



Coeliac Disease in the South: what the data tell us

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Outline of presentation

- ▶ Brief overview of the study
- ▶ What I did
- ▶ What I found
- ▶ What it might mean
- ▶ Acknowledgements

Recognising and managing Coeliac Disease in New Zealand

- There is widespread evidence worldwide that Coeliac Disease is not well recognised, and is therefore substantially under-diagnosed.
- There is also evidence that it is inconsistently managed.
- This project arose out of a desire to determine whether New Zealand is any different with respect to these issues.
- Has involved three studies:
 - A survey of Gastroenterologists
 - A survey of GPs
 - An interrogation of laboratory data relating to testing for Coeliac Disease in selected regions

The Laboratory Study

- Involved analysing data provided by SCL Dunedin relating to coeliac-related testing which has been conducted over a 10 year period.
- Asked the following questions:
 - Which coeliac serology tests are doctors requesting and how many of each have been requested?
 - How has this changed over time?
 - Which doctors (i.e. GP, Gastroenterologist, Paediatrician, or other specialist) are requesting coeliac tests?
 - How many tests are positive?
 - **How many positive serology tests are leading to patients having duodenal biopsies?**
 - **How many of those biopsies are positive?**
 - How many patients are having more than one serology test, either with or without biopsy evidence of CD?
 - What are the demographic characteristics of people tested for coeliac disease, and those with positive tests?
 - Are there any regional differences in patterns of testing?

What I did

- Obtained data, in the form of Excel spreadsheets, from SCL Dunedin, pertaining to CD-related tests that had been performed over the previous decade.
- Cleaned and sorted the data by year and region.
- Once I had collated all the positive antibody results I then went back to SCL to determine which patients had gone on to have a duodenal biopsy and who had not.
- Also included patients who were IgA deficient and those with equivocal results.
 - To do this I was given access to SCL's results databases and manually searched on every NHI number looking for histology results. This was possible for Otago-Southland, South Canterbury and Nelson Marlborough.
- Using NHI information, obtained Ethnicity data from the Ministry of Health for every person who had been tested.
- Analysed all the available information to answer my research questions.

Data provided

The initial dataset provided included over 100,000 lines of data.

Inclusion criteria for full analysis:

- ▶ came from a complete calendar year
- ▶ SCL was the only laboratory provider in the region

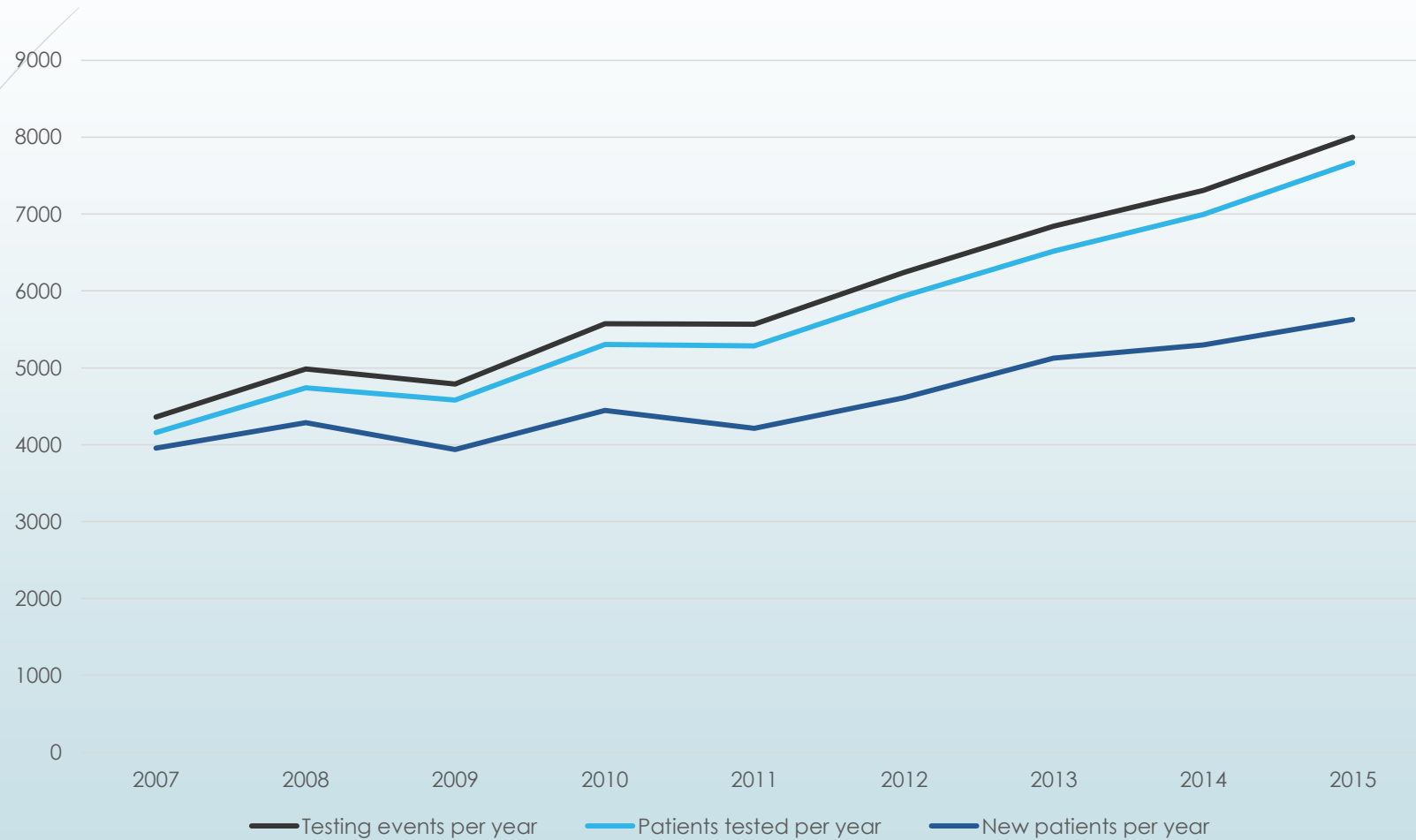
This left 65,263 lines of data:

- ▶ Otago Southland: 2007 – 2015
- ▶ South Canterbury: 2013 – 2015
- ▶ Nelson Marlborough: 2013 – 2015

Otago Southland: Tests requested

- In the 9-year period from 1 January 2007 and 31 December 2015 there were 53,665 occasions on which some form of CD-related blood test was requested from SCL in Otago Southland.
- Test requests have steadily increased from 4362 in 2007 to 8001 in 2015.
- Tests were carried out on 51,175 patients, increasing from 4157 in 2007 to 7669 in 2015. (Includes patients tested on more than one occasion.)
- By the end of 2015, 13.8% of the Otago Southland population had been tested for CD at least once in the preceding decade.
- Annual rate of new patients being tested increased from 1.37% of the population in 2007, to 1.87% of the population in 2015.

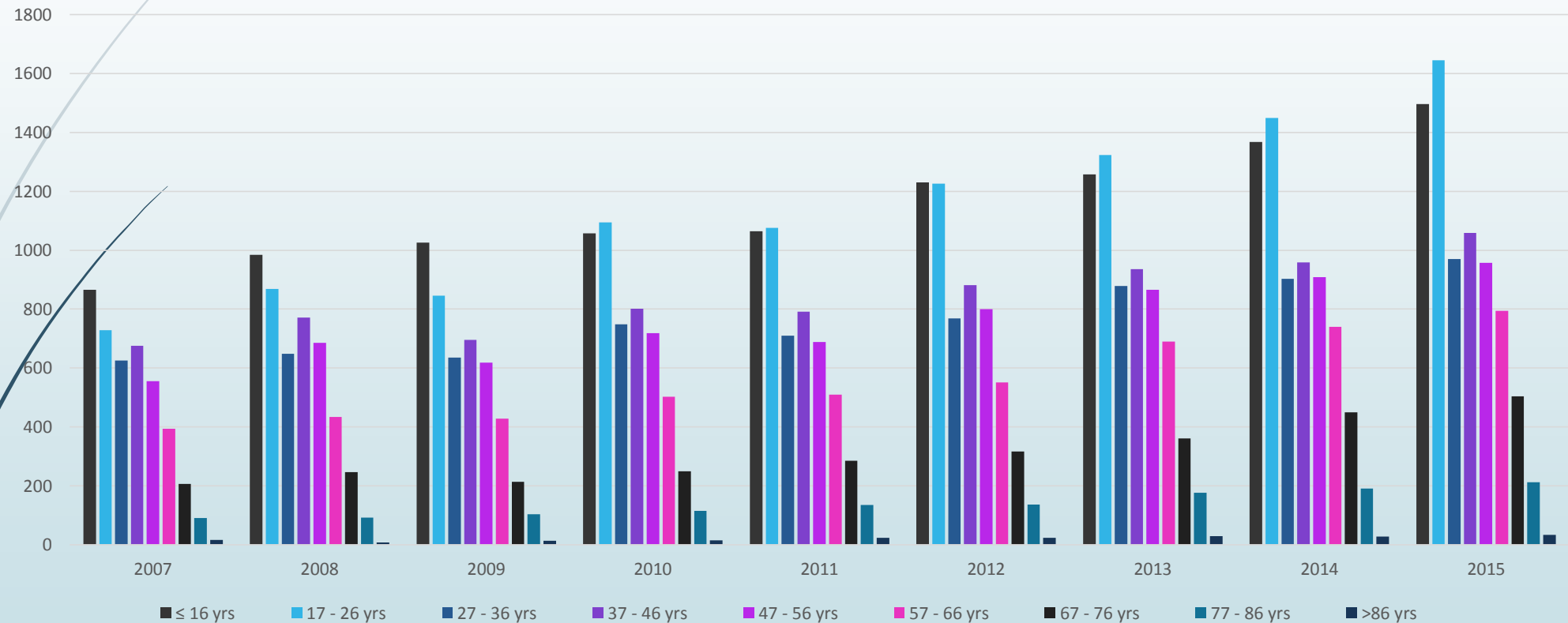
Otago Southland CD testing rates over time



Who was tested in Otago-Southland?

- Consistently more women than men, generally in a ratio of 2:1. This holds for numbers of 'testing events' per year, numbers of patients tested per year, numbers new patients tested per year, and numbers of repeat tests per year.
- Also holds across the other regions.
- Patients overwhelmingly of "NZ European" or "Other European" ethnicity.
 - 90.3% in 2007; 87.2% in 2015
- Age range: 9 days old to 98 years old.
- Mean age adults tested: 42 years old.
- Mean age children tested: 8 ½ years old.

Age ranges being tested per year



Who is doing the testing?

- ▶ Approximately 80% coming from General Practice
- ▶ Between 5% – 7% coming from Paediatrics
- ▶ Between 5% - 7% coming from Gastroenterologists
- ▶ About 10% coming from other specialty disciplines combined

Testing protocols SCL Dunedin

- ▶ SCL Dunedin uses the Inova Diagnostics Quantalite tTG kits which have an upper limit of normal of 20.
- ▶ Results are reported numerically up to 150; results higher than this are reported as >150.
- ▶ EMA tests initially carried out with Immuglo slides from Immco Diagnostices but changed to Inova kits in 2015.
- ▶ EMA tests are added when there is a high normal or raised tTG result.
- ▶ Total IgA tests are now only performed when the tTG result is not high enough for there to be certainty that the patient is not IgA deficient.
- ▶ From late 2015 DGP tests on all children up to age of 6 years, and on equivocal tTG results.

IgA-tTG test results from Otago Southland

Year	New patient tTGs	Positive tTG	% of new patient tTGs
2007	3954	137	3.46
2008	4312	173	4.01
2009	3974	155	3.90
2010	4494	166	3.69
2011	4273	154	3.60
2012	4651	142	3.05
2013	5182	157	3.03
2014	5370	164	3.05
2015	5706	171	3.00

Correlation between positive IgA-tTG and EMA results

tTG range	EMA done	EMA positive	EMA percentage positivity
≥150	647	646	99.9%
100 - 149	251	244	97.2%
60 - 99	304	245	80.6%
50 - 59	118	53	44.9%
40 - 49	238	58	24.4%
30 - 39	317	58	18.3%
21 - 29	530	24	4.5%

Rates of biopsy per IgA-tTG level

Year	Biopsy rate IgA-tTG > 150	Biopsy rate IgA-tTG 100 - 149	Biopsy rate IgA-tTG 60 - 99	Biopsy rate IgA-tTG 21 - 59
2007	73.3%	57.9%	50%	24.6%
2008	68.9%	90.5%	77.8%	42.9%
2009	65.1%	54.5%	50%	41.8%
2010	83%	80%	52.9%	43.3%
2011	81.3%	75%	50%	30%
2012	80.9%	85.7%	66.7%	35.6%
2013	72.7%	47.6%	76.9%	45.2%
2014	73.2%	52.9%	70.4%	51.4%
2015	75.4%	71.4%	77.8%	45.1%

Biopsy outcomes versus IgA-tTG level

IgA-tTG	Biopsy done	Biopsy CD positive	Positivity Rate	Biopsy normal
≥150	411	400	97.8%	6/411 (1.5%)
100 - 149	138	122	88.4%	15/138 (10.9%)
60 - 99	143	119	83.2%	18/143 (12.6%)
21 - 59	369	196	53.1%	152/369 (41.2%)

Biopsy outcomes versus EMA result

	Positive Biopsy	Normal Biopsy	Uncertain Biopsy	Totals
Positive EMA	695 (93.3%)	48 (6.4%)	2	745
Weak positive EMA	51 (79.7%)	12 (18.8%)	1	64
Equivocal/ Indeterminate EMA	9 (64.3%)	3 (21.4%)	2	14
Negative EMA	54 (29.2%)	127 (68.6%)	4	185
Totals	809	190	9	1008

Incidence of Coeliac Disease in Otago Southland

Year	Positive biopsies	Total population	Incidence rate per 100,000	Male incidence rate	Female incidence rate
2007	45	287,824	15.6	8.5	22.5
2008	70	289,424	24.2	14	34.0
2009	76	291,024	26.1	16.8	35.1
2010	75	292,624	25.8	13.2	37.6
2011	90	294,224	30.6	23.6	37.4
2012	96	295,824	32.5	18.6	45.8
2013	72	297,423	24.2	14.4	33.6
2014	98	299,023	32.8	17.1	47.8
2015	93	300,623	30.9	15.0	46.3

Incidence of Coeliac Disease in Nelson-Marlborough and South Canterbury

Year	Positive biopsies	Total population	Incidence rate per 100,000	Male incidence rate	Female incidence rate
Nelson-Marlborough					
2013	24	136,995	17.5	15.0	19.9
2014	21	137,985	15.2	17.9	12.7
2015	32	138,975	23.0	11.8	33.6
South Canterbury					
2013	7	55,626	12.6	3.7	21.2
2014	8	55,876	14.3	21.9	7.0
2015	6	56,126	10.7	18.2	3.5

What does all this mean?

- ▶ Very high IgA-tTG results using Quantalite kits are almost always associated with a positive biopsy result: supports the suggestion that biopsy might not be required to confirm the diagnosis in these patients
- ▶ Biopsy rates fluctuate among patients with IgA-tTG levels that are elevated but not in the very high range (>150). These are the people we should be encouraging to have a biopsy as the outcome is less certain and will therefore influence subsequent management.
- ▶ The incidence of CD in Otago Southland is high: it is not clear why this is the case and this warrants further investigation.
- ▶ Similar studies need to be repeated in other regions to compare the performance of tTG antibody test kits, and to determine incidence elsewhere.



Acknowledgements

- My PhD supervisors: Associate Professor Chrys Jaye, Professor Andrew Day, Associate Professor Michael Schultz
- Coeliac NZ, RNZCGP and Otago University for grants which have enabled me to obtain the necessary data
- Helen van der Loo and Roger Barton, SCL Dunedin
- Brent Glanville HealthScope
- Richard Steele and Andrew Hunter SCL Wellington
- Simon Ross, Ministry of Health and Nicole Morris, Southern DHB