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Nicole D'Rozario
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Dear Ms D'Rozario

**Investigation into the death of Baby D
Court Reference COR 2012 001474**

I refer to the findings and recommendation made by His Honour Judge Gray in relation to the death of Baby D.

The Department of Health and Human Services and the Department of Education and Training are considering His Honour's recommendation and provide the information included in the attached response.

Yours sincerely

Kym Peake
Secretary

4/7/2016

FINDINGS AND RECOMMENDATION IN RELATION TO THE DEATH OF BABY D

No. COR 2012/1474

SUBMISSIONS IN RESPONSE

ON BEHALF OF THE DEPARTMENT OF EDUCATION AND TRAINING

AND THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

On 5 April 2016, His Honour Judge Gray published his findings and recommendation in the inquest into the death of Baby D.

His Honour made the following recommendation:

"I recommend that relevant government departments (including the Department of Education and Training and the Department of Health and Human Services), in collaboration with the Municipal Association of Victoria and other stakeholders involved in delivering Maternal and Child Health services, examine the feasibility of the creation of a shared database, being in effect a single health record, of the monitoring and treatment of infants and children passing through the Maternal and Child Health system in Victoria. The purpose of the database would be to enable those monitoring and treating the infant/child to inform themselves, in real time, of progress and/or changes in the health or development of that infant/child by accessing the full medical record to that point in time."

In response to this recommendation, the Department of Education and Training and the Department of Health and Human Services are exploring policy and legislative enhancements to create opportunities for service providers to more accurately and reliably access, reference and share information about the welfare of a child consistent with the intent of the recommendation.

This work will build upon a number of existing Commonwealth and Victorian initiatives to improve information sharing between those service providers tasked with supporting and safeguarding the welfare of infants and young children.

The Departments' work will be undertaken in conjunction with whole of Government consideration of related recommendations made in the Final Report of the Royal Commission into Family Violence. These recommendations relate to how information sharing between Government agencies, specialist family violence services and others working to prevent family violence and provide support to victims, can be more readily facilitated.

The Departments also anticipate that findings and recommendations from the Commonwealth Royal Commission into Institutional Responses to Child Sexual Abuse may be relevant to the ability to share information in order to ensure the protection and welfare of children.

CONSIDERATIONS IN RELATION TO THE IMPLEMENTATION OF THE RECOMMENDATION

LEGAL CONSIDERATIONS

Victorian Legislative landscape

The *Health Records Act 2001* (Vic) and the Health Privacy Principles (HPPs) within this Act govern how “health information” can be collected, used, and disclosed in Victoria. The definition of health information includes information or an opinion about the following:

- The physical, mental or psychological health (at any time) of an individual
- A disability (at any time) of an individual
- An individual’s expressed wishes about the future provision of health services
- Health service provided, or to be provided to the individual
- Other personal information to provide, or in providing, a health service.¹

This Act applies to various individuals and organisations which include:

- The public sector
- A denominational hospital within the meaning of the *Health Services Act 1988* (HS Act)
- A privately operated hospital within the meaning of the HS Act
- Any natural person, body corporate, partnership, trust, unincorporated association that is a health service provider or collects, holds or uses health information.²

A health service provider is defined as an organisation that provides a health service such as:

- Assessing, maintaining or improving an individual’s health
- Diagnosing an individual’s illness, injury or disability
- Treating an individual’s illness, injury or disability or suspected illness, injury or disability
- Providing a disability service, palliative care service or aged care service
- Dispensation of a drug or medicinal preparation by a pharmacist registered under the Health Practitioner Regulation National Law.³

The Health Privacy Principles only permit the collection of health information by an organisation if the following relevant criteria have been met:

- It is necessary for one or more of the organisation’s functions and activities; and
- At least one of the following applies:
 - The individual has consented
 - The collection is required, authorised or permitted, whether expressly or impliedly, by or under law
 - The information is necessary to provide a health service to the individual and the individual is incapable of giving consent and either they do not have an authorised representative, or it is not reasonably practicable to obtain the consent of the authorised representative
 - The information is provided by another organisation, the information is provided to achieve a secondary purpose which is directly related to the primary purpose for which the information was collected by the first organisation, and the individual would reasonably expect the first organisation to have disclosed the information

¹ *Health Records Act 2001*, section 3

² *Health Records Act 2011*, sections 10-11

³ *Health Records Act 2001*, section 3

- The collection is necessary to prevent or lessen a serious and imminent threat to the life, health, safety or welfare of any individual, and is collected in accordance with guidelines issued or approved by the Health Services Commissioner
- The collection is necessary to prevent or lessen a serious threat to public health, public safety or public welfare, and is collected in accordance with guidelines issued or approved by the Health Services Commissioner.⁴

The Health Privacy Principles only permit the disclosure and sharing of health information in the following circumstances:

- The disclosure is for the primary purpose for which the information was collected
- The disclosure is for a secondary purpose which is directly related to the primary purpose, and the individual would reasonably expect the organisation to disclose the information for the secondary purpose
- The individual or their authorised representative has consented
- The disclosure is required, authorised or permitted, expressly or impliedly by or under law
- The information is necessary to provide a health service to the individual and the individual is incapable of giving consent and either they do not have an authorised representative, or it is not reasonably practicable to obtain the consent of the authorised representative
- The disclosure is necessary to lessen or prevent a serious and imminent threat to an individual's life, health, safety or welfare
- The disclosure is necessary to lessen or prevent a serious threat to public health, public safety or public welfare.⁵

Creation of shared database

The Department of Education and Training and the Department of Health and Human Services own and manage various databases that collect and store health information for specific purposes. For example, the Department of Education and Training maintains databases such as the following:

- Kindergarten services - Kindergarten Information Management System (KIM);
- School nursing services - Health Activity Recording Tool (HART);
- Maternal and Child Health services - MCH Central (MCH); and
- Allied Health professionals in schools - Student Online Case System (SOCS).

In addition, each health service owns and manages its own database.

In order to create a shared database that would act as a single full health record, the record would need to contain data sourced from all of the child's treating health professionals. In terms of infants/children passing through the MCH system, this could potentially include data held by various health professionals and services such as general practitioners, public and private hospitals, paediatricians, psychologists, social workers, physiotherapists, occupational therapists, optometrists, dentists, audiologists, speech therapists, chiropractors, and podiatrists.

The Department of Education and Training and the Department of Health and Human Services do not have access to these databases nor is either Department able to compel the relevant health professionals to provide them with access to these databases.

⁴ *Health Records Act 2001*, Schedule 1, HPP 1.1

⁵ *Health Records Act 2001*, Schedule 1, HPP 2.2

The creation of a database as envisaged by His Honour would (in the absence of any legislative changes requiring, permitting or authorising reporting of health records in a specific way) be expected to require each and every health service to agree to using a shared database, uploading health information to that database, and using relevant health information uploaded by other health professionals to ensure information flows. If one or more health professionals do not agree to use the shared database, the integrity and purpose of the shared database would be undermined.

OPERATIONAL CONSIDERATIONS

Input of health information in 'Real Time'

His Honour's recommendation refers to a database which would enable those monitoring an infant/child to inform themselves, *in real time*, of progress and/or changes in the health or development of that infant/child.

The obtaining of 'real time' information from health professionals is difficult at a practical level because it would require health professionals to enter health information obtained during a consultation, at the time of the consultation, or immediately after the consultation. In practice, many health services may not be able to do this due to the lack of availability of the required technology, inability to access the database, and/or because of time constraints.

Access to health information

The effectiveness of the recommendation would also be dependent on health professionals accessing health information on the shared database immediately prior to the consultation, or during the consultation with the individual. Again, many health services may not be able to do this due to the lack of availability of the required technology, inability to access the database, and/or because of time constraints.

TECHNOLOGICAL CONSIDERATIONS

Security

Consideration would need to be given to the security and safeguarding measures that would be required to safeguard the health information held in the shared database against loss, modification, and unauthorised access and disclosure.

The relevant Commonwealth bodies spent much of the planning phase of the 'My Health Record' system (described below) considering the technical and administrative measures needed to safeguard the system against these issues. Work by the Commonwealth on refining and strengthening the security of the 'My Health Record' is ongoing. The knowledge the Commonwealth has gained in developing and refining the technological safeguarding aspects of 'My Health Record' may be of assistance in considering the issues involved.

Integrating and matching data

The most significant technological challenge associated with his Honour's recommendation would be the compilation and integration of the proposed data. While such compilation and integration is technologically possible (as was shown in the development of the 'My Health Record'), consideration would need to be given to how this time consuming process (which currently takes several years to complete) could be streamlined.

RELEVANT COMMONWEALTH INITIATIVES

The Commonwealth Department of Health has, over the last two decades, spent considerable time and money investigating the feasibility of a national electronic health record system.

In the late 1990's, work on a national electronic health system was initiated by the then Commonwealth Department of Health and Family Services with the establishment of the National Health Information Management Advisory Committee (NHIMAC).

To investigate and action work in relation to electronic health records, the NHIMAC established a sub-committee known as the National Electronic Health Records Taskforce. The brief of the Taskforce was to investigate the business case for electronic health records, and to produce a report for health ministers recommending a way to develop an electronic records system for Australia. In 2000, the Taskforce released a comprehensive report entitled *A Health Information Network for Australia*⁶ which considered the benefits and difficulties of a national approach to electronic health records.

Then in 2001, Australian, state and territory governments commenced a two-year research and development project, known as *HealthConnect*, to assess the feasibility of a national electronic health record system.

Since 2001, a number of national bodies have been set up to manage the direction and implementation of a national electronic health record system. In this time a large amount of work and research was undertaken to deal with the range of operational, policy and legal complexities associated with developing a national electronic health record system.

INDIVIDUAL HEALTHCARE IDENTIFIER

On 1 July 2010, Individual Healthcare Identifiers (IHIs) were automatically allocated to all Australians who were enrolled with Medicare. The creation, use and disclosure of IHIs is regulated by the *Healthcare Identifiers Act 2010* (Cth).

An IHI is a unique 16 digit number used to identify individuals accessing healthcare in Australia. The IHIs were issued by the Healthcare Identifiers Service, which is operated by the Commonwealth.

A limited amount of identifying information such as a person's name, date of birth and gender is associated with their IHI in the database maintained by the Healthcare Identifiers Service. The Healthcare Identifiers Service database does not hold any clinical information.

A person's IHI is currently used to help ensure that the right clinical documents are associated with a person's 'My Health Record' (described below).

Healthcare providers are able to automatically access a person's IHI from the Healthcare Identifiers Service in the course of providing healthcare to that person, with or without that person's consent. However, healthcare providers and other organisations that obtain a person's IHI may only use or disclose the IHI for the purpose of communicating and managing health information and only in the following circumstances:

⁶ *A Health Information Network for Australia*, Report to Health Ministers by the National Electronic Health Records Taskforce, Commonwealth of Australia, http://www.health.gov.au/healthonline/ehr_rep.pdf

- To provide healthcare to the individual⁷
- To manage, fund, monitor or evaluate health care service⁸
- To provide medical indemnity cover⁹
- To conduct research approved by a Human Research Ethics Committee¹⁰
- For the purposes of the My Health Record system.¹¹

MY HEALTH RECORD

On 1 July 2012, the National 'My Health Record' system was launched. The *My Health Records Act 2012* (Cth), *My Health Records Rule 2016* (Cth) and *My Health Records Regulation 2012* (Cth) create the legislative framework for the My Health Record system.

The objective of the My Health Record is to provide an individual and their healthcare providers with a secure online summary of the individual's health information. It is not intended to be a complete record of the individual's health information.

The system in most States / Territories is an opt-in model¹². This means that a person must apply to register a 'My Health Record'. In Victoria, approximately eleven percent of the population have currently registered a 'My Health Record'.

It also means that the individual has a high degree of control over whether a healthcare provider can access his or her information.

With the agreement of the individual, healthcare providers connected to the 'My Health Record' system¹³, such as general practitioners, hospital staff and maternal and child health service providers, are able to upload the individual's health information; and access the individual's health information when they are providing healthcare to the person.

In cases where a healthcare provider reasonably believes that the collection, use or disclosure of information on the 'My Health Record' is necessary to lessen or prevent a serious threat to an individual's life, health, or safety and it is unreasonable or impracticable to obtain the individual's consent, the healthcare provider can access the 'My Health Record' without the consent of the individual.¹⁴

⁷ Section 14(1), *Healthcare Identifiers Act 2010*

⁸ Section 14(1), *Healthcare Identifiers Act 2010*

⁹ Section 14(1), *Healthcare Identifiers Act 2010*

¹⁰ Section 14(1), *Healthcare Identifiers Act 2010*

¹¹ Sections 15(a) & (b), *Healthcare Identifiers Act 2010*

¹² New South Wales and Queensland are currently participating in a trial that involves an opt-out model. This means that in specified local health areas in these States, all infants, children and adults who have a Medicare number or a Department of Veterans' Affairs number are registered for a My Health Record and must elect not to be registered if they do not wish to participate. These opt-out trials will be evaluated in late 2016.

¹³ An organisation needs to register to participate in Australia's My Health Record system. Once the organisation is registered, Individual Healthcare Providers and other relevant employees can be authorised to access the My Health Record system on the organisation's behalf.

¹⁴ See sections 64 and 65 of the *My Health Record Act 2012* (Cth)

AUSTRALIAN DIGITAL HEALTH AGENCY

The Australian Digital Health Agency (ADHA) is the single accountable organisation for national digital health systems in Australia. ADHA is governed by a skills-based Board which will be responsible for deciding ADHA's objectives, policies and strategies, and for ensuring the proper and efficient performance of ADHA's functions.

ADHA has the following functions:

- to coordinate, and provide input into, the ongoing development of the National Digital Health Strategy;
- to implement those aspects of the National Digital Health Strategy as directed;
- to develop, implement, manage, operate and continuously innovate and improve specifications, standards, systems and services in relation to digital health, consistently with the national digital health work program;
- to develop, implement and operate comprehensive and effective clinical governance, using a whole of system approach, to ensure clinical safety in the delivery of the national digital health work program;
- to develop, monitor and manage specifications and standards to maximise effective interoperability of public and private sector digital health systems;
- to develop and implement compliance approaches in relation to the adoption of agreed specifications and standards relating to digital health; and
- to liaise and cooperate with overseas and international bodies on matters relating to digital health.¹⁵

The functions of the ADHA commenced on 1 July 2016, replacing the current National E-Health Transition Authority.

These Commonwealth initiatives could be used to achieve the objectives of His Honour's recommendation but only on a voluntary basis, with the consent of the individual involved.

RELEVANT DEPARTMENT INITIATIVES

The Victorian Auditor General's (VAGO) Report *Early Childhood Development Services: Access and Quality* (2011) and the *Report on the Protecting Victoria's Vulnerable Children Inquiry* (2012) identified significant systemic limitations in the capacity to share information and track children at risk across early childhood services and schools. To address the original suite of VAGO recommendations¹⁶, the Department approved a business case and associated funding for early childhood IT system improvements in 2012.

¹⁵ *Public Governance, Performance and Accountability (Establishing the Australian Digital Health Agency) Rule 2016*

¹⁶ The VAGO Report recommended that the Department "review all child-level and service-level data collected by it from maternal and child health services, and early childhood education and care providers in order to (a) ensure that the collected information is sufficient and appropriate for the Department of Education and Training to monitor the impact of these services on children's long-term educational outcomes, and (b) develop reporting requirements to collect and record this information in a way that allows the Department of Education and Training to link child-level data collected prior to school with data collected after school enrolment."

The Department of Education and Training has embarked upon a series of projects focused on developing and implementing the policy and technology changes required to enable the linking and effective use of information across a number of Department systems.

OTHER INITIATIVES SPECIFIC FOR MCH SERVICES

CHILD DEVELOPMENT INFORMATION SYSTEM

In 2015, the Department of Education and Training provided funding to the Municipal Association of Victoria (MAV) to develop and implement a new MCH Service data system, known as the Child Development Information System (CDIS).

The CDIS is currently operating in 42 local councils and 2 community health services that provide the MCH Service. By the end of November 2016, a total of 67 MCH Services will have migrated from the previous MCH systems to the CDIS.

Unlike the previous MCH data system, the CDIS enables:

- All MCH Nurses and coordinators across Victoria on CDIS to have access to all client records entered into CDIS (where parental consent to such access is given).
- An alert to be placed on any child/infant's client record where a MCH Nurse has a concern about the infant/child or their family. The alert is represented as a 'red' box on the summary screen of the client record. Currently each local council/MCH Service has its own process for assigning alerts. The MAV is in the process of developing a common alert procedure across all MCH Services that use CDIS.

MCH CENTRAL

In addition, the Department of Education and Training is working on the 'MCH Central Project.' The objectives of this project are to electronically transfer all MCH client records from CDIS and Expedite to a centralised Department of Education and Training database, which will be known as 'MCH Central.' This database will be accessed by the Department of Education and Training staff involved in MCH high level administration, policy and planning.

REVISION OF THE MCH PRACTICE GUIDELINES

The Department of Education and Training is in the process of revising its Maternal and Child Health Practice Guidelines. The updated MCH Practice Guidelines will contain:

- Detailed information about the identification of and response to indicators of all types of abuse in infants consistent with the revised Child Safety Standards. This will include guidance on the identification of infant trauma, pattern, history and accumulative harm indicators.
- Information regarding the ways in which the sharing of information between MCH Nurses and other services can be facilitated.
- Information about recording and accessing patient notes to inform consultation.
- A clearer description of the obligations and clinical practice surrounding mandatory reporting, referral and follow up strategies.

REVISION OF THE COLLECTION NOTICE PROVIDED BY MCH NURSES

The *Health Records Act 2001 (Vic)* requires an organisation that collects health information to take reasonable steps to ensure that an individual is aware of the following:

- The identity of the organisation and how to contact it
- The fact that he or she is able to gain access to their health information
- The purposes for which the health information is being collected
- To whom the organisation usually discloses the health information
- Any law that requires particular health information to be collected
- The main consequences (if any) if all or part of the health information is not provided.¹⁷

The Department of Education and Training and the MAV will work in partnership to update the current Collection Notice that is provided to parents and families who engage with MCH services to provide further clarity around what information can be shared with other health providers.

PROFESSIONAL DEVELOPMENT

The Department of the Education and Training, in partnership with the MAV, provide regular state-wide MCH Conferences. The last Conference was held on 22 April 2016. This Conference was attended by approximately 1,000 MCH Nurses (in person or by video link-up). Amongst other professional development opportunities, attendees were provided with an update on information gathering, mandatory reporting requirements, and the role of the Department of Health and Human Services (Child Protection).

CONTINUITY OF CARE

The Department of Education and Training and the Department of Health and Human Services will continue to work together (and consult with the MAV) to strengthen information transition between maternity services and the MCH Services. The aims of this work are to:

- enhance continuity of care for new mothers and their babies from pregnancy through early parenthood, as provided by maternity and MCH services;
- promote and strengthen professional partnerships between maternity and MCH services;
- clarify processes to identify and actively engage families, with emphasis on those who are vulnerable or at risk;
- promote mutual understanding of the respective roles and responsibilities of MCH and maternity and newborn services; and
- promote standardised and complementary approaches to the transfer of information between maternity and MCH services.

Maternity and MCH staff are already or will be expected to document all referral consultations and discussions relevant to the ongoing care and support of the mother and her baby, including medical issues, risk and protective factors, clinical and psycho-social issues, community supports and referrals and care planning agreements.

¹⁷ *Health Records Act 2001*, Schedule 1, HPP 1.4

RELEVANT WHOLE OF VICTORIAN GOVERNMENT INITIATIVES

The importance of developing and maintaining information sharing protocols between organisations was recently highlighted in the Final Report of the Royal Commission into Family Violence (**FV Final Report**).

The Commission found that improved information sharing should be facilitated through both a more permissive legislative regime¹⁸ and the development of an 'information-sharing culture'¹⁹. For example, the Commission noted that, 'risk aversion and non-disclosure must be replaced by proactive, coordinated and timely information sharing'.²⁰

The Commission held that Government agencies, specialist family violence services and others working to prevent family violence and support victims cannot adequately achieve their aims without sharing risk-related information about perpetrators.²¹

The Commission placed a strong emphasis on information sharing between agencies, and found that sharing information about risk within and between organisations, is crucial to keeping victims safe and holding perpetrators accountable.²² Evidence was provided to the Commission that effective information sharing is, in many cases, contingent on positive working relationships across organisations, and between individuals.

The Department of Premier and Cabinet is currently co-ordinating the whole of Victorian Government response to the FV Final Report.

The Department also anticipates that the findings and recommendations from the Commonwealth Royal Commission into Institutional Responses to Child Sexual Abuse may be relevant to the ability to share information in order to ensure the protection of children.

For example, in May 2016 the Commonwealth Royal Commission published a research report which considered the legislative, and related key policy and operational frameworks for sharing information relating to child sexual abuse in institutional contexts, between institutions, and across jurisdictions in Australia.²³

The Commonwealth Royal Commission will provide its final report to the Australian Government by 15 December 2017.

¹⁸ See 'Recommendation 5', State of Victoria, Royal Commission into Family Violence: Summary and recommendations, Parl Paper No 132 (2014–16), page 46

¹⁹ See 'Recommendation 6', State of Victoria, Royal Commission into Family Violence: Summary and recommendations, Parl Paper No 132 (2014–16), page 47

²⁰ State of Victoria, Royal Commission into Family Violence: Report and recommendations, Volume I, Parl Paper No 132 (2014–16), page 194

²¹ State of Victoria, Royal Commission into Family Violence: Report and recommendations, Volume I, Parl Paper No 132 (2014–16), page 185

²² State of Victoria, Royal Commission into Family Violence: Summary and recommendations, Parl Paper No 132 (2014–16), page 20; See 'Recommendation 134', State of Victoria, Royal Commission into Family Violence: Summary and recommendations, Parl Paper No 132 (2014–16), page 81

²³ Adams, C & Lee-Jones, K, 2016, *A study into the legislative – and related key policy and operational – frameworks for sharing information relating to child sexual abuse in institutional contexts*, Royal Commission into Institutional Responses to Child Sexual Abuse, Sydney