

Genetics testing in NZ



Canterbury Health
Laboratories



Canterbury Health Laboratories

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Canterbury
District Health Board
Te Poari Hauora o Waitaha

General Manager's perspective



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The Hospital Support and Labs Division

- Canterbury Health Laboratory
- Maintenance and Engineering (Including Tech and Sterile Services)
- Support Services (Including food, cleaning, fleet, taxis, travel etc)
- 800 CDHB staff plus contractors
- 11.3% of CDHB cost centres

“I am a General Manager - I manage generally”

Mark Leggett 2006

Genetics testing



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NZ Genetics picture



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- The total Clinical Genetic services capacity is small (\$5m)
- Community and specialist referral are larger (\$9m)
- Laboratory testing for genetics/molecular (\$10m)
 - Auckland
 - Hamilton
 - Wellington
 - Christchurch

DTC Genetics



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- Very little
- Concern about costs to the health system that this type of testing may drive.
- DHB Labs will probably not drive.
- We don't have a pay for tests ethos.

BUT

- Canterbury innovation hub

There have been a number of reports



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- 1998 The Health Funding Authority – “Through the eyes of a child” National review of Paediatric services has recommendations on genetic services,
- 2002 Reports to the NHC
 - Sarfati D. Some practical aspects of genetic testing.
 - Genetic Testing Advisory Group (CTAG) Genetic Testing
 - Department of General Practice. A survey of NZ General Practitioners’ knowledge and current practice.
- 2003 The National Health Committee’s report – Molecular Genetic Testing
-
- 2009 LECG Report – Development of a National Genetic Service

Most reports say the same thing



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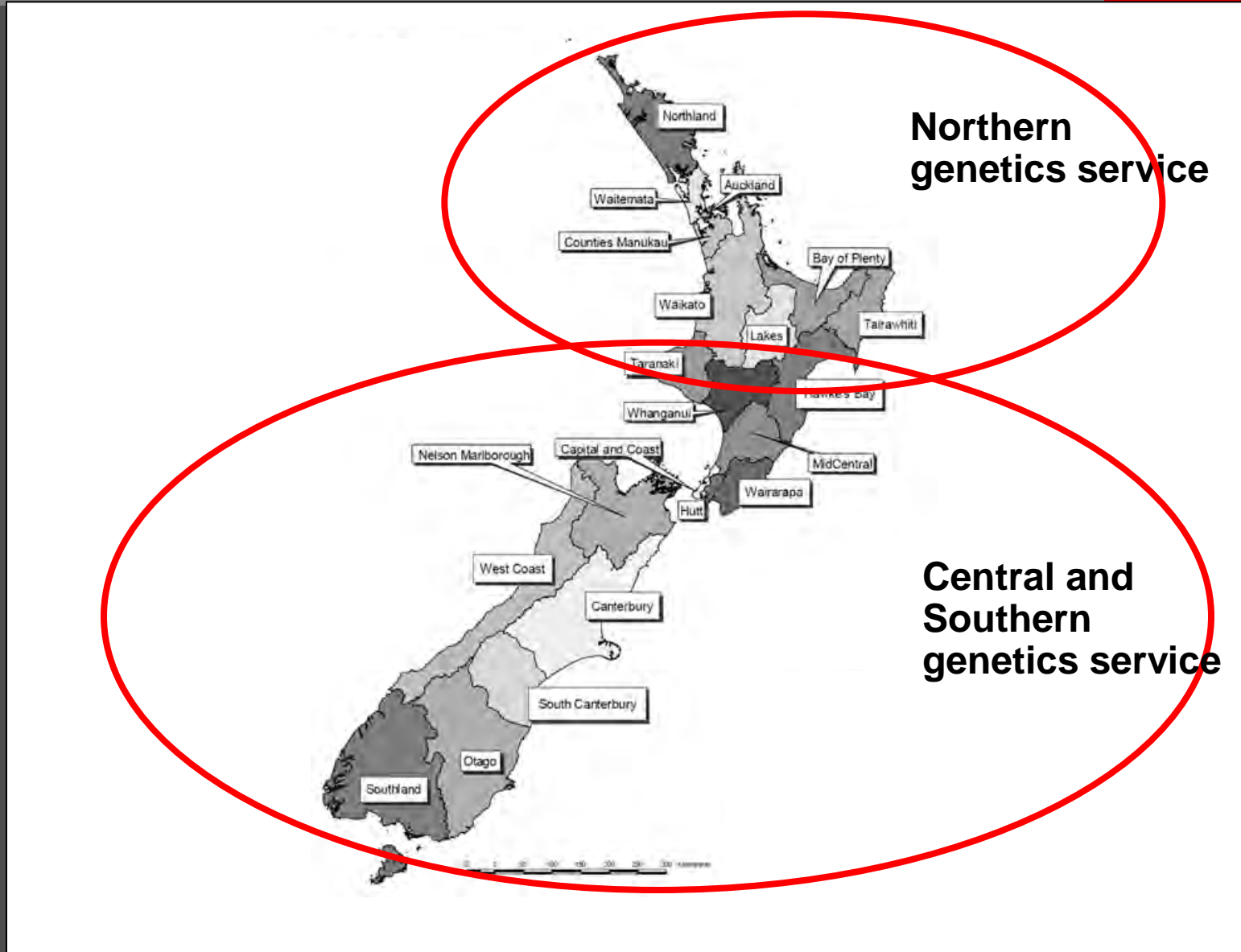
The NHC recommends that:

- the genetics workforce be increased to meet internationally recommended levels
- the provision of clinical genetic services be funded and coordinated nationally, with regional delivery
- the national service be adequately resourced to improve access to safe and effective genetic testing, with pathways identified for increasing capacity as necessary
- clinical genetic services allow for more sub-specialisation and that the specialty areas be complementary and nationally co-ordinated
- attempts be made to recruit Māori to be a part of the provision of genetic services; service provision needs to reflect the wider cultural diversity in the community where possible.

Clinical Genetics services in NZ



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NZ Population



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Ethnic Groups¹

(percentage)

European	80.1%
Māori	14.7%
Pacific peoples	6.5%
Asian	6.6%
Other	0.7%

Maori and genetics testing



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- Defined by their descent.
- Part of an interrelated universe
- Acceptance of a place for genetic testing
 - Should genetic questions be decided by individuals or collectively?
 - Who owns their genealogy (whakapapa)?
 - Whanau
 - Iwi
- Against
 - Attempts to achieve ‘perfection’
 - Change the way individuals -
 - are perceived.
 - Perceive themselves.
- Intellectual property rights to results



The NZ Laboratories



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Laboratory	Cyto genetics	Molecular genetics	Prenatal testing	Antenatal screening	Integrated clinical services	Registrar training
Lab plus	++	++	+	++ (NBS & MSS)	+/-	+
Waikato	+	+/-				
Wellington Genetic Services	+++	+	+		++	
CHL	++	+++	++ (PGD)	+	+/-	+++
IGENZ	FISH – mainly cancer					

Workforce



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CLINICAL	ADHB	CCDHB	
Clinical geneticists	3.6	3.4	
Registrar	1	1	
Associate	4.6	5.4	
Clinical Director	1	0	
Administration	2.6	3.9	

LABORATORY	ADHB	CCDHB	CDHB
Scientists / Technicians	39	22	25

NZ Funding effects



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- DHB funding has driven significant variance in
 - provision of services
 - access to testing
- Supports the status quo
- Has the potential to severely restrict testing based on economic decisions.
- Has not aligned testing to clinical practice.

- Pre-implantation Genetic Diagnosis
- Haemophilia project including ODHB, CHL and CFC
- Successful delivery of healthy twins
- Haemophilia Foundation of NZ refused ongoing funding – not treatment
- Interim funding provided from CHL operation budget
- Follow-up funding (2 years) now available



Antenatal screening



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- Down Syndrome - Funded directly from the MoH through the National Screening Unit
- Joint providers - CHL and LabPlus
 - Arrangement covered agreement between labs
 - Procurement by ADHB
- Capability funding contract
- Lead organisation required by the MoH
 - LabPlus
 - Contract between the MoH and LabPlus

NZ Laboratory Issues



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- Coordination at best is adhoc.
- Technology growth and costs.
- Capacity is small.
- Workforce and training.
- National data on genetics testing is poor.
- Poorly understood.
- Funding

Threats to Genetic Test access



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- Ministerial Review Group
 - NZ Laboratory business
 - Clinical genetics review
 - Centralisation
 - Funding
- Laboratory testing could be bound into the review of clinical genetics – LECG Report
- Not all of the population is supportive

The proposed health changes :



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- There will be a **new National Health Board (NHB)** set up within the MoH
- It will **integrate infrastructure** planning around IT, workforce and capital.
- **National responsibility** for vulnerable health services such as paediatric oncology, **clinical genetics** and major burns. **Clinical networks will play a large part in supporting and guiding these services.**
- A **shared services** board will consolidate the 21 DHBs' back office administrative functions such as payroll and bill payments.
- **Consolidation of DHB administration** like IT, payroll and purchasing are estimated to save up to \$700 million over five years.
- The changes to the health system administrative staff are expected to produce a **reduction of up to 500 jobs.**

Genetics hits the NZ radar -



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In 2007 a working group from clinical genetics services in NZ developed a proposal to establish a national NZ Genetic Service (NZGTS)

- In 2007 the National DHB CEO's not a priority
- To National Service and Technology Review committee in August 2008.
- NSTR assessed as sufficient justification for Service Planning and Intervention Assessment (SPINA) process – development of full business case.
- RFP released.
- LECG prepared draft report and circulated for consultation.
- Back for consideration and development of recommendations
- Final report to CEO's and DG with recommendations – released in a week or so.

Regulation of test access.



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The NHC recommends that:

- protocols be developed for each test approved for use and, distinguishing between diagnostic, carrier, and prediction or predisposition testing, include:
 - consent protocols
 - when and how each test should be used
 - which practitioner has access to which genetic test, based on education and training
 - the appropriateness of the use of each test for children
 - sensitivity to cultural issues and in particular, to the needs and expectations of Māori as tangata whenua
 - appropriate levels of support in decision-making for those whose decision-making may be compromised, such as those with sensory or intellectual disabilities
- a process be devised for the development of such protocols including involvement from medical geneticists, other health professionals, consumer groups, and disabled people's organisations
- GPs, specialists and medical students have increased access to genetic education; this will feed into any review of the medical curricula
- ways of making information about genetics more accessible to the public be investigated, including information about the limitations of genetic testing.

Information systems



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- First formally funded genetic registry in 2008 – Familial Bowel Cancer registry.
- Register development is adhoc.
- Given that families are across NZ and move between the North and South Islands regularly, we consider a single genetics information system is appropriate for NZ.

LECG Report

- There is no national collection of test information
 - Types and number
 - Results

Referrer Knowledge



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- The majority of genetic tests are ordered by non-geneticists
- GPs have little knowledge of:
 - Less common genetic conditions
 - Test availability, use and cost

And they do not feel confident working in this area!

Question	Correct answers	Incorrect answers	'Not sure' answers	Other	Not answered
Risk estimate					
Cystic fibrosis (n=243)	21 (8.6%)	146 (60.1%)	65 (26.8%)	–	11 (4.5%)
Huntington (n=228)	75 (32.9%)	51 (22.4%)	84 (36.8%)	–	18 (7.9%)
Type of test					
Breast cancer (n=306)	182 (59.5%)	13 (4.2%)	97 (31.7%)	9 (2.9%)	5 (1.6%)
Huntington (n=228)	50 (21.9%)	111 (48.7%)	47 (20.6%)	8 (3.5%)	12 (5.3%)



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Note: Only the electronic version is controlled. Once printed, this is no longer a controlled document.

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NZGTS - what it might look like



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- Recommendations
- Funding via a single national funder
- Provision be a lead DHB
- 3 service hubs
 - Auckland
 - Wellington
 - Christchurch
- Revised purchase framework that emphasises referrer education and utilization management as well as direct clinical service provision.
- Investment of additional funding of \$200k to support the technology assessment and utilisation management and
- Investment of \$300k to bring access in the Midland area up to that of the rest of NZ

What about the labs?



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- Probably not in this review.
- Genetic testing will be affected by the review.
- There will be a push to revisit the laboratory testing associated with genetics.
- The appropriateness of testing will be scrutinised.
- Ordering patterns are likely to be looked at.
- There will be a push to get access to national information on testing.

Labs and utilisation management



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- Coordination of test development and provision is essential.
- No one NZ lab will be able to diversify itself across all genetic diseases.
- Laboratories should play a role in
 - Education
 - Demand management
 - Development of clinical pathways.
- Laboratories have the information – it needs to be used.

Can we afford the future?



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“40 – 60 % of New Zealanders will experience a disease with a genetic component...”

Moving from testing for rare diseases to applications associated with more common diseases affecting large sections of the population.

Public awareness is growing which will increase demands on the health sector to provide genetic tests.

If we fund Genetics who misses out?



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Thank you

