
**Service Model for
National Perinatal
Pathology Services**

Consultation

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1. Purpose of this document

The Ministry of Health has undertaken a review of the service delivery model for Perinatal Pathology Services, with a view to implementation of a sustainable national service.

This consultation document outlines the main recommendations of the Perinatal Pathology Working Group for establishment of a Service Model for Perinatal Pathology Services in New Zealand. We are seeking feedback on those recommendations, and on the proposed Service Model from a range of stakeholders.

The full list of recommendations from the Service Model Report is included in Section 4.

A copy of the Report: Service Model for Perinatal Pathology Services can be found at:

<http://nsfl.health.govt.nz/national-services>

2. Overview of Perinatal Pathology Services

Background

Perinatal pathology provides post mortem examinations of perinatal related death. Perinatal related mortality is defined by the Perinatal and Maternal Mortality Review Committee (PMMRC) as:

- Fetal death is the death of a fetus at 20 weeks gestation or beyond (≥ 20 weeks) or weighing at least 400g if gestation is unknown. Fetal death includes stillbirth and termination of pregnancy. Note that the term 'stillbirth' does not include terminations. Where a termination of pregnancy died after birth, the pregnancy is included as a termination of pregnancy and therefore as a fetal death rather than as a neonatal death.
- Neonatal death is the death of any baby showing signs of life at 20 weeks gestation or beyond or weighing at least 400g if gestation is unknown. Early neonatal death is a death that occurs up until midnight of the sixth day of life. Late neonatal death is a death that occurs between the seventh day and midnight of the 27th day of life.

A post mortem is one of a range of strategies for optimal investigation of the causes of perinatal related death. A post mortem is important, as information gained from autopsy can assist in the understanding of events surrounding the death, and in future pregnancy planning by enabling consideration of the risk of recurrence, alongside different management strategies (Paediatric Society of Australia and New Zealand 2009)ⁱ.

In 2008 a report on Perinatal and Paediatric Pathology Service Provision in New Zealand was released by PMMRCⁱⁱ. The Review highlighted a range of issues with the service model in place at that time, particularly in relation to a shortage of pathologists. The review recommendations included recruitment and retention plans, development of national guidelines for referral, and provision of administrative support for the service.

In September 2010 the, then National Health Board (NHB) received advice concerning paediatric and perinatal pathology services. The NHB board paper outlined workforce vulnerability, particularly succession planning and a lack of critical mass to maintain staffing levels during leave periods as key drivers for establishing a single national service model. This model was subsequently endorsed by the Minister of Health.

An implementation process was initiated in late 2010, working with a range of key stakeholders. While some progress was made to establish the national Paediatric and Perinatal Service there were a number of unresolved challenges which prevented agreement being reached on configuration of the national service.

Key barriers were related to differing requirements for paediatric and perinatal services, the role of Southern District Health Board (DHB) as a provider, and the impact of a Ministry of Justice review of their procurement of coronial and forensic pathology services.

In 2016 providers of perinatal pathology services approached the Ministry with a request to revisit the service model. A workshop was convened, and agreement reached that a Service Model for a National Perinatal Pathology Service be developed.

Lifting rates of post mortems for perinatal related death

Rates of parental consent to post mortems are one of the principal drivers of the number of non-coronial post mortems undertaken. Improving rates of consent is a key strategy to increase post mortem rates, so that accurate cause of death can be identified, along with determining whether there were disorders with implications for counselling and monitoring of future pregnancies.

Knowledge is important in assisting with reducing inequalities, with Maori and Pacific people over represented in perinatal mortality statistics, and with the grieving process as parental understanding of events surrounding the death is enhanced. Maori and Pacific perinatal related deaths are less likely to be optimally investigated than deaths in all other ethnic groups. Practice changes to support culturally appropriate conversations will be an important aspect of lifting post mortem rates.

In an article in NZ Doctor, (Thomas, 2016)ⁱⁱⁱ reinforced the need for health professionals being prepared to have conversations about investigating causes of stillbirth in a culturally sensitive way, and that staff should be supported in this area.

In their Tenth Annual Report, published in June 2016, PMMRC reported against two recommendations related to rates of post mortems.

The first is that the low rate of uptake of post mortems amongst families and whānau who experience perinatal loss should be investigated, and noted the information contained in the 2015 Survey of Bereaved Women, which looks at information provided to women and their decisions about post mortem examination.

The second recommendation is that the reasons for the difference in rates of optimally investigated perinatal deaths between DHBs should be investigated, and noted that DHBs with post mortem rates of less than 50 percent were asked to provide a progress update on their implementation of this recommendation. Reported results were that geographical distance, length of time families and whānau are separated from their babies and family or whānau cultural beliefs can all be barriers to consenting to post mortems.

The incidence of perinatal related mortality in New Zealand in 2014 (the most recent data available) was 656 deaths, or a rate of 11.2 deaths per 1000 births. Numbers and rates of perinatal deaths have been relatively stable in New Zealand and are lower than rates in Australia which have been falling in recent years

A post mortem is one of three potential strategies identified as optimal investigation of death. The others include karyotype to confirm chromosomal abnormality and clinical examination/ investigations (including Magnetic Resonance Imaging).

Optimal investigation rates in New Zealand are reported by the PMMRC in their Annual Reports. PMMRC have identified that in the five years between 2010 and 2014 optimal investigation occurred in 45 – 53 per cent of perinatal related deaths (n = 295 – 324 per annum).

Of the optimal investigations, a post mortem was performed in 34 – 42 per cent of perinatal related deaths each year, or around 250 perinatal related post mortems per annum. A post mortem is offered to families and whānau who have experienced a perinatal related death in most cases (89 – 94 per cent between 2012 and 2014), however around 55 per cent of bereaved families and whānau declined the offered post mortem.

Taking into account the increase in non-post mortem investigations, it is recommended that the initial goal is to lift perinatal related post mortem rates to at least 50 per cent by 2025 (or around 273 post mortems per annum, if mortality reduced, or 329 post mortems per annum if mortality remained stable). This rate would be consistent with the level at which PMMRC has sought DHB progress reports when considering reasons for difference in rates of optimally investigated perinatal deaths.

The Service's capacity to achieve projected increases in perinatal related post mortems should be reviewed over time, based on actual post mortem rates, and regional distribution. Where pathologist capacity is constrained, options to remove low value added or non-clinical tasks should be developed to ensure pathologist resource is not a barrier to increasing rates of post mortems.

Priorities for a Perinatal Pathology Service

The Working Group identified that the provision of high-quality services presents challenges for New Zealand given the wide geographic distribution of our small population. They identified that the purpose of the Service Model is one that:

1. Supports delivery and sustainability of the Service
 - a. Includes a streamlined and effective operational and administrative infrastructure
 - b. Provides an effective service and clinical governance structure
 - c. Has effective coordination of the service for family, whānau and pathologists
 - d. Ensures sufficient activity for each centre to be safe and sustainable.
2. Provides access for family and whānau
 - a. Culturally sensitive and appropriate interactions with family and whānau
 - b. Offered and available to all families and whānau that experience a fetal or neonatal death
 - c. Is provided with the informed consent of the family and whānau, free of coercion
 - d. Is provided as close to home as possible within the bounds of quality, safety and timeliness
 - e. Is provided equitably
3. Meets quality and safety expectations
 - a. Is provided in line with agreed guidelines, referral pathways and consent process
 - b. Meets agreed standards for performance and reporting of post mortem and placenta examinations
 - c. Meets agreed quality improvement indicators
 - d. Has a common data collection and reporting system
 - e. Has a common clinical record or shared care portal
 - f. Monitored against a consistent reporting framework, and evaluated regularly
4. Supports development of the workforce
 - a. Is provided by a sustainable, qualified, workforce
 - b. Provides access to post graduate training for pathologists
 - c. Has a clinical leadership, peer review and support framework

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- d. Has a workforce recruitment and development plan
5. Makes best use of available funds
 - a. Is fiscally responsible
 - b. Receives funding that meets costs of providing the Service, and which is not a disincentive to referral for service

Service configuration

Perinatal Pathology Services are provided from DHB mortuaries in Auckland, Wellington, Christchurch and Dunedin Hospitals, and are part of wider Anatomical Pathology Services. The service employs (or utilises through contracting arrangements) 3.1 Full Time Equivalents (FTE) of perinatal pathologists nationally across the four sites, or five individuals (two in Auckland, and one each in Wellington, Christchurch and Dunedin).

Auckland DHB's LabPlus provides perinatal pathology services for the Northern and Midland Region DHBs, either in the Auckland or Wellington mortuary.

Southern Community Laboratories (SCL) Wellington provides perinatal pathology services for the Central Region, and Nelson Marlborough DHBs, through the Wellington mortuary. SCL Dunedin contracts with a local Dunedin based pathologist to provide services for Southern DHB.

Canterbury Health Laboratories provides services for Canterbury, West Coast and South Canterbury DHBs.

There was consensus from the working group that the service should be retained in the existing four centres to support access for family and whānau closer to home, without reducing existing access levels. However, the group felt that efficiencies could be gained through reducing the number of "hosts" employing perinatal pathologists. A reduced number of hosts, or employers, provides greater opportunity to:

- streamline operational and administrative support
- reduce variation in information technology in use
- support greater consistency in reporting and monitoring of the service
- support clinical teams
- support succession planning for the service.

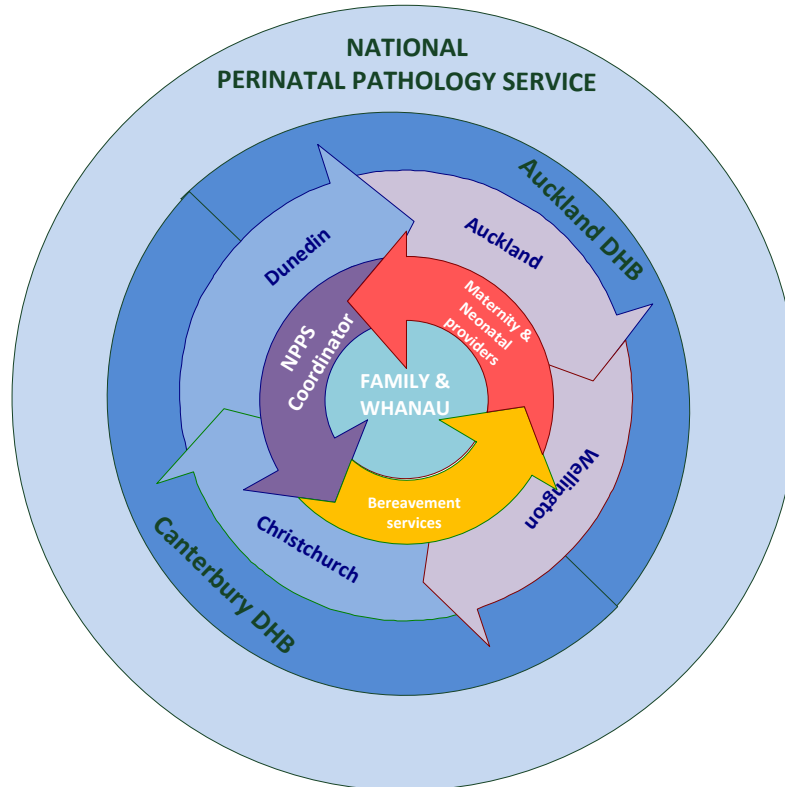
The Service is primarily provided Monday to Friday, normal business hours, but staff are available afterhours if required. There is no formal on call arrangement within the service, although leave is covered by other pathologists as required.

It is recommended that an implementation plan to reconfigure the services be actioned. The revised configuration should ensure that quality and safety requirements are met, including participation in a service wide peer review and clinical audit for all pathologists.

The recommended configuration, which minimises change, is:

- Auckland, who currently has pathologists in Auckland and Wellington, takes on responsibility for providing Services to the Central Region and Nelson Marlborough DHB¹, in addition to their current Services for Northern and Midland Regions.
- Canterbury takes on responsibility for the whole South Island, expanding to include Southern, noting the volume of post mortems provided by this hub are expected to be relatively small.

Figure 1: The National Perinatal Pathology Service Model



The working group confirmed that the appropriate scope of a national Perinatal Pathology Service should be non-coronial post mortem services, external examinations and placenta examinations and testing, in the following situations:

- Stillbirths and terminations of pregnancy from 14 weeks gestation for high risk pregnancy, terminations and intrauterine deaths
- Neonatal and infant deaths (up to one year).

Placenta examination is also performed by other pathologists, but the Perinatal Pathology Service will continue to perform these examinations for their local populations, and upon request for other DHBs. Referrals from other regions may be a request for full examination or review of slides, either as the primary placenta examination or as a second opinion.

The Service is provided primarily during normal business hours, but with afterhours cover by local arrangement when circumstances warrant more urgent access.

¹ Nelson Marlborough DHB receives Maternal Fetal Medicine and Neonatal Services through Capital & Coast DHB. These Services have important relationships with the Perinatal Pathology provider and current alignment should be maintained.

The existing Tier Two Service Specification for Paediatric and Perinatal Pathology services should be updated to reflect the change in scope.

Streamlining the referral process

Referral is from the hospital or DHB where the stillbirth or death occurred to the regional Perinatal Pathology Service provider. The referral is made either directly to the pathologist, or via the on call mortuary staff. Only one provider has a documented referral process and out of hours contact number.

Decisions on whether to proceed with a post mortem out of hours are made on a case by case basis where exceptional circumstances exist. The circumstances may be clinical or based on the expectation that consent would be withdrawn if delay occurred.

Placenta examination is an important investigation in improving pregnancy outcomes, both maternal and fetal. Optimum handling of the placenta following delivery is to send the fresh placenta and cord, along with a detailed request form, to the laboratory. If the referral is from another DHB, it is recommended that the Service be contacted to ensure appropriate handling, packaging and transportation.

Greater consistency in referral pathways for post mortem and placenta examinations should be achieved. It is recommended that current pathways are reviewed, documented and made available to referrers. This needs to include clarity about when and how after-hours access is provided.

Consistency of funding model

Perinatal Pathology Services are funded inconsistently from other hospital services. They are not included in normal Inter District Flow (IDF) payments for inpatient hospital services, and are not included in national reporting for non-admitted services.

Perinatal Pathology Services are either invoiced under a fee for service arrangement by the host Laboratory, or provided as part of the Laboratory and Pathology service agreements within the host DHB.

A single funding model for the Service should be implemented and applied by all providers. The recommended approach is a mixed model which includes:

- Activity based funding, using a fee for service model. Requirements for this include:
 - A memorandum of understanding with DHBs so that the DHB of maternal residence agrees to be invoiced for the post mortem
 - An endorsed fee schedule for the post mortem and placenta examination. It is proposed that post mortem and placenta examination fees are set for one year, using the existing fee as the basis (see Appendix 2). The National Pricing group will then be asked to use the most recent costing data to confirm a national price for the Service for use in 2018/19.
- A Programme Fee which covers the cost of administering the National Service configuration and coordination. This funding would be used to support the Governance model, a National clinical leader (0.1 FTE), and a full time Service Coordinator). The ongoing cost of the programme coordination is projected at \$185,000. A one off additional amount of \$100,000 would be used to develop

training resources, referral pathways, and the quality improvement framework (see Appendix 3 for the Programme Fee breakdown).

Improving support for families and whānau in decision making

A post mortem is a valuable mechanism to identify accurate cause of death, identify disorders with implications for counselling and monitoring of future pregnancies, and assist in the grieving process by enhancing parental understanding of events surrounding the death. Improving rates of post mortems will assist in reducing future perinatal mortality.

Identifying areas where either the rate of offer of a post mortem, or the rate of consent to proceed, is low will allow more targeted training to improve post mortem rates, and more accurately diagnose cause of death or factors contributing to death.

If the National Perinatal Pathology Service aims to ensure families and whānau are supported to make an informed decision on whether to proceed with a post mortem, then supporting maternity and paediatric providers in their engagement with families and whānau to seek consent is important.

A survey of bereaved women asked about post mortems^{iv}. Trust was identified as an important factor in deciding whether or not to proceed with a post mortem. Respondents identified that the key attributes of the 'most trusted' maternity providers were that they:

- were understanding and supportive
- made the women, family and whānau feel they could be trusted
- used words that could be understood
- appeared to know what they were talking about.

It was agreed that a service coordinator working in partnership with pathologists, referrers and families or whānau could facilitate the post mortem process for all concerned. The coordinator would focus particularly in DHBs where opportunities to improve outcomes can be achieved through increasing the rate of offer of a post mortem, or the rate of consent to a post mortem.

Because of the relatively low rates of consent for a post mortem, particularly for Maori or Pacific deaths, it was identified that a training package for maternity and paediatric providers dealing with bereaved families and whānau would be useful. The goal would be to support staff to have culturally appropriate conversations with bereaved families and whānau so that an informed choice can be made.

A family and whānau co-design approach would ensure that there is a factors important to consumers are incorporated, so that the training package can be more effective. This work should also include input from maternity and neonatal providers to ensure all factors taken into account.

Leadership and governance

The Service operates under the operational and clinical leadership in place in the DHB/provider' laboratory. There is an informal clinical leadership model within the Perinatal Pathology Service, provided through peer review and mentoring of less experienced staff. The decentralised model of management, leadership and governance limits the ability to take a whole of service overview, with local priorities taking precedence over a national planning and performance approach.

While the existing operational oversight of the Service by each provider should continue, as a National Service with more than one provider it is important that there is a framework for broader oversight to ensure equity of access and consistency of service provision.

A clinical leadership and governance framework is recommended with a governance group established that includes representation from key stakeholders within the Service, and representation from interested external parties, including DHB funders, and Service referrers.

A national clinical leader should be appointed with responsibilities for ensuring clinical and quality standards are in place and being achieved through leadership, mentoring and support.

Reporting and quality improvement

Perinatal post mortem and placenta examination information is entered at the site of examination, and reported in the local database. In most cases the report is included in the local clinical repository. The information is only accessible locally, with regional shared health records not fully implemented. Where a pathologist works across two sites, access is via the local database only. The multiple systems mean that tracking, updating and sharing reports is difficult, and that tissue, slides and blocks may be moved and stored away from the site of the actual post mortem.

Data on post mortems is only available 2-3 years in arrears through the PMMRC reports. The delay in available information limits the ability to leverage quality improvement. Other than consent, post mortem and optimal investigation rates there are no national indicators of quality for Perinatal Pathology Services.

Standardised capture and reporting of post mortem referrals and activity is required to allow assessment of the effectiveness of the Service, with particular reference to reducing inequalities and improving post mortem rates where perinatal mortality remains high. This is particularly important because of the scope of the Service which is broader than the key improvement area of perinatal related pathology

Quality improvement indicators based on the defined referral pathway should be developed, and a reporting framework established to monitor quality. Referral and data management processes will need to be reviewed to ensure data capture of information to support monitoring and reporting of Service activity and performance.

The long term solution to allow the Service access to information regardless of location is through the National Electronic Health Record, expected to have initial roll out in mid-2018. In the interim, options to develop or access a shared electronic clinical record should be explored, which leverage on existing Regional IT solutions. Options to maximise access without requiring new IT investment should be considered that will support:

- Best possible access for pathologists to reports and relevant clinical information, regardless of where the post mortem was conducted or the pathologist based
- Best possible access for referrers to the completed report, regardless of the location of the post mortem.

Approaches to be progressed include ensuring reports are distributed and accessible through DHB and regional electronic platforms and considering whether the required access could be achieved through the new National Maternity Collection.

Workforce

Perinatal pathologists are trained in anatomical pathology. There is no specific formal perinatal pathology examination or qualification. Training is achieved through identification of interested candidates, and funding them to undertake international fellowships. It is expected these candidates will complete the International Paediatric Pathology Association course in Europe, but this requirement is not part of the Service Specification.

Attracting registrars with an interest in perinatal pathology has been identified as challenging, with a need to increase the visibility and profile to attract quality candidates to the Service.

Mortuary technicians support pathologists in providing post mortems. Mortuary technicians are generally employed by the DHB. There is no perinatal pathology standard training programme available, and training occurs on site. It is estimated there are 8-10 mortuary technicians nationally that are able to assist with perinatal post mortems and reconstruction.

A workforce plan should be documented, describing minimum requirements for a pathologist or mortuary technicians to support high quality perinatal pathology service delivery. Draft accreditation requirements are identified in Appendix 1. These should be agreed and finalised.

A summary of the recommendations to achieve the Perinatal Pathology Service priorities is detailed in the next section.

3. Proposal

The Ministry of Health should work with current perinatal pathology providers to establish a National Perinatal Pathology Service.

The Service would be delivered in four centres, provided through two host DHBs (Auckland and Canterbury DHBs). The priorities for the Service Model are to:

1. Support delivery of the Service
2. Provide access for family and whānau
3. Meet quality and safety expectations
4. Support development of the workforce
5. Make best use of available funds.

A governance group would be established to oversee implementation of the Service Model. Endorsed recommendations will be developed into an implementation Action Plan.

4. Recommendations

Criterion 1: Supports delivery of the Service

Demonstrated by	Recommendations
<ul style="list-style-type: none"> • Streamlined and effective operational and administrative infrastructure • Effective service and clinical governance structure • Effective service coordination • Sufficient activity for each centre to be safe and sustainable 	<p>Recommendation 1: The Service’s capacity to achieve projected increases in perinatal related post mortems is reviewed over time, based on actual post mortem rates, and regional distribution. Where an increase in post mortems is putting pressure on existing pathologist capacity a review should be initiated to explore options to remove low value added or non-clinical tasks.</p> <p>Recommendation 2: The current Service configuration, including where provided, and who hosts the service, is reviewed. The goal would be to retain perinatal pathologists in four centres.</p> <p>It is recommended that Auckland LabPlus continue to provide services based in Auckland and Wellington for the North Island, and that Canterbury Health Laboratories provide services in Christchurch and Dunedin for the South Island.</p> <p>The revised configuration should ensure that quality and safety requirements are met, including participation in a service wide peer review and clinical audit for all pathologists.</p> <p>Recommendation 3: The scope of the Service should be confirmed as:</p> <ul style="list-style-type: none"> • non-coronial post mortem services, external examinations, placenta examinations, and testing in the following situations: <ul style="list-style-type: none"> • Stillbirths and terminations of pregnancy from 14 weeks gestation for high risk pregnancy, terminations and intrauterine deaths • Neonatal and infant deaths (up to one year) <p>The Tier Two Service Specification for Paediatric and Perinatal Pathology Services should be updated to reflect the change in scope.</p> <p>Recommendation 8: A clinical leadership and governance framework is established.</p> <ul style="list-style-type: none"> • A national governance group should be convened, with terms of reference describing the group’s responsibilities in relation to service provision, improving equity, and ensuring performance indicators are met. Membership of the governance group should include representatives from:

Demonstrated by	Recommendations
	<ul style="list-style-type: none"> ○ the host DHBs (funder and provider arms, as well as a laboratory lead) ○ SCL (as provider of facilities and staff in some sites) ○ the national clinical director for perinatal pathology (when established) ○ a referring DHB General Manager, Planning & Funding ○ a referring clinician (LMC, obstetrician or neonatologist) ○ a family, whānau or consumer representative ○ a member of the PMMRC. <ul style="list-style-type: none"> ● A national clinical leader position description should be developed describing the expected responsibilities for the national clinical leader, who should be part of the service governance. <p>Recommendation 9: Administrative functions within the service should be reviewed and, if necessary, realigned to ensure pathologists are adequately supported, and that service activity is correctly captured and reported.</p>

Criterion 2: Provides access for family and whanau

Demonstrated by	Recommendations
<ul style="list-style-type: none"> ● Culturally sensitive and appropriate interactions with family and whānau ● Offered and available to all families and whānau that experience a fetal or neonatal death ● Is provided with the informed consent of the family and whānau, free of coercion ● Is provided as close to home as possible within the bounds of quality, safety and timeliness 	<p>Recommendation 12: A training package for referrers should be considered. The training package would need to adopt a family and whānau co-design to incorporate learnings from their experiences. Referrers should also be involved in the design to ensure all clinician perspectives are also considered. Once developed, training could be delivered to maternity and neonatal providers, supported with appropriate resources, so that bereaved family and whānau receive information on post mortems that is:</p> <ul style="list-style-type: none"> ● Easily understood ● Provided in a supportive and culturally appropriate way that does not presuppose the outcome ● Gives confidence that the person offering the post mortem is trustworthy and well informed ● Enables family and whānau to make an informed decision on a post mortem. <p>Recommendation 13: A service coordination function should be implemented. The coordinator would:</p>

Demonstrated by	Recommendations
<ul style="list-style-type: none"> • Is provided equitably 	<ul style="list-style-type: none"> • Work in partnership with pathologists to develop relationships with referrers • Provide an interface between the Perinatal Pathology Service and local DHBs or referrers to ensure that interaction with the Service is well managed and that pathologist and, family and whānau needs are identified and met. • Work with family or whānau where appropriate to facilitate the post mortem process for them • Capture and provide information on family reasons for not proceeding with post mortem to inform improvement work • Deliver training to support referrers in seeking consent to the post mortem with grieving families and whānau. <p>The coordinator would focus particularly in DHBs where opportunities to improve outcomes can be achieved through increasing the rate of offer of a post mortem, or the rate of consent to a post mortem.</p>

Criterion 3: Meets quality and safety expectations

Demonstrated by	Recommendations
<ul style="list-style-type: none"> • Is provided in line with agreed guidelines, referral pathways and consent process • Meets agreed standards for performance and reporting of post mortems and placenta examinations • Meets agreed quality improvement indicators • Has a common data collection and reporting system 	<p>Recommendation 4: Referral pathways for a post mortem and placenta examination need to be reviewed and documented to ensure that:</p> <ul style="list-style-type: none"> • the scope of the service is clearly documented • the information required by the pathologist for the post mortem is available, relevant and appropriate • clinicians using perinatal pathology services are competent in issues of consent for a post mortem and in providing feedback regarding the post mortem results to families and whānau • situations where out of hours referral is appropriate and arrangements to access the Service out of hours • referrals for post mortem services are streamlined and directed to the appropriate provider, particularly if occurring afterhours • families and whānau have access to appropriate support and advice, including bereavement services. <p>Recommendation 5: Quality improvement indicators based on the defined referral pathway should be developed, and a</p>

Demonstrated by	Recommendations
<ul style="list-style-type: none"> • Has a common clinical record or shared care portal • Monitored against a consistent reporting framework and evaluated regularly 	<p>reporting framework established to monitor quality. These should be incorporated into the updated Tier Two Service Specification.</p> <p>Recommendation 10: Referral and data management processes are reviewed to ensure data capture of information to support monitoring and reporting of Service activity and performance.</p> <p>The Tier Two Service Specification should be updated with any purchase units or reporting requirements for capturing of perinatal pathology activity within national collections.</p> <p>Recommendation 11: Options to access a shared electronic clinical record should be explored, which leverage on existing Regional IT solutions to support:</p> <ul style="list-style-type: none"> • best possible access for pathologists to reports and relevant clinical information, regardless of where the post mortem was conducted or the pathologist based • best possible access for referrers to the completed report, regardless of the location of the post mortem.

Criterion 4: Supports development of the workforce

Demonstrated by	Recommendations
<ul style="list-style-type: none"> • Is provided by a sustainable, qualified, workforce • Provides access to post graduate training for pathologists • Has a clinical leadership, peer review and support framework • Has a workforce recruitment and development plan 	<p>Recommendation 7: A workforce plan is documented, describing accreditation requirements, including:</p> <ul style="list-style-type: none"> • the number, location and hours of availability of perinatal pathologists to ensure capacity to deliver equitable access to post mortems across DHB regions, and minimum volumes to maintain competency • training pre-requisites for completing perinatal post mortems (including coronial which are outside the service) • a training programme for mortuary technicians to support pathologists.

Criterion 5: Makes best use of available funds

Demonstrated by	Recommendations
<ul style="list-style-type: none">• Is fiscally responsible• Receives funding that meets costs of providing the Service, and which is not a disincentive to referral for service	<p>Recommendation 6: Funding arrangements for the Service should be reviewed, to ensure they are consistent, meet the averaged costs of providing service, and are not a disincentive for referrers to seek a post mortem or placenta examination.</p> <p>The preferred funding model is to retain the current fee for service arrangement. This would require:</p> <ul style="list-style-type: none">• A signed memorandum of understanding with DHBs for the provision of perinatal pathology services and agreed fee schedule• The fee for service funding model should be supplemented with a modest Programme Fee to allow administration of identified national functions, e.g. service coordination, training and development, governance, clinical leadership. This approach would require Agreement from GMs P&F on the level of programme funded. The Programme Fee would include one off funding in the first year to support the development of referral pathways, quality indicators and training resources.

4 Making a Submission

This consultation document is aimed at a range of audiences. The questions that accompany each section are intended to help focus feedback on specific areas of concern. The primary questions are reasonably general, but you may wish to comment on more detailed elements of the recommendation/s. Submissions may be completed on line through the Survey Monkey Link provided, emailed or posted.

Email to: Elective_Services@moh.govt.nz
Post to: Electives & National Services, Integrated Service Design
Service Commissioning, Ministry of Health
PO Box 5013, Wellington 6145.

The closing date for submissions is 5pm on Friday, 10 February 2017.

Details of your submission may be requested under the Official Information Act 1982. If this happens, the Ministry will normally release your submission to the person who asks for it. If you consider there are good reasons to withhold your submission details, please clearly indicate these in your submission.

If you are an individual or individuals, we will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you ask for us to withhold them.

We appreciate you taking the time to comment.

Submitter details

It is helpful, when assessing submissions, if submitters provide information about themselves. However, providing this information is not required for a submission to be considered, and you can choose to withhold this information if you wish.

This submission was completed by: *(name)* _____
Address: *(street/box number)* _____
(town/city and postcode) _____
Email: _____
Organisation (if applicable): _____
Position (if applicable): _____

Are you making this submission *(tick one box only)*:

as an individual? on behalf of a group or organisation?

6. Official Information Act 1982

The Official Information Act 1982 (the OIA) applies to any submission you make and to any personal information you provide. The OIA requires information held (by the Ministry of Health) to be made available unless there is good reason to withhold it. Accordingly, if the Ministry of Health does receive a request under the OIA for your information, we will discuss that with you before responding to the request.

Questions for Consultation

1 Supporting delivery of Perinatal Pathology Services

Demonstrated by:

- Streamlined and effective operational and administrative infrastructure
- Effective service and clinical governance structure
- Effective service coordination
- Sufficient activity for each centre to be safe and sustainable

Recommendation: Service Configuration

The current Service configuration, including where provided, and who hosts the service, is reviewed. The goal would be to retain perinatal pathologists in four centres.

It is recommended that Auckland LabPlus continue to provide services based in Auckland and Wellington for the North Island, and that Canterbury Health Laboratories provide services in Christchurch and Dunedin for the South Island.

The revised configuration should ensure that quality and safety requirements are met, including participation in a service wide peer review and clinical audit for all pathologists.

Is the recommended service configuration supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any comments?

Recommendation: Scope of the Perinatal Pathology Service

The scope of the Service should be confirmed as:

- non-coronial post mortem services, external examinations, placenta examinations, and testing in the following situations:
 - Stillbirths and terminations of pregnancy from 14 weeks gestation for high risk pregnancy, terminations and intrauterine deaths
 - Neonatal and infant deaths (up to one year)

The Tier Two Service Specification for Paediatric and Perinatal Pathology Services should be updated to reflect the change in scope.

Is the recommended service scope supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: The rate of perinatal related post mortem should increase to 50 per cent of perinatal related deaths by 2025/26.

The rate of 50 per cent takes into account the increase in non-post mortem investigations.

Is the recommendation to aim for a rate of perinatal related mortality of 50 per cent supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Service capacity to achieve an increase in perinatal related post mortem

The Service's capacity to achieve projected increases in perinatal related post mortems is reviewed over time, based on actual post mortem rates, and regional distribution. Where an increase in post mortems is putting pressure on existing pathologist capacity a review should be initiated to explore options to remove low value added or non-clinical tasks.

Is the recommendation to periodically review service capacity supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Administrative support

Administrative functions within the service should be reviewed and, if necessary, realigned to ensure pathologists are adequately supported, and that service activity is correctly captured and reported.

Is the recommendation to review administrative support for the Service supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Clinical leadership and governance framework

A clinical leadership and governance framework is established.

- A national governance group should be convened, with terms of reference describing the group's responsibilities in relation to service provision, improving equity, and ensuring performance indicators are met. Membership of the governance group should include representatives from:
 - the host DHBs (funder and provider arms, as well as a laboratory lead)
 - SCL (as provider of facilities and staff in some sites)
 - the national clinical director for perinatal pathology (when established)
 - a referring DHB General Manager, Planning & Funding
 - a referring clinician (LMC, obstetrician or neonatologist)
 - a family, whānau or consumer representative
 - a member of the PMMRC.
- A national clinical leader position description should be developed describing the expected responsibilities for the national clinical leader, who should be part of the service governance.

Is the recommendation to establish a clinical leadership and governance framework supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

2 Providing access to Perinatal Pathology Services for family and whānau

Demonstrated by:

- Culturally sensitive and appropriate interactions with family and whānau
- Offered and available to all families and whānau that experience a fetal or neonatal death
- Provided with the informed consent of the family and whānau, free of coercion
- Provided as close to home as possible within the bounds of quality, safety and timeliness
- Provided equitably

Recommendation: Training for referrers

A training package for referrers should be considered. The training package would need to adopt a family and whānau co-design to incorporate learnings from their experiences. Referrers should also be involved in the design to ensure all clinician perspectives are also considered.

Once developed, training could be delivered to maternity and neonatal providers, supported with appropriate resources, so that bereaved family and whānau receive information on post mortems that is:

- Easily understood
- Provided in a supportive and culturally appropriate way that does not presuppose the outcome
- Gives confidence that the person offering the post mortem is trustworthy and well informed
- Enables family and whānau to make an informed decision on a post mortem.

Is the recommendation to develop a training package for referrers supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Service coordination

A service coordination function should be implemented. The coordinator would:

- Work in partnership with pathologists to develop relationships with referrers
- Provide an interface between the Perinatal Pathology Service and local DHBs or referrers to ensure that interaction with the Service is well managed and that pathologist and, family and whānau needs are identified and met.
- Work with family or whānau where appropriate to facilitate the post mortem process for them
- Capture and provide information on family reasons for not proceeding with post mortem to inform improvement work
- Deliver training to support referrers in seeking consent to the post mortem with grieving families and whānau.

The coordinator would focus particularly in DHBs where opportunities to improve outcomes can be achieved through increasing the rate of offer of a post mortem, or the rate of consent to a post mortem.

Is the recommendation to establish a Perinatal Pathology Service Coordinator supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

3 Meets quality and safety expectations

Demonstrated by:

- Provided in line with agreed guidelines, referral pathways and consent process
- Meets agreed standards for performance and reporting of post mortems and placenta examinations
- Meets agreed quality improvement indicators
- A common data collection and reporting system
- A common clinical record or shared care portal
- Monitored against a consistent reporting framework and evaluated regularly

Recommendation: Referral pathways are reviewed and documented

Referral pathways for a post mortem and placenta examination need to be reviewed and documented to ensure that:

- the scope of the service is clearly documented
- the information required by the pathologist for the post mortem is available, relevant and appropriate
- clinicians using perinatal pathology services are competent in issues of consent for a post mortem and in providing feedback regarding the post mortem results to families and whānau
- situations where out of hours referral is appropriate and arrangements to access the Service out of hours
- referrals for post mortem services are streamlined and directed to the appropriate provider, particularly if occurring afterhours
- families and whānau have access to appropriate support and advice, including bereavement services.

Is the recommendation to review and document referral pathways supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Quality improvement indicators are developed

Quality improvement indicators based on the defined referral pathway should be developed, and a reporting framework established to monitor quality. These should be incorporated into the updated Tier Two Service Specification.

Is the recommendation to develop quality improvement indicators supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Referral and data management processes are reviewed

Referral and data management processes are reviewed to ensure data capture of information to support monitoring and reporting of Service activity and performance.

The Tier Two Service Specification should be updated with any purchase units or reporting requirements for capturing of perinatal pathology activity within national collections.

Is the recommendation to review data management processes supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

Recommendation: Accessing a shared electronic clinical record

Options to access a shared electronic clinical record should be explored, which leverage on existing Regional IT solutions to support:

- best possible access for pathologists to reports and relevant clinical information, regardless of where the post mortem was conducted or the pathologist based
- best possible access for referrers to the completed report, regardless of the location of the post mortem.

Is the recommendation to consider options for accessing a shared electronic clinical record supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

4 Support for development of the Perinatal Pathology workforce

Demonstrated by:

- Provided by a sustainable, qualified, workforce
- Provides access to post graduate training for pathologists
- A clinical leadership, peer review and support framework
- A workforce recruitment and development plan

Recommendation: A workforce plan is developed and documented

A workforce plan is documented, describing accreditation requirements, including:

- the number, location and hours of availability of perinatal pathologists to ensure capacity to deliver equitable access to post mortems across DHB regions, and minimum volumes to maintain competency
- training pre-requisites for completing perinatal post mortems (including coronial which are outside the service)
- a training programme for mortuary technicians to support pathologists.

Is the recommendation to develop a workforce plan is supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree

Agree

Undecided

Disagree

Strongly Disagree

Are there any alternatives that should be considered? Do you have any additional comments?

5 Perinatal Pathology Services make best use of available funds

Demonstrated by:

- Fiscally responsible
- Receives funding that meets costs of providing the Service, and which is not a disincentive to referral for service

Recommendation: Funding arrangements are reviewed

Funding arrangements for the Service should be reviewed, to ensure they are consistent, meet the averaged costs of providing service, and are not a disincentive for referrers to seek a post mortem or placenta examination.

The preferred funding model is to retain the current fee for service arrangement. This would require:

- A signed memorandum of understanding with DHBs for the provision of perinatal pathology services and agreed fee schedule
- The fee for service funding model should be supplemented with a modest Programme Fee to allow administration of identified national functions, e.g. service coordination, training and development, governance, clinical leadership. This approach would require Agreement from GMs P&F on the level of programme funded. The Programme Fee would include one off funding in the first year to support the development of referral pathways, quality indicators and training resources.

Is the recommendation to review Perinatal Pathology Service Funding supported?

Please indicate the level of your agreement with this recommendation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are there any alternatives that should be considered? Do you have any additional comments?

ⁱ Paediatric Society of Australia and New Zealand. 2009. *Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, Section 4: Perinatal post-mortem examination*

ⁱⁱ Perinatal and Maternal Mortality Review Committee. 2008. *Perinatal and Paediatric Pathology Service Provision in New Zealand 2008*. Wellington.

ⁱⁱⁱ Thomas, F. (2016). Cultural gap still to be bridged for perinatal mortality investigation. *NZ Doctor*, p17.

^{iv} Ministry of Health. 2015. *Survey of Bereaved Women*. Wellington.
<http://www.health.govt.nz/publication/maternity-consumer-survey-2014>