possible after delivery and before six weeks postpartum.

The referring health professional is invited to participate in this review.

Process for lodging Child Protection Alert on the Medical Warning System

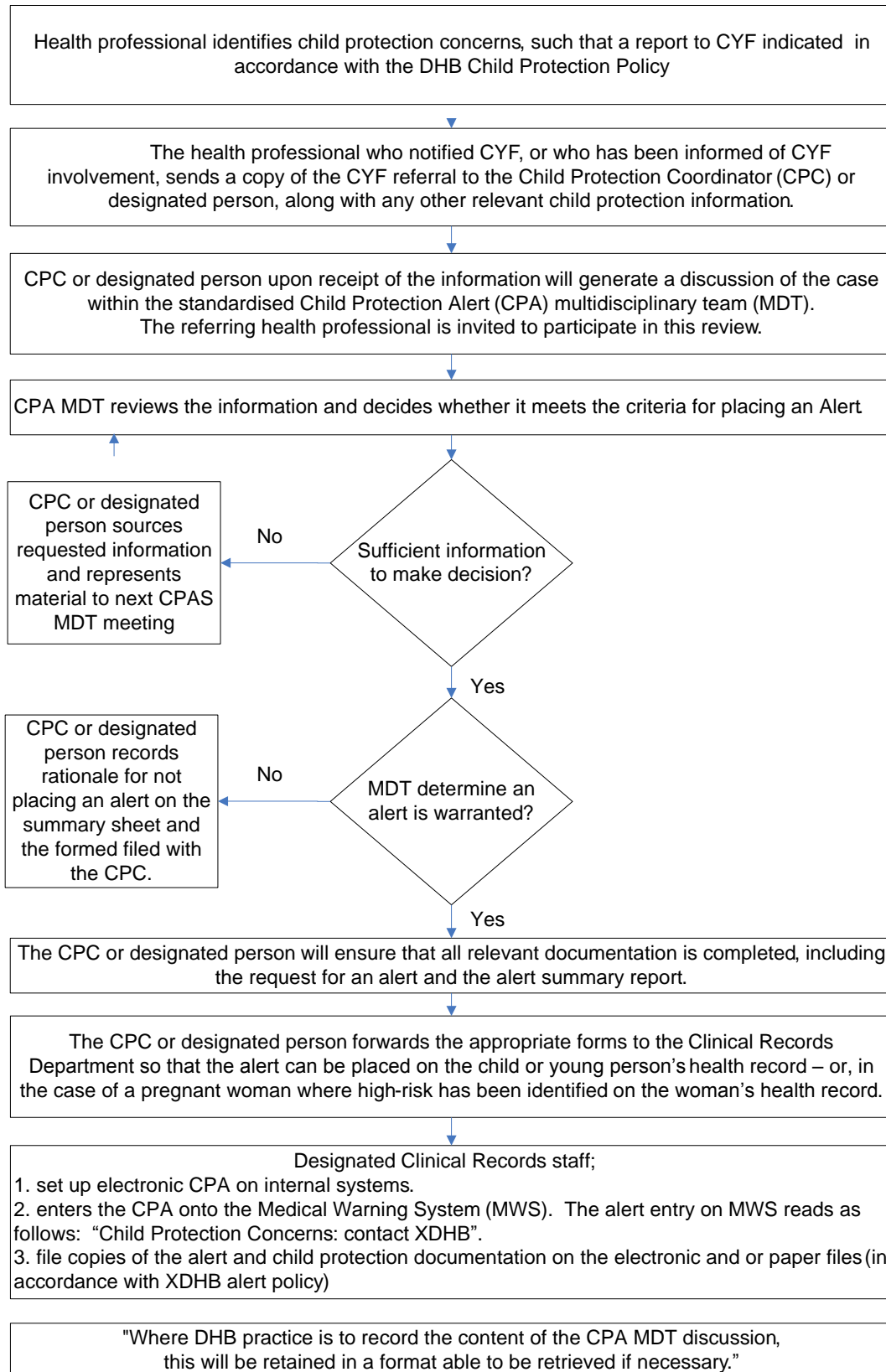


Figure 1: Process for lodging a child protection alert on the Medical Warning System

2. Management of Information Flow within the MWS

Maintenance of information

The responsibility for maintaining the content of the MWS rests primarily with its users, the healthcare providers. Providers with “update access” may amend the information on the MWS as necessary. The MOH is the custodian of the information on the MWS. The MOH does not amend the information on the MWS unless requested to do so by a provider that cannot amend the MWS itself. (Some providers with “update access” can add information to the MWS, but have difficulty editing information that is already on the MWS).

Security of information

Messaging from the source to the MWS is encrypted and travels over a secure private network. The MWS is protected by standard IT security protocols.

Access to information

Currently, only NHI users with “update access” can view the MWS. At present, only DHBs, the Centre for Adverse Reactions and Monitoring, and some MOH staff have “update access”. Those in the primary sector have “read only” access. While it was intended that primary providers who are authorised and have a “read-only” connection should be able to view medical warnings, there is a known technical issue preventing this. This technical issue is under investigation by the Ministry. However, what priority this work will receive is unknown. In the primary care setting access to the NHI is generally via a particular computer.¹⁷ The primary care provider is required limit access to that computer to staff whose jobs require them to access the NHI (or MWS in the future).

Retention and destruction of information

The clinicians who use the MWS have the responsibility for ensuring that the information relating to their patients is correct and up-to-date. Providers with “update access” can generally remove information from the MWS. The MOH does not remove information from the MWS unless requested to do so by a provider that cannot remove the information itself.

3. Clinician response to a Child Protection Alert (Figure 2)

The quality of the response by a health professional to the information supporting the Alert is just as critical for the integrity of the system, as the information itself. Any health professional accessing a Child Protection Alert must be supported by adequate training, policies and procedures and backed up by access to other professionals with expertise in child protection.

¹⁷ Generally speaking, in the primary care setting a stand-alone front end (NOAH) is installed on a specific PC(s) because access is governed by Digital certificates (which are specific to a user or organization) that must reside on the PC or server which is using the NOAH application.

DHB health professional receives training about CPA

The DHB provides child protection training which includes the existence of the CPAS, where to look for it, how to access the information behind the Alert, and how to respond to a CPA.

DHB health professional notices a CPA exists for a child in their care

The health professional checks for any Alerts as part of the routine health assessment for any child presenting for care, and notices that a CPA exists.

DHB health professional obtains the information behind the CPA

The health professional identifies the source of the alert from the alert information, "Child protection concerns; contact XDHB". If the alert was lodged by their DHB the health professional accesses information via the DHB paper or electronic files, according to appropriate processes stipulated by their DHB.

If the alert was lodged by another DHB, the health professional requests via Clinical Records the alert information from that DHB in accordance with their health record information policy.

If there is insufficient information available e.g. no Alert Summary Report available then the health professional contacts the clinician who lodged the CPA.

DHB health professional incorporates the information in their assessment

Upon receipt of the CPA information, the health professional assesses the relevance of the information in context of the child's presenting concerns and current living situation.

DHB health professional consults prior to discharge

The health professional discusses the case with a senior clinician prior to discharge.

DHB health professional documents assessment in the Clinical Record

The health professional documents their assessment and intervention (including details of consultation) within the health record in accordance with child protection policy.

Child Protection Alert: Flowchart of health professional response

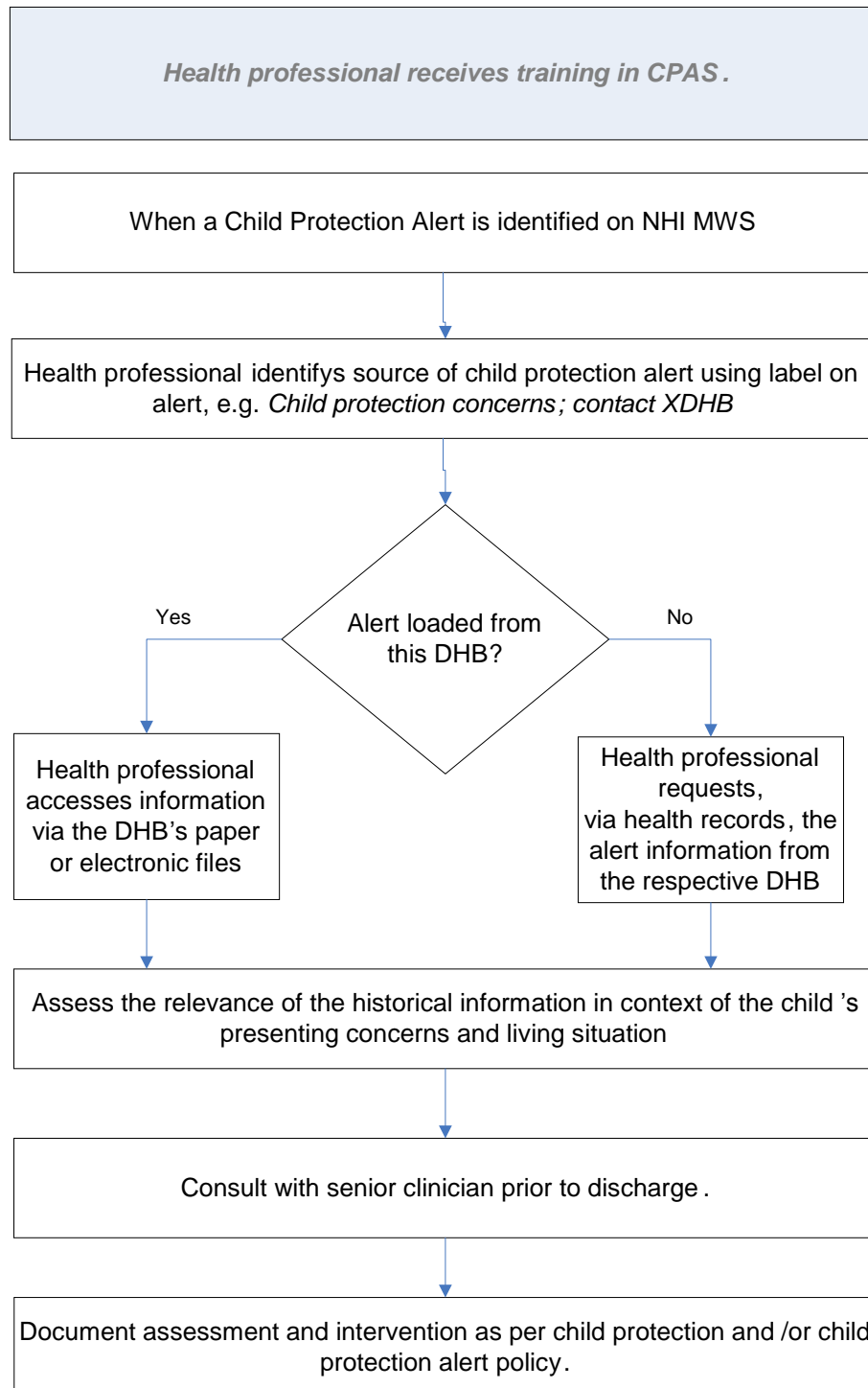


Figure 2: Responding to a child protection alert; Flowchart of clinician response

C. The Privacy Analysis

Introduction

Issues of privacy have been considered from both an organisational perspective and the patient/guardian perspective.

Organisational (District Health Boards)

- An Alert points to information that has already been collected by a health provider as part of the provision of health care services.
- Pre-emptive transfer of information to an information store outside the DHB, even if the information is only “Child protection concerns: contact Hawkes Bay DHB”, might be regarded as problematic. However, in this case, the MWS is owned by the Sector Services within the Ministry of Health. The NZHIS collects and holds information on the MWS to facilitate the provision of significant clinical information to other health care providers. Identifiable information on the MWS, or to which the MWS points, is not disclosed to a health care provider, until the provider asks for it.
- Health providers within the context of providing patient care can access patient information under Section 22F of the Health Act 1956.
- DHB internal patient information systems routinely require both pro-active security measures, and “role-based” access.

Organisational (Medical Warning System, Ministry of Health)

- NHI access agreements set out the responsibilities of the accessing agency with regard to protecting the privacy of the information on the NHI/MWS.
- Any alert system which places information on a child on a national system runs a potential risk that people may access the information who have no right to do so. Each source DHB has no control over monitoring, compliance and discipline in other agencies, particularly if private providers seek access to the alert system. However this is a general issue for the entire NHI system, and for all types of alert placed on the MWS, not merely CPA.

Child / parent / guardian (District Health Boards)

- As the representative of the child, parents/guardians have the right to know what information is collected on their child and how it is used, until the child turns 16.
- All DHB have Policies governing access to patient information. If parents or guardians of any child in the care of a DHB, approach that DHB requesting access to the child’s clinical records, those policies apply. There is a presumption in favour of disclosure to the child’s representative.
- However, the right of the parent/ guardian is not absolute, and the lawful exceptions are recognised in DHB policy. Exceptions include:
 - Information may be disclosed to other health care providers who access information (S22F of the Health Act 1956) without consent, or in accordance with the purpose for which information was collected.

- If disclosure to the parents of their child's health information is not in the best interests of the child, the DHB is not obliged to disclose it (S29 Privacy Act 1993).
 - Other withholding grounds, such as the unwarranted disclosure of the affairs of a third party.
- General points relevant to this issue are as follows:
 - Child protection procedures exist in all DHB. Standard practice is to inform the family where a case has been referred to the statutory authorities, unless this would imperil the safety of child or referrer.
 - Therefore, although a family may be unaware that an Alert has been placed, almost always they will be well aware that the DHB has serious care and protection concerns, and they will be aware of the detailed content of those concerns.
 - If the parent or guardian of a child notified to CYF by a DHB, approach that DHB for access to the child's clinical record, in most cases the DHB will (after consultation with the lead clinician) release copies of the record to the parent or guardian. This is, in effect releasing to them information they have already been told, and is consistent with the transparent approach to child protection practice noted above.
 - Withholding grounds may still apply to aspects of the clinical record – for example, genital diagrams or clinical photographs (which it would not be in the interest of the child to release to parties who may misuse them); or information in the record which would entail unwarranted disclosure of the affairs of a third party (such as a friend or relative who has made disclosures in confidence to clinical staff)
- A specific issue concerns whether parents/guardians are informed that a CPA exists.
 - Delayed presentation is a common feature of child abuse and neglect, and may be associated with worse outcomes (this is particularly well documented in the case of abusive head injury)
 - Presentation to multiple healthcare providers may also be a feature of child abuse. Caregivers may assume that clinicians in any given healthcare facility have ready access to past clinical records (an assumption which may in fact be incorrect), and will therefore present somewhere else, assuming that clinicians "somewhere else" will not have access to the records of previous healthcare providers.
 - There is a risk that knowledge that a CPA exists may discourage a caregiver from seeking medical care for the child in the future.
 - Of children notified to CYF by a DHB for care and protection concerns, it is impossible to predict those to whom this risk applies.
 - Routine notification that a CPAS exists, therefore risks undermining the purpose of the system. Consequently, it is reasonable to assume that the clinician considering whether or not to inform parents/guardians of the CPA will generally come to the conclusion that it would not be in the best interests of the child.
 - However, if a parent or guardian approaches the DHB with a specific query as to whether a CPA exists, it is reasonable to assume that the parent already has a degree of knowledge about health information systems which is likely to influence their behaviour with regard to future care of the child. In this situation (which is extremely rare in the experience of the authors), it would seem pointless to deny the existence of the Alert.

- Establishment of a CPAS and placement of an alert without parental consent have not been tested in court. Consultation in relation to this has been undertaken. The advice offered was to ensure a robust process to maximise the potential for good and minimise the potential for harm.
- As noted above, child abuse is often missed. There is ample evidence to show that this is often related to the failure of professionals and agencies to share relevant information about a child. While there is no evidence in the scientific literature to prove that a CPAS of the type described here will make a difference, there is also no evidence, from experience over the last decade in New Zealand, that CPAS cause harm.
- As with all alert systems, this is merely a common-sense quality assurance procedure, designed to ensure that health care providers have access to relevant health information about a child in their care.
- An alert system, as a part of a comprehensive child protection programme, should improve identification of child abuse, and reduce risk to children. This will be investigated as part of evaluation of the CPAS.

Child / parent / guardian (MWS, Ministry of Health)

The MOH may receive a request from a parent or guardian as the child's representative for information held about that child, including information on the MWS. The MOH should consult with the relevant DHB about whether or not it was in the child's best interests to release the information. However, given that the MOH would be required to disclose that it held personal information on the child and that it was withholding access to some of that information because it was not in the best interests of the child to release the information, withholding access to the knowledge that a CPA exists may be pointless, as the parent could deduce that an Alert was being withheld. Even if the MOH considered that it could withhold the information under s 27(1)(d) "the disclosure of the information would be likely to endanger the safety of any individual" and section 32 therefore applied "... agency ...may...give notice in writing to the applicant that it neither confirms nor denies the existence or non-existence of the information", the notice itself would be confirmation. In this situation, the same reasoning used in answering a question specifically asked of a DHB about the existence of a CPA, would seem to apply. Consequently, it is likely that the information would be supplied.

D. Privacy Risk Assessment

The following considers the national CPAS in relation to the 12 Health Information Privacy Code (HIPC) rules. Many of these issues are generic to the placement of any Alerts on the MWS.

Information Collected or Obtained

The goal of the National CPAS is to improve information sharing between health providers. The outcome of this system should be enhanced patient care and improved child safety.

Rule 1

Personal information should not be collected unless it is necessary for a lawful purpose connected with a function or activity of the agency.

Under the CPAS, health information is being collected by:

- The DHB that creates the report that the CPA points to
- the MOH (the CPA on the MWS which states “Child protection concerns: contact XDHB”)
- the DHBs that obtain the report from the DHB that placed the CPA.

The collection of this health information by these health agencies is necessary for the purpose of enabling clinicians to take indications of child abuse into account when making clinical decisions about a child. This is a lawful purpose connected with a function or activity of these health agencies. The functions or activities are the provision of healthcare (the DHBs) and the provision of associated national information systems (the MOH).

As the Child Protection Alert flag will be held on the MWS, it is advisable to consider whether the description of the use of the information held on the MWS needs to be amended. The overall purpose of the MWS is stated on the MOH website to be “to warn healthcare providers of the presence of any known risk factors that may be important when making clinical decisions about patient care.”

The PIA notes that two categories of information are collected:

1. An Alert flag for a child, indicating that:
 - 1.1 A child health professional within a DHB has reached a level of concern about child abuse sufficient to justify referral to CYF
 - 1.2 This level of concern, and the decision to place a flag on a national level, has been approved by a multi-disciplinary team
2. An Alert flag for a pregnant woman, indicating that:
 - 2.1 A maternal health professional within a DHB has reached a level of concern about the risk of harm to the unborn child, sufficient to justify referral to CYF
 - 2.2 This level of concern, and the decision to place a flag on a national level, has been approved by a multi-disciplinary team

Both categories are in line with the overall purpose for which the MOH states that it collects the information that is stored on the MWS.

Recommendation

The Child Protection Alert System complies with HIPC Rule 1. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Rule 2

Information should be collected directly from the person concerned.

Standard healthcare practice with pregnant women and with children is to collect information from the person concerned and/or their guardian or representative. Consequently, information about the pregnant woman/child in the report informing the Child Protection Alert will have been collected directly from the person concerned.

Where a clinician becomes aware of a Child Protection Alert on the MWS, it will generally not be reasonably practical for the clinician to obtain the relevant information directly from the child or his or her guardian or representative. Consequently, Rule 2(2)(d) permits it to be obtained from the DHB that holds the report.

It is also not reasonably practical for the MOH to collect the information on the MWS directly from the child or his or her guardian or representative. Consequently, Rule 2(2)(d) permits it to be obtained from the DHB that holds the report.

Recommendation

The Child Protection Alert System complies with HIPC Rule 2. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Rule 3

An agency collecting personal information should ensure that the individual concerned is aware of purpose of the collection, of their rights in respect of that information, and of the agencies that will hold or have access to the information.

Where the individual concerned is a young child, the parent or guardian will generally exercise, on the child's behalf, the child's right to be informed of the purpose of collection, etc, unless certain exceptions apply. These include where the agency believes that it would prejudice the interests of the child or prejudice the purposes of the collection (Rule 3(4)(b)(i)).

Child protection procedures exist in all DHB. Standard practice is to be open and honest with families about the purpose of any questions asked, including child protection concerns. This includes any decision to notify the statutory authorities. Such transparency is generally in the best interests of the child, as there is often an element of secrecy to child abuse and neglect. This is often the case even within the same household, where the perpetrator is aware of their behaviour towards the child, but other adults are not. Informing family of the child protection concerns, may assist them to secure the child's health and wellbeing. However, the same argument does not apply to informing the family of the child protection alert, where the exceptions to Rule 3 that are set out above will frequently be engaged.

Internal child protection alert systems are operative in seven DHB, providing healthcare services for more than half the children of New Zealand. In some cases, these have been operative for a decade or more. While the families of children in these DHB are almost always aware that the DHB has serious care and protection concerns, and are aware of the detailed content of these

concerns, they have never been routinely informed that a CPA exists. The reason for not routinely informing parents that an Alert has been placed, is the risk that they may not bring their child back for necessary healthcare, as detailed in the Privacy Analysis. This risk cannot be reliably predicted on the basis of any known features of the history or clinical presentation.

Consequently, while the clinician must consider whether or not to inform the parents or guardian of the placement of a CPA in each case, it is highly likely that in most cases the clinician will decide that it is not in the best interests of the child to do so.

Recommendation

The Child Protection Alert System complies with HIPC Rule 3. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Rule 4

Health agencies should not collect health information by means that are, unlawful unfair, or that intrude to an unreasonable extent in the personal affairs of the individual concerned.

The collection of health information by a health agency by means of the CPA system is not unlawful, or unfair and does not intrude to an unreasonable extent in the personal affairs of the individual concerned.

The collection of health information from previous health providers is normal procedure. Under S22F of the Health Act 1956, a request for health information about an individual from a person providing health services to the individual is treated like an access request by the individual themselves (although the request may be refused where the information holder considers the individual does not or would not wish the information disclosed).

Recommendation

The Child Protection Alert System complies with HIPC Rule 4. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Security of personal information

Rule 5

Agencies are required to protect personal information with reasonable security safeguards.

As has been noted above, there are concerns about the outdated structure of the MWS, and the absence of audit procedures. These concerns are generic to all Alerts currently placed on the MWS. Access to the MWS is governed by access agreements between the user agency and the MOH that require the participating agency to ensure that only authorised employees, contractors and agents of the user who have a legitimate need to access Health Information are permitted access to the NHI and MWS.

At the level of access by DHB clinicians, all health professionals are bound by ethical and professional obligations to respect the privacy of personal information, and are subject to disciplinary action for any breach.

At the DHB level, there is a robust process, involving health professional concern, notification to CYF and multi-disciplinary team review, before an Alert is placed.

The National CPAS places minimal information on the MWS: "Child Protection Concerns: contact X DHB". The National CPAS does not establish a separate database or "Child Protection Register".

Any DHB health professional wanting to obtain the information behind the Alert, must either have role-based access to clinical information within their own DHB, or must follow standard processes to access clinical records from another DHB.

- DHB role-based access is tracked and reviewed by standard DHB Information Technology processes. Audits are carried out on a regular and random basis in accordance with agreed audit protocols. Any anomalies in the records are investigated. DHB have standard processes, including disciplinary processes, where an employee has inappropriately accessed information.
- Standard processes to access clinical records are likewise subject to audit and tracking, and are subject to review by the DHB Privacy Officer.

Recommendation

The Child Protection Alert System complies with HIPC Rule 5. However, it is recommended that the MOH give consideration to developing audit procedures for the MWS.

Access to and correction of personal information

Rule 6

Individuals are entitled to have access to their personal information.

In each DHB, child protection information is stored under the child's NHI number in the Clinical Record system. All the child's clinical records, including any child protection information, can be accessed by the child or their representative according to standard DHB procedures. As already noted, in most cases, the family will be well aware of the fact that child protection concerns existed, and a notification to CYF occurred, but will not be aware that an Alert has been placed.

If a Child Protection Alert exists on a child's notes, Clinical Records procedure will include consultation with the lead clinician as to whether full disclosure will be made. In some circumstances, withholding grounds may apply. For example, the health professional believes that access is not in the best interests of the child (Section 29(1)(d), Privacy Act 1993), or would imperil the safety of the child or any other person (Section 27(1)(d), Privacy Act 1993).

If for some reason full disclosure of the detail of the care and protection concerns is not made, the child or their representative will be made aware of that fact, according to standard procedures for Release of Information.

Recommendation

The Child Protection Alert System complies with HIPC Rule 6. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Rule 7

Individuals are entitled to request correction of their personal information

Subject to any limitations on disclosure described under Rule 6, individuals will have the right to request correction of the information, or to have a statement of a correction sought but not made attached to the clinical record.

Such requests must be responded to within statutory timeframes (as soon as possible, but within a maximum of twenty working days) and will follow standard procedures for DHB Clinical Records departments.

Under rule 7, only the individual has the right to request correction of information about themselves.

If a child is aware that a Child Protection Alert exists, and requests its removal, or the amendment / removal of the information it was based on, this request will be forwarded to the multi-disciplinary team for review in line with the statutory timeframe. If it is agreed that the Alert can be removed, it will be removed both from the DHB Clinical Record and the MWS, following standard procedure. The health information behind the Alert will remain on the Clinical record, unless it has been amended or deleted with the agreement of the multi-disciplinary team.

When the multi-disciplinary team does not agree that the Alert should be amended or deleted, it is obliged to take reasonable steps to attach any statement provided by the child to his or her record in such a way that it will always be read with the disputed information.

This statement will become part of the child protection information which supports the Alert, and will be provided to enquiring clinicians along with the concerns of the multi-disciplinary team.

Recommendation

The Child Protection Alert System complies with HIPC Rule 7. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Accuracy etc of personal information

Rule 8

An agency must take reasonable steps before using health information to ensure that it is complete, accurate up-to-date and not misleading.

The steps involved in the CPAS process (health clinician concern, formal notification to CYF and review by a multi-disciplinary team) are reasonable steps to ensure that the information being used is accurate.

A robust infrastructure has been developed to support the CPAS process. This includes a governance process to ensure that the system will only be established in DHB that have this infrastructure. This infrastructure includes a systems checklist to ensure that the DHB:

1. Has signed a Memorandum of Agreement regarding appropriate implementation of CPAS with the National Health Board Business Unit.
2. Has endorsed a policy on the application, use and removal of CPA. This includes a process for loading Alerts on the MWS and Clinical Records department response to alert information requests.
3. Has established a CPA Multidisciplinary Team, with Terms of Reference.
4. Has information technology systems which make MWS alerts highly visible for clinicians on patient information screens.
5. Has standardised documentation for recording child protection information relevant to the child protection alert.

6. Has a procedure for managing health record requests that includes 24/7 access and standard response time (response to requests within four hours).
7. Has flowchart resources for staff to use when Alert identified (optional).
8. Has routine Violence Intervention Programme and child protection training, in which training regarding Alert management has been included.
9. Has a process to monitor implementation of the CPAS.

A toolkit has been drafted in consultation with a multidisciplinary working group. The purpose of the toolkit is to support DHB to establish the required infrastructure to enable consistent implementation of CPAS within DHB.

It is important to ensure that those able to access the MWS understand the meaning of a CPA.

Recommendation

The Child Protection Alert System complies with HIPC Rule 8. However, it is recommended that any sector participants, other than DHBs, who can view the MWS are informed of the system and what a CPA means.

Retention of personal information

Rule 9

An agency should keep personal information only for as long as necessary.

The Child Protection Alert will be routinely removed at age 17, both from the DHB internal system and from the MWS. This is the age when the Children Young Persons and Their Families Act 1989 (in almost all cases) no longer applies. The Alert may be removed earlier, as noted under Rule 7.

Where an alert has been placed on the record of a pregnant woman, the case will be reviewed by the CPA multidisciplinary team after the birth. Standard practice will be to remove the Alert from the mother's file at the time of this review, unless the CPA multidisciplinary team decides there is a strong likelihood that the risk will apply to future pregnancies. If there is a strong likelihood that the risk will persist into any future pregnancy, an Alert will remain on the mother's MWS. This decision will be reviewed at each subsequent pregnancy.

The health information on the Clinical Record will be retained according to standard DHB policy and any General Disposal Authorities issued under the Archives Act for child health records.¹⁸

Recommendation

The Child Protection Alert System complies with HIPC Rule 9. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Use of health information

Rule 10

An agency that holds health information should use it only for the purpose for which that information was obtained. (subject to exceptions)

¹⁸ DHB General Disposal Authority Implementation Guide. Available from URL:
<http://continuum.archives.govt.nz/files/file/Publications/DHB%20Implementation%20guide.pdf>

The health information behind the Child Protection Alert flag has been collected for the purpose of providing health care for pregnant women, children and young people in accordance with Rule 1 and Rule 3, as discussed above. This purpose includes taking indications of child abuse into account when making clinical decisions about a child.

Recommendation

The Child Protection Alert System complies with HIPC Rule 10. . No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Disclosure

Rule 11

Agencies should not disclose personal information unless the disclosure is one of the purposes for which the information was obtained, the individual concerned authorises the disclosure, or one of the exceptions to the rule applies.

Promoting the health of children by ensuring their safety is one of the purposes for which a health provider collects information about child protection concerns, as noted above (Rules 1 and 3). Communicating these concerns to other healthcare providers is one of the purposes for which the information is obtained.

Disclosure to another health provider, on request, is permitted under S22C and S22F of the Health Act 1956.

Recommendation

The Child Protection Alert System complies with HIPC Rule 11. No changes to the Child Protection Alert System with regard to improved compliance are recommended.

Unique Identifiers

Rule 12

A health agency must not assign a unique identifier to an individual unless the assignment of that identifier is necessary to enable the health agency to carry out any one or more of its functions efficiently. Authorised health agencies may assign an NHI to an individual

DHB are authorised to assign an NHI to an individual. The use of this unique identifier, in conjunction with the CPAS, enables necessary health information regarding child protection concerns to be transferred to other DHB around the country when and if the child presents for health care services. The use of the unique identifier, in conjunction with the other security practices described above, helps protect personal information being transferred from one DHB to another.

Recommendation

The Child Protection Alert System complies with HIPC Rule 12. . No changes to the Child Protection Alert System with regard to improved compliance are recommended.

E Compliance mechanisms

Governance of the National Child Protection Alert System

Consultation with Senior DHB Managers in Information Technology and the Information Strategy and Architecture Directorate, Ministry of Health has confirmed that the MWS is the only practical national option available for sharing Alerts between health providers.

However, the MWS is (technologically) an antiquated system. Because the integrity of data is relatively poorly controlled by the MWS itself, it is vital that all DHB are bound to a standardised system for the implementation and management of CPA. The resource kit that has been developed provides just such a system for DHB to use. Anything less will impact on the utility of the CPAS for protecting children from adverse health events.

The best national forum to secure a national agreement with DHB is DHBNZ. It has been agreed with the Chief Operating Officers of DHBNZ, the National Health Board Business Unit and the Paediatric Society of New Zealand (PSNZ) that a Memorandum of Agreement will be established between each DHB and the Ministry of Health National Health Board Business Unit and the PSNZ. No DHB will enter CPA on the MWS, unless they are compliant with the agreed standards.

Progressive implementation of the national CPAS in DHB

The proposed national CPAS will only reach its full potential when all DHB participate. However, the quality of the system is the first priority.

At present, only two DHB are placing CPA on the MWS in a manner compliant with the standards developed. All DHB can already access those alerts.

Other DHB, once they comply with the quality standards, and “opt in” to the National CPAS, will begin to lodge CPA on the MWS. It is hoped that at least six further DHB will opt in to the system within the next 12 months. It may well take several years before all DHB are participating fully in the system. Such a staged implementation will enable careful and collaborative evaluation of the system, and identification and appropriate resolution of any privacy issues that may arise.

G Conclusion

A nationally consistent Child Protection Alert System is achievable and would enhance information sharing between DHB. The system has national and local level support and its implementation would be consistent with national recommendations regarding effective child protection intervention. The proposed plan balances competing ethical principles and is compliant with the Health Information Privacy Code rules. The outcome of implementing such a system should be enhanced practice and improved child safety.