BMJ open

The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003975
Article Type:	Research
Date Submitted by the Author:	09-Sep-2013
Complete List of Authors:	Chan, Wing Cheuk; Counties Manukau District Health Board, Population Health Jackson, Gary; Health Partners Consulting Group, Wright, Craig; Sapere Research Group, Orr-Walker, Brandon; Counties Manukau District Health Board, Endocrinology and Diabetes Service Drury, Paul; Auckland District Health Board, Auckland Diabetes Centre Boswell, D; Counties Manukau District Health Board, Laboratory Services Lee, Mildred; Counties Manukau District Health Board, Population Health Papa, Dean; Counties Manukau District Health Board, Population Health Jackson, Rod; University of Auckland, School of Population Health
Primary Subject Heading:	Epidemiology
Secondary Subject Heading:	Diabetes and endocrinology, Evidence based practice, General practice / Family practice, Health informatics, Public health
Keywords:	EPIDEMIOLOGY, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

TITLE: THE FUTURE OF POPULATION REGISTERS: LINKING ROUTINE HEALTH DATASETS TO ASSESS A POPULATION'S CURRENT GLYCAEMIC STATUS FOR QUALITY IMPROVEMENT

Authors' names

Corresponding author:
WC Chan, Public Health Physician, Counties Manukau District Health Board.
Address: Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand
Email: wingcheuk.chan@cmdhb.org.nz
Phone: + 64 9 2599658
Fax: +64 9 259 9665

Authors' positions and Addresses

Wing Cheuk Chan, FNZCPHM, Public Health Physician, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: wingcheuk.chan@cmdhb.org.nz

Gary Jackson, FNZCPHM, Public Health Physician, Health Partners Consulting Group. PO Box 147209, Ponsonby, Auckland, New Zealand. Email: gary@healthpartnersconsulting.com

Craig Shawe Wright, BSc, Senior Managing Consultant, Sapere Research Group, PO Box 587, Wellington, 6140. Email:cwright@srgexpert.com

Brandon Orr-Walker, FRACP, Clinical Head, Endocrinology and Diabetes Service, Counties Manukau District Health Board, Private Bag 94052, 2240, South Auckland Mail Centre, New Zealand. Email: Brandon.Orr-Walker@middlemore.co.nz

Paul L Drury, FRCP, Clinical Director, Auckland Diabetes Centre, Auckland District Health Board. Greenlane Clinical Centre, PO Box 92189, Auckland, New Zealand. Email: PaulD@adhb.govt.nz

D Ross Boswell, PhD, Clinical Director of Laboratory Services, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email:Ross.Boswell@middlemore.co.nz

Mildred Ai Wei Lee, MSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: Mildred.Lee@middlemore.co.nz

Dean Papa, BSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: j.papa@xtra.co.nz

Rod Jackson, PhD, Professor of epidemiology. School of Population Health, University of Auckland, Auckland, New Zealand. Private Bag 92019, Auckland, 1142, New Zealand. Email: rt.jackson@auckland.ac.nz

Number of tables: 3

Number of figures: 2

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Abstract:

Objectives: To determine screening levels and the glycaemic status of all individuals within a defined geographic location in a timely and consistent way to facilitate systematic disease prevention and management.

Design: Retrospective observational study.

Setting: Auckland region of New Zealand.

Population: We used an encrypted national health identification number to link multiple routine health datasets to identify almost all individuals eligible to utilise health service in the Auckland region of New Zealand in 2010.

Outcome measures: The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004. The two outcomes measures were glycaemia-related blood testing coverage (HbA1c, fasting and random glucose and glucose tolerance tests), and the proportions and number of people with known dysglycemia in 2010 using modified ADA and WHO criteria.

Results: There were 1,475,347 people in the health service utilisation population in 2010 in the Auckland region. Within the health service utilisation population, 792,560 people had had at least one glucose or HbA1c blood test in the previous 5·5 years. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,982) in the recommended age groups for diabetes screening had a blood test to assess their glycaemic status. Estimated age-standardised prevalence of dysglycemia was highest in people of Pacific Island ethnicity at 11·4% for males and 11·6% for females, followed closely by people of Indian ethnicity (10·8% and 9·3%). Among the indigenous Maori population the prevalence was 8·2% and 7·0%, while for 'Others' (mainly Europeans) it was 3·0% and 2·2%.

Conclusion: We have demonstrated that a laboratory repository can be linked to national administrative datasets to provide individual level clinical information relevant to quality improvement, for a large geographically defined population.

Keywords: diabetes mellitus, hyperglycemia, quality improvement, quality indicators, prevalence, epidemiology, health status disparities, mass screening.

Article summary

Article focus

- This article aims to demonstrate the potential value of data linkage of multiple routine health datasets to determine screening levels and the glycaemic status of all individuals within a defined geographic location to facilitate systematic disease prevention and management.

Key messages

- Glycaemia related blood testing is common. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for cardiovascular risk assessment had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010.
- The prevalence of dysglycaemic status as defined by a consistent definition varies markedly by age and ethnicity.
- If the data linkage methodology used in this study were implemented in a live electronic population register, one could readily identify individuals who were yet to be screened for diabetes and people who more likely to benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way.

Strengths and Limitations of the study

- This study applied a method that aims to address the common systematic biases seen in many population diabetes prevalence studies such as incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, and misdiagnosis.
- The definition of dysglycaemia included people with confirmed diabetes as well as people who require follow up tests to confirm the formal diagnosis of diabetes.
- The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

Introduction

The number of people with diabetes globally increased by almost 200 million from 1980 to 2008.[1] In the context of a potential "diabetes epidemic", an accurate and timely measure of diabetes prevalence is critical to inform policy making, resource allocation and planning and implementation of interventions to improve the quality of care for the people with diabetes. Moreover, a consistent and systematic way to identify individuals for diabetes screening, follow-up and management is necessary to ensure people with diabetes receive the most appropriate care. Indeed, randomised controlled trials have demonstrated that the use of electronic patient registers, patient and clinician reminders are associated with quality improvement in diabetes management.[2] However, the limitations of existing methods to identify populations with diabetes include incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, misdiagnosis, lack of precision by age, gender or ethnicity, and inadequate adjustments for migrations or deaths.[1,3-6]

Auckland (New Zealand) has an ethnically diverse population of over 1·4 million people. The aim of this study is to use longitudinal laboratory results from a regional laboratory repository to estimate glycaemia test coverage and glycaemic status in a geographical defined population in 2010. This study proposes a set of methods that utilise "real-world" routinely collected data in a practical manner that can provide critical and succinct information for the responsible clinicians that is robust enough at the individual level for quality improvement as well as estimates at the aggregated population level.

Methods

Date sources

TestSafe is a comprehensive data repository containing all the community and hospital laboratory test results requested in the Auckland metropolitan region in New Zealand since July 2006. Individual patient laboratory tests can be requested by general practitioners, privately or publicly funded specialists, resident medical staff or other allied health workers. Prior to July 2006 only hospital test results and community results that were sent to secondary care clinicians were recorded in the data repository. Fasting glucose, random glucose, 2 hour post glucose load values (standard 75g oral glucose tolerance test OGTT), and HbA1c results from 1 Jan 2004 to 30 Jun 2010 were sourced from the TestSafe repository. The following routine administrative datasets were sourced from the Analytical Services team within the National Health Board of the Ministry of Health (MOH) (formerly known as the New Zealand Health Information service (NZHIS)):

- National Minimum Dataset (hospital events) (NMDS)
- National Non-admitted Patient Collection (outpatients and community visits) (NNPAC)
- Pharmaceutical Collection (PHARMHOUSE)
- Laboratory Claims Collection (note: does not include test results)
- Primary Health Organisation Enrolment Collection
- General Medical Subsidy Data Mart
- National Mortality Collection
- National Immunisation Register.

Data linkage

Virtually all health service users in New Zealand are assigned a unique identifier called National Health Index (NHI). The NHI coverage is estimated to be 98% of the New Zealand population.[7] All NHIs used in this study were encrypted to protect privacy and confidentiality of health information. Record linkage of various data sources were carried out using encrypted NHIs. Ethical approval was obtained from The New Zealand Northern X Regional Ethics Committee (NTX/10/EXP/153) and access of TestSafe laboratory results was approved by Auckland Regional Information Systems Group (RISG).

Inclusion criteria of the study

The linkage of the available administrative datasets by unique encrypted NHI was undertaken to derive the "health service utilisation (HSU) population". This was defined as New Zealand residents who resided within the boundaries of the three District Health Boards located in the Auckland metropolitan region and received any of the publicly-funded health services in New Zealand between 1 July 2009 and 30 June 2010, namely:

- Currently enrolled in a Primary Health Organisation (PHO) or people who had a health service contact with a PHO,
- Publicly funded inpatient and outpatient secondary care events (including mental health and emergency department contact),
- Any community pharmaceutical dispensing,
- Any community laboratory test (including outside the Auckland metropolitan region) including the ones requested by privately funded health professionals,
- Any immunisation received as indicated by the national immunisation register.

Deceased individuals were excluded from the HSU population using the National Mortality Collection. In New Zealand, PHOs supply general practitioner services and are publicly funded, receiving a capitation payment for each enrolee. PHOs are required to provide a defined set of essential services which include appropriate evidence based screening, risk assessment and the use of recall and reminder systems.[8]

Numerator 1: glycaemic status test coverage

The glycaemic status test coverage by age and ethnicity was estimated as the proportion of the HSU population who had at least one glucose or HbA1c blood test recorded in TestSafe repository from 1 Jan 2004 to 30 Jun 2010. Lab tests with missing results or results with <1mmol/L for glucose test, or <1% of HbA1c were excluded.

$$\text{The glycaemic status test coverage} = \frac{\text{The number of people who had at least one diabetes blood test in Auckland metro from 1/01/2004 to 30/06/2010}}{\text{Corresponding number of people in the health service utilisation population.}}$$

Definition of dysglycemia

The definition of diabetes recommended by American Diabetes Association in 2010 and the World Health Organization consultation in 2011 was modified for this "real-world" study,[9,10] and termed

"dysglycemia". The operational definition of this study was to identify a cohort of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications rather than only the people who had a confirmed diagnosis of diabetes. This defined cohort should be followed up by the health care system for ongoing clinical support and management. The dysglycemic status was derived directly from the laboratory results recorded in a TestSafe laboratory repository for each person in the HSU population. Duplicated test results with identical lab numbers for the same person were removed. A person was defined to have dysglycemia if they had:

- at least one **HbA1c** test ≥ 6·5% (equivalent to 48 mmol/mol) or
- at least one 2 hour post glucose load ≥ 11·1 mmol/l on a **Glucose tolerance test (GTT)**
- two or more tests of **random glucose** ≥ 11·1 mmol/L and/or **fasting glucose** ≥ 7·0 mmol/L on a different day.

For young children less than 10 years of age in 2010, hospital requested glucose tests were not examined because high glucose results in hospital for young children are more likely to relate to artificial nutritional feeds or parenteral nutrition than to diabetes.

Comparison to hospital diagnosis

People within the HSU population who had a previous hospitalisation with a primary or secondary diagnosis of diabetes (ICD 10 codes Edition 3 E10-E14, and O240-O243) from 1 July 1999 to 30 June 2010 in New Zealand were compared against the laboratory diagnosis of dysglycemia as defined by this study.

Demographic variables

The dysglycemic status for each person within the HSU population was determined by the blood test results. The demographic variables including adjustment for migration and deaths were made in an identical way for both the numerator (people who had at least one glucose or HbA1c blood test or people with dysglycemia) and denominator (HSU population which includes people with dysglycemia or diabetes). Ethnicity was determined as per ethnicity data protocols published by the New Zealand Ministry of Health using the prioritised method.[11] Age was calculated from date of birth with reference to 1 Jan 2010.

Age standardisation

The prevalence proportions were separated into 5-year age groups from <15 to ≥85 for direct age standardisation using the World Health Organization (WHO) World population as the standard.[12] 95% confidence intervals are presented.

Results

There were 1,475,347 people living in the Auckland metropolitan region as defined by the HSU population in June 2010. A total of 4,281,599 glucose and HbA1c blood tests were analysed from 792,588 people who had at least one glycaemia related blood test in the study period. There were 1,458,350 tests performed in laboratories based in hospitals (34% of the total) and 2,823,249 tests performed by community laboratories (66%). There were 38 people who had a glycaemia related blood test but did not have a gender recorded, and all had age recorded. The proportions of people receiving at least one glucose or HbA1c blood test by age, gender and ethnicity are shown in Tables

1 and 2. The age groups highlighted in yellow are the recommended age ranges for diabetes screening as per New Zealand Cardiovascular Guidelines.[13]

Table 1: Proportion of males receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	15·1%	15·6%	16·1%	10·5%	10·9%	14·3%	14·4%	24,465
15-19	25·9%	23·9%	23·7%	16·9%	17·1%	25·5%	24·2%	12,989
20-24	41·1%	38·5%	36·4%	26·3%	28·3%	38·3%	37·3%	18,590
25-29	44·2%	43·0%	42·2%	29·0%	34·5%	40·2%	39·9%	18,811
30-34	49·9%	51·2%	54·5%	36·5%	40·0%	43·4%	45·8%	20,744
35-39	58·7%	60·5%	66·9%	49·7%	51·7%	51·1%	54·5%	28,010
40-44	66·8%	70·4%	78·0%	58·6%	59·1%	61·7%	64·2%	34,175
45-49	75·1%	77·4%	83·5%	66·8%	68·1%	70·9%	72·5%	38,417
50-54	82·4%	84·8%	87·5%	76·9%	76·4%	79·3%	80·4%	36,440
55-59	88·3%	89·1%	88·2%	79·2%	80·3%	85·2%	85·4%	32,353
60-64	92·5%	90·9%	88·9%	84·4%	86·3%	89·3%	89·2%	30,043
65-69	94·3%	92·1%	87·8%	84·5%	88·2%	92·0%	91·4%	22,206
70-74	95·8%	92·1%	88·6%	87·1%	88·3%	94·2%	93·1%	16,649
75-79	95·1%	92·2%	90·1%	88·3%	85·7%	94·9%	93·9%	11,730
80-84	96·1%	90·6%	89·8%	87·8%	84·7%	96·0%	95·0%	8,276
>85	98·3%	87·6%	87·0%	85·0%	84·7%	95·9%	95·1%	5,670
Total								**359,567**

Note: table order reflects ethnicity priority order; "Other" includes those of European descent.

Table 2: Proportion of females receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	12·9%	12·9%	14·5%	8·8%	8·8%	12·7%	12·5%	20,123
15-19	36·6%	27·4%	29·4%	18·1%	17·7%	33·4%	30·6%	16,855
20-24	59·9%	52·1%	50·3%	32·5%	36·1%	50·3%	50·2%	27,144
25-29	65·8%	64·4%	61·0%	40·6%	47·3%	52·3%	54·9%	31,348
30-34	67·4%	68·4%	70·7%	54·4%	53·3%	58·5%	61·5%	34,129
35-39	69·5%	71·0%	76·7%	61·6%	56·6%	63·0%	65·2%	39,085
40-44	72·2%	75·2%	80·1%	68·1%	63·3%	66·9%	69·2%	41,014
45-49	79·4%	81·2%	85·7%	76·7%	68·3%	71·8%	74·6%	42,334
50-54	84·8%	85·8%	89·1%	81·0%	77·7%	78·5%	80·6%	38,528
55-59	88·6%	88·8%	87·8%	81·4%	83·5%	83·2%	84·3%	33,735
60-64	92·3%	91·4%	88·0%	85·9%	86·4%	86·9%	87·6%	30,489
65-69	94·6%	91·4%	89·2%	86·9%	86·3%	90·3%	90·3%	23,404
70-74	95·2%	93·4%	89·7%	87·7%	87·5%	92·7%	92·3%	18,120
75-79	94·8%	92·3%	89·0%	89·1%	85·8%	94·6%	93·7%	13,754
80-84	95·5%	89·0%	87·8%	87·2%	88·4%	95·6%	94·6%	11,095
>85	97·4%	90·8%	87·3%	88·6%	80·2%	96·1%	95·5%	11,796
Total								**432,953**

The test coverage varies by age, gender and ethnicity. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for diabetes screening had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010. There were a total of 78,828 people with dysglycemia as defined by this study living in the Auckland metropolitan region in 2010 identified by the laboratory results. Crude prevalence was 5·3% overall (with 5·7% males, 5·0% females). Pacific and Indian ethnicities had the highest age standardised prevalence in Auckland metropolitan region. There were 31,282 people in the HSU population who had been discharged from hospital in New Zealand with a discharge diagnosis of diabetes between 1 July 2000 and 30 June 2010. Of these people, 91% (n=28,489) also had laboratory results consistent with dysglycemia defined by this study.

Table 3: Estimated prevalence of dysglycemia in Auckland metropolitan region by gender and ethnicity

Males							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,378	10,078	4,440	2,343	1,911	17,415	40,565
HSU population number	83,473	114,660	41,571	42,358	34,081	392,962	709,105
Crude prevalence (%)	5·2	8·8	10·7	5·5	5·6	4·4	5·7
Age standardised prevalence (%) with 95% confident interval	8·2 (7·9 – 8·4)	11·4 (11·2-11·5)	10·8 (10·6-11·1)	4·6 (4·4-4·7)	6·4 (6·2-6·7)	3·0 (3·0 - 3·1)	4·9 (4·8-4·9)
Females							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,570	11,751	3,738	2,476	1,773	13,952	38,260
HSU population number	89,808	121,935	42,438	53,527	42,583	415,830	766,121
Crude prevalence (%)	5·1	9·6	8·8	4·6	4·2	3·4	5.0
Age standardised prevalence (%) with 95% confident interval	7·0 (6·8-7·2)	11·6 (11·4-11·8)	9·3 (9·1-9·6)	3·9 (3·8-4·0)	4·9 (4·7-5·1)	2·2 (2·1-2·2)	4·1 (4·1-4·2)

Figure 1: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (males)

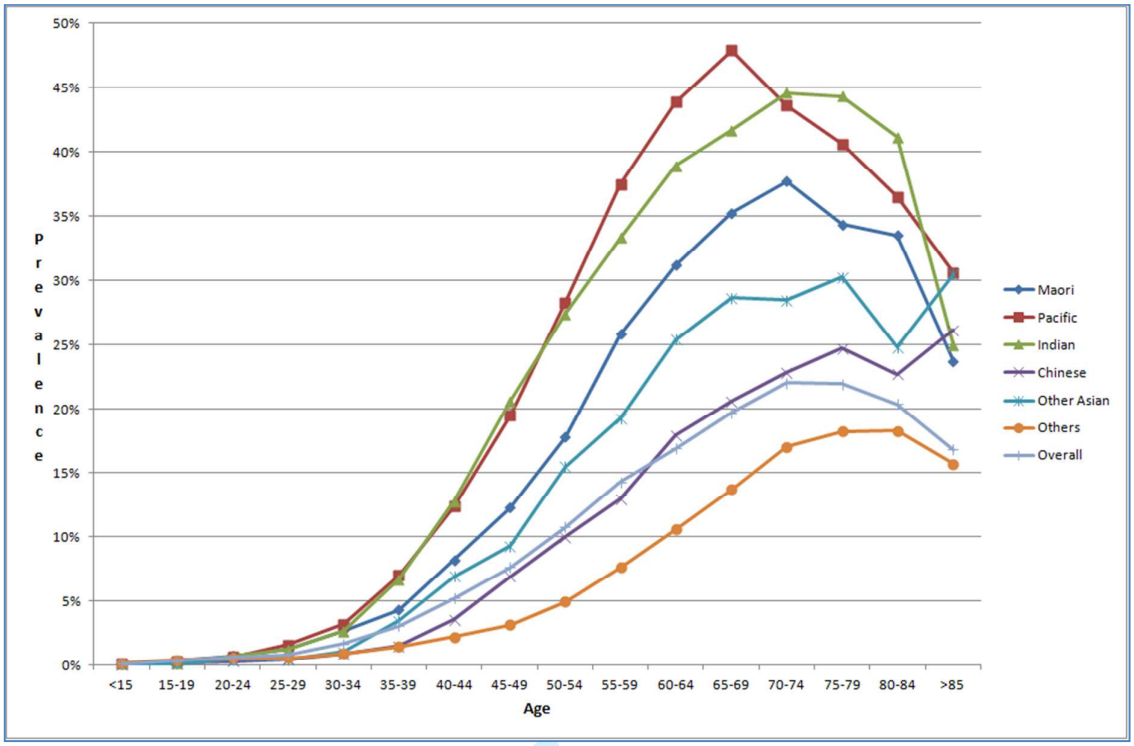
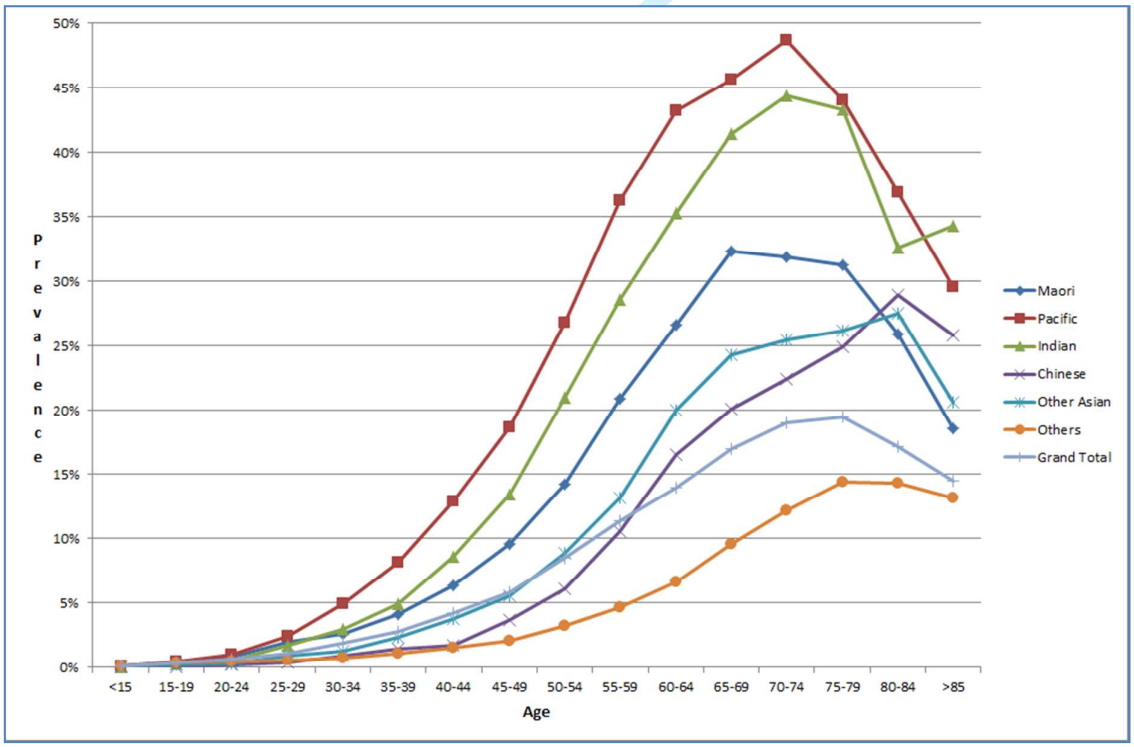


Figure 2: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (females)



Discussion

This study estimated prevalence of dysglycemia in a consistent manner within a geographically defined population of over 1·4 million, by age, gender and ethnicity based on longitudinal laboratory results sourced from a comprehensive regional laboratory repository. If the data linkage methodology used in this study were implemented in a live electronic population register, one could readily identify individuals who were yet to be screened for diabetes and people who would probably benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way. We have demonstrated that glycaemia-related blood testing coverage is very high in the Auckland metropolitan region, and apparently higher than previously reported in Ontario, Canada in 2005.[6] In Auckland, more than 85% of men and 84% of women over 55 in 2010 have had one or more glucose or HbA1c blood tests since 2004. Females of child-bearing age (aged 15-49) were also more likely to have glucose or HbA1c blood tests than their male counterparts for comparable age and ethnic groups. Overall, the blood test coverage of females between 15 and 49 years of age was 7·7% higher than males.

Consistent with the New Zealand CVD risk management guideline recommendation to screen Maori, Pacific and Indian people 10 years earlier than others, the age-specific blood test coverage was higher in these ethnic groups than other groups in the age groups between 35 and 45 years for males and between 45 and 55 years for females.[13] Since 34% of blood tests were carried out in hospital laboratories, it was likely that a number of tests were undertaken because of symptoms related to diabetes rather than opportunistic screening for diabetes. Since the rate of hospital admissions increases with advancing age, the relatively high coverage of diabetes testing in the older groups may be in part a result of routine glucose testing for most patients admitted to hospitals.

Consistent with previous reports, the ethnic disparities in prevalence of dysglycemia were alarming.[14] The age-specific prevalence of Pacific and Indian people were more than 25% higher in absolute terms across a number of age groups compared to 'others' where the highest age-specific prevalence estimates were below 19% in males, and 15% in females. These findings highlight the critical need for both primary and secondary prevention efforts to reduce ethnic disparities in diabetes-related morbidity and mortality. A previously published estimate of diabetes prevalence for the southern part of the region (CMDHB) in 2006/7, was about 20% lower in relative terms (a difference of >5,000 people) than in the current study.[15] The key methodological difference between the studies was the availability of blood test results in the current study, whereas the previous study relied on an algorithm based on hospitalisations, drug treatment and the number of HbA1c tests (without the test results being available) to estimate diabetes prevalence. Demographic changes; improvement in screening; differences in definitions of diabetes and dysglycemia and a real increase in the underlying diabetes prevalence since 2006/7 are likely to explain the difference of results between the studies.

The HSU population (denominator) was constructed from national routinely collected administrative data; it defined the population at risk and effectively adjusted for migration and deaths. The use of current PHO enrolment and/or evidence of health service contact are pragmatic proxies to indicate

that the HSU population residing in the Auckland metropolitan area within the defined period of the study. The novelty and strength of this study was that both the test coverage and the dysglycemic status of each individual in the HSU population in 2010 were determined by the longitudinal laboratory results in a consistent manner through individual person record linkage using a unique identifier, the encrypted NHI.

The use of the HSU population as the denominator on which to base future population registers for many long-term conditions has many technical and practical advantages in policy making and quality improvement. The HSU population (n=1,475,347) was very similar to the estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 (n=1,477,600).[16] In practical terms, virtually everyone with significant disease who resides in the Auckland metropolitan area is likely to be currently enrolled in a primary care practice and/or have had a contact with publicly funded health services in the year. The way the HSU population was defined means that if identifiable data were used as part of a population register, it can identify any potential performance gaps that a health care provider can address at the individual level. Eligible patients could be readily recalled based on latest contact details from primary care enrolment or from the last health service contact. This is particularly important in a context where the actual care that patients received might be suboptimal.[17] For example, a systematic recall system can theoretically be set up for those people who are yet to be screened using the identical record linkage carried out by this study. As pharmaceutical dispensing data can be linked by NHI in New Zealand, a similar systematic system could also be implemented to monitor the care provision for people who are at high risk of complications. For example, it would be possible to recall those with diabetes and microalbuminuria that were not dispensed an angiotensin-converting enzyme inhibitor or angiotensin II receptor antagonist, or people with poorly-controlled diabetes who may need further clinical review or self-management support. Many chronic care models such as Wagner's emphasised the value of clinical information systems and the role of a population registry to facilitate the provision of systematic proactive care to patients with long term conditions.[18] Indeed, an integrated electronic health record system that contains laboratory results, pharmaceutical use, and utilisation of services has recently been highlighted as critical components to measure the quality of care provided.[19]

Other advantages of the HSU population used in this study include the elimination of numerator-denominator biases highlighted in previous reports.[20,21] Furthermore, the participation of all of the laboratories serving the area in the study, meaning virtually 100% of the laboratory tests performed in the Auckland metropolitan area were included. The long-standing use of the data repository, and its incorporation in day-to-day general practice also contributes to the completeness and robustness of the data stored.

This study addressed many of the limitations of common sources of data that are used to estimate diabetes prevalence – these are summarised in Table 4.[1,3,4,22-25] Many traditional epidemiological studies are based on surveys that are subject to selection bias and patient recall biases.[1,4] Self-reported diabetes prevalence estimates are often lower than estimates based on biochemical results.[4] Most epidemiological surveys have relied on one single laboratory measurement, however glucose tolerance tests have limited repeatability and glucose measurements have considerable intra-individual variations.[22,26] While some registers have sourced data from primary care, the quality of input data and consistency of coding could be highly variable.[3,23,27] While the UK NHS

Quality and Outcomes Framework (QOF) recommends a systematic approach to diagnose diabetes, primary care providers are not required to provide supporting description on how the diabetes diagnoses are made, other than a record of a diabetes diagnosis for the purpose of the QOF indicator.[28] Indeed, QOF openly acknowledges that there are a substantial number of people who are undiagnosed or misdiagnosed.[28] The ability to keep an up to date record of people with 'diagnosed' diabetes would also be more challenging in places where there is a highly mobile population such as in New Zealand, certain parts of Great Britain and the United States.[29-31] Furthermore, a significant number of blood test results may not be requested by the general practices that are currently responsible for the patients' care. For example, as demonstrated in this study, significant numbers of laboratory tests were carried out in hospitals.

For these reasons, applying the methodology used in this study to construct a population register could enable a systematic approach to identifying the population eligible but yet to be screened for diabetes within a defined period or people who might have abnormal diabetes laboratory results who would benefit from proactive follow up as defined by this study to allow a more systematic recording of people who had known diabetes according to the biochemical results in a consistent manner.

Table 4: The limitations of common sources of data used to estimate diabetes prevalence

Sources of data	Limitations
Self-report survey	Selection/ sample bias, patient recall bias, limited sample size
Survey with one laboratory test	Selection bias; cross-sectional measure, poor repeatability with glucose tests, estimates the undiagnosed diabetes based on patient recall or medical records, not necessarily unknown to the entire health system
Primary care records	Inconsistency in primary care coding, subject to migration bias, may miss diagnosis at secondary care or other health care providers, limited sensitivity in general
Hospitals	Only identifies those with diabetes who attended hospital, recent changes in ICD coding standards may affect consistency. Major undercount
Pharmaceutical dispensing data	Diet-controlled diabetes would not be captured; adherence is not perfect in the community. Medications may have other indications such as metformin in polycystic ovarian syndrome or may be being used to 'prevent' diabetes
Combination of datasets	Depends on quality of the datasets combined. Needs a unique patient identifier for linkage to avoid double counting. The definition of diagnoses may not be consistent across the datasets
Capture- recapture	Identifies people with diabetes not captured by the system, (note - not undiagnosed diabetes). Assumes list independence, and probability of being captured by each dataset is the same. The estimates can be influenced by factors that are completely unrelated to diabetes prevalence such as changes in ICD coding standards, or admission threshold, and treatment trends. One cannot identify the individuals.

The definition of dysglycemia used in this study is a pragmatic one which identifies a group of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications and need to be followed up by the health care system for ongoing clinical support and management.[32-35] People with borderline elevated HbA1c may be offered dietary advice and the HbA1C test may not necessarily be repeated immediately in the "real-world" as it does not change immediate

management. Strictly speaking, these people would not yet have met the diagnostic criteria of diabetes. However, they should have follow up tests to confirm or exclude the diagnosis of diabetes. Moreover, the proposed method of this study can be refined further to apply the different diagnostic threshold of HbA1C according to ethnicity or to local recommendations.[36,37]

Another limitation of this study is the imperfect sensitivity as it was based on "real-world" data of relatively short duration, and the way dysglycemia is currently defined the study would not have identified people with dysglycemia or diabetes who were lost to follow-up. However, more than 91% of the HSU population who had a diabetes-related hospitalisation in New Zealand between 1 July 2000 and 30 June 2010 also had laboratory results consistent with the diagnosis. This finding suggests a regional laboratory repository of such duration (community test results for 4 years and hospital test results for 6·5 years) would already capture a substantial proportion of people with diabetes. Many people who had a single elevated glucose test might not be followed up (to get the second test required for diagnosis). This study would also miss people who had diabetes diagnosed by laboratory tests performed outside the Auckland metropolitan area or diagnosed before 2004 and subsequently had had excellent diabetes control. However, these cohorts would be identified in subsequent iterations of the population register if their diabetes control deteriorated in the future. The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

In conclusion, a regional laboratory result repository linked to administrative datasets can provide highly relevant and consistent information to inform clinical decision making in a comprehensive and timely manner as well as being an excellent epidemiological surveillance tool.

Role of funding source:

This study was conducted as a result of the work undertaken for Counties Manukau District Health Board (CMDHB), New Zealand. WCC, GJ, BOW, DRB, MAWL, and DP were paid employees of CMDHB at the time of the study. Views expressed in this publication are those of the authors and not necessarily those of CMDHB.

Conflicts of interests:

We declare no support from any organisation for the submitted work; BOW had received remuneration from the New Zealand Ministry of Health, as the former National clinical director responsible for sector engagement on population health targets. BOW had received payment for lectures from Novo-Nordisk, AstraZeneca, Sanofi and MSD.

Contribution statements:

WCC designed the study methods, applied approval for access for all the relevant data, undertook literature search, record linkage, cross checking, statistical analysis, and drafted up and revised the paper. He is the guarantor. GJ designed the study methods, and revised the paper. CW designed the study methods, linked the administrative data to construct the health service utilisation population, and revised the paper. BO-W designed the study methods and revised the paper. PLD provided clinical diabetes input and revised the paper. DRB designed the study methods and revised the paper.

MAWL undertook record linkage, cross checking, and statistical analysis. DP undertook record linkage and data extraction for cross checking. RJ designed the study methods and revised the paper.

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BMJ open

The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003975.R1
Article Type:	Research
Date Submitted by the Author:	17-Feb-2014
Complete List of Authors:	Chan, Wing Cheuk; Counties Manukau District Health Board, Population Health Jackson, Gary; Health Partners Consulting Group, Wright, Craig; Sapere Research Group, Orr-Walker, Brandon; Counties Manukau District Health Board, Endocrinology and Diabetes Service Drury, Paul; Auckland District Health Board, Auckland Diabetes Centre Boswell, D; Counties Manukau District Health Board, Laboratory Services Lee, Mildred; Counties Manukau District Health Board, Population Health Papa, Dean; Counties Manukau District Health Board, Population Health Jackson, Rod; University of Auckland, School of Population Health
Primary Subject Heading:	Epidemiology
Secondary Subject Heading:	Diabetes and endocrinology, Evidence based practice, General practice / Family practice, Health informatics, Public health
Keywords:	EPIDEMIOLOGY, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

TITLE: THE FUTURE OF POPULATION REGISTERS: LINKING ROUTINE HEALTH DATASETS TO ASSESS A POPULATION'S CURRENT GLYCAEMIC STATUS FOR QUALITY IMPROVEMENT

Authors' names

Corresponding author:
WC Chan, Public Health Physician, Counties Manukau District Health Board.
Address: Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand
Email: wingcheuk.chan@cmdhb.org.nz
Phone: + 64 9 2599658
Fax: +64 9 259 9665

Authors' positions and Addresses

Wing Cheuk Chan, FNZCPHM, Public Health Physician, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: wingcheuk.chan@cmdhb.org.nz

Gary Jackson, FNZCPHM, Public Health Physician, Health Partners Consulting Group. PO Box 147209, Ponsonby, Auckland, New Zealand. Email: gary@healthpartnersconsulting.com

Craig Shawe Wright, BSc, Senior Managing Consultant, Sapere Research Group, PO Box 587, Wellington, 6140. Email:cwright@srgexpert.com

Brandon Orr-Walker, FRACP, Clinical Head, Endocrinology and Diabetes Service, Counties Manukau District Health Board, Private Bag 94052, 2240, South Auckland Mail Centre, New Zealand. Email: Brandon.Orr-Walker@middlemore.co.nz

Paul L Drury, FRCP, Clinical Director, Auckland Diabetes Centre, Auckland District Health Board. Greenlane Clinical Centre, PO Box 92189, Auckland, New Zealand. Email: PaulD@adhb.govt.nz

D Ross Boswell, PhD, Clinical Director of Laboratory Services, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email:Ross.Boswell@middlemore.co.nz

Mildred Ai Wei Lee, MSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: Mildred.Lee@middlemore.co.nz

Dean Papa, BSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: j.papa@xtra.co.nz

Rod Jackson, PhD, Professor of epidemiology. School of Population Health, University of Auckland, Auckland, New Zealand. Private Bag 92019, Auckland, 1142, New Zealand. Email: rt.jackson@auckland.ac.nz

Number of tables: 3

Number of figures: 2

Title: The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Abstract:

Objectives: To determine diabetes screening levels and known glycaemic status of all individuals by age, gender and ethnicity within a defined geographic location in a timely and consistent way to potentially facilitate systematic disease prevention and management.

Design: Retrospective observational study.

Setting: Auckland region of New Zealand.

Participants: 1,475,347 people who had utilised publicly funded health service in New Zealand and domicile inthe Auckland region of New Zealand in 2010. The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004.

Outcome measures: The two outcomes measures were glycaemia-related blood testing coverage (HbA1c, fasting and random glucose and glucose tolerance tests), and the proportions and number of people with known dysglycemia in 2010 using modified ADA and WHO criteria.

Results: Within the health service utilisation population, 792,560 people had had at least one glucose or HbA1c blood test in the previous 5.5 years. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,982) in the recommended age groups for diabetes screening had a blood test to assess their glycaemic status. Estimated age-standardised prevalence of dysglycemia was highest in people of Pacific Island ethnicity at 11.4% (95% CI: 11.2%-11.5%) for males and 11.6% (11.4%-11.8%) for females, followed closely by people of Indian ethnicity 10.8% (10.6-11.1%) and 9.3% (9.1% to 9.6%). Among the indigenous Maori population the prevalence was 8.2% (7.9%-8.4%) and 7.0% (6.8%-7.2%), while for 'Others' (mainly Europeans) it was 3.0% (3.0-3.1%) and 2.2% (2.1-2.2%).

Conclusion: We have demonstrated that the data linkage between a laboratory repository and national administrative datasets has the potential to provide a systematic and consistent individual level clinical information that are relevant to medical auditing for a large geographically defined population.

Keywords: diabetes mellitus, hyperglycemia, quality improvement, quality indicators, prevalence, epidemiology, health status disparities, mass screening.

Article summary

Article focus

- This article aims to demonstrate the potential value of data linkage of multiple routine health datasets to determine the diabetes screening levels and the known glycaemic status of all

individuals within a defined geographic location to facilitate systematic disease prevention and management.

Key messages

- Glycaemia related blood testing is common. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for cardiovascular risk assessment had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010.
- The prevalence of dysglycaemic status as defined by a consistent definition varies markedly by age and ethnicity.
- If the data linkage methodology used in this study were implemented in a live electronic population register, one has the potential to identify individuals who were yet to be screened for diabetes and people who more likely to benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way.

Strengths and Limitations of the study

- This study applied a method that aims to address the common systematic biases seen in many population diabetes prevalence studies such as incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, and misdiagnosis.
- The definition of dysglycaemia included people with confirmed diabetes as well as people who require follow up tests to confirm the formal diagnosis of diabetes.
- The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

Introduction

The number of people with diabetes globally increased by almost 200 million from 1980 to 2008.[1] In the context of a potential "diabetes epidemic", an accurate and timely measure of diabetes prevalence is critical to inform policy making, resource allocation and planning and implementation of interventions to improve the quality of care for the people with diabetes. Moreover, a consistent and systematic way to identify individuals for diabetes screening, follow-up and management is necessary to ensure people with diabetes receive the most appropriate care. Indeed, randomised controlled trials have demonstrated that the use of electronic patient registers, patient and clinician reminders are associated with quality improvement in diabetes management.[2] However, the limitations of existing methods to identify populations with diabetes include incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, misdiagnosis, lack of precision by age, gender or ethnicity, and inadequate adjustments for migrations or deaths.[1,3-6]

Auckland (New Zealand) has an ethnically diverse population of over 1·4 million people. The aim of this study is to use laboratory results (between 1 Jan 2004 and 30 Jun 2010) from a regional laboratory repository to estimate glycaemia test coverage and glycaemic status in a geographical defined population in 2010. This study proposes a set of methods that utilise "real-world" routinely collected data in a practical manner that has the potential to provide critical and succinct information for the responsible clinicians that is robust enough at the individual level for quality improvement as well as estimates at the aggregated population level.

Methods

Date sources

TestSafe is a comprehensive data repository containing all the community and hospital laboratory test results requested in the Auckland metropolitan region in New Zealand since July 2006. Individual patient laboratory tests can be requested by general practitioners, privately or publicly funded specialists, resident medical staff or other allied health workers. Prior to July 2006 only hospital test results and community results that were sent to secondary care clinicians were recorded in the data repository. Fasting glucose, random glucose, 2 hour post glucose load values (standard 75g oral glucose tolerance test OGTT), and HbA1c results from 1 Jan 2004 to 30 Jun 2010 were sourced from the TestSafe repository. The following routine administrative datasets were sourced from the Analytical Services team within the National Health Board of the Ministry of Health (MOH) (formerly known as the New Zealand Health Information service (NZHIS)):

- National Minimum Dataset (hospital events) (NMDS)
- National Non-admitted Patient Collection (outpatients and community visits) (NNPAC)
- Pharmaceutical Collection (PHARMHOUSE)
- Laboratory Claims Collection (note: does not include test results)
- Primary Health Organisation Enrolment Collection
- General Medical Subsidy Data Mart
- National Mortality Collection
- National Immunisation Register.

Data linkage

Virtually all health service users in New Zealand are assigned a unique identifier called National Health Index (NHI). The NHI coverage is estimated to be 98% of the New Zealand population.[7] Additional information regarding the purpose, and the use of NHI is available on the New Zealand Ministry of Health website.[8] All NHIs used in this study were encrypted to protect privacy and confidentiality of health information. Record linkage of various data sources were carried out using encrypted NHIs. Ethical approval was obtained from The New Zealand Northern X Regional Ethics Committee (NTX/10/EXP/153) and access of TestSafe laboratory results was approved by Auckland Regional Information Systems Group (RISG).

Inclusion criteria of the study

The linkage of the available administrative datasets by unique encrypted NHI was undertaken to derive the "health service utilisation (HSU) population". This was defined as New Zealand residents who resided within the boundaries of the three District Health Boards located in the Auckland metropolitan region and received any of the publicly-funded health services in New Zealand between 1 July 2009 and 30 June 2010, namely:

- Currently enrolled in a Primary Health Organisation (PHO) or people who had a health service contact with a PHO,
- Publicly funded inpatient and outpatient secondary care events (including mental health and emergency department contact),
- Any community pharmaceutical dispensing,
- Any community laboratory test (including outside the Auckland metropolitan region) including the ones requested by privately funded health professionals,
- Any immunisation received as indicated by the national immunisation register.

Deceased individuals were excluded from the HSU population using the National Mortality Collection. In New Zealand, PHOs supply general practitioner services and are publicly funded, receiving a capitation payment for each enrolee. PHOs are required to provide a defined set of essential services which include appropriate evidence based screening, risk assessment and the use of recall and reminder systems.[9]

Numerator 1: glycaemic status test coverage

The glycaemic status test coverage by age and ethnicity was estimated as the proportion of the HSU population who had at least one glucose or HbA1c blood test recorded in TestSafe repository from 1 Jan 2004 to 30 Jun 2010. Lab tests with missing results or results with <1mmol/L for glucose test, or <1% (<0mmol/mol) of HbA1c were excluded.

$$\text{The glycaemic status test coverage} = \frac{\text{The number of people who had at least one diabetes blood test in Auckland metro from 1/01/2004 to 30/06/2010}}{\text{Corresponding number of people in the health service utilisation population.}}$$

Definition of dysglycemia

The definition of diabetes recommended by American Diabetes Association in 2010 and the World Health Organization consultation in 2011 was modified for this "real-world" study,[10,11] and termed

"dysglycemia". The operational definition of this study was to identify a cohort of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications rather than only the people who had a confirmed diagnosis of diabetes. This defined cohort should be followed up by the health care system for ongoing clinical support and management. The dysglycemic status was derived directly from the laboratory results recorded in a TestSafe laboratory repository for each person in the HSU population. Duplicated test results with identical lab numbers for the same person were removed. A person was defined to have dysglycemia if they had:

- at least one **HbA1c** test ≥ 6·5% (equivalent to 48 mmol/mol) or
- at least one 2 hour post glucose load ≥ 11·1 mmol/l on a **Glucose tolerance test (GTT)**
- two or more tests of **random glucose** ≥ 11·1 mmol/L and/or **fasting glucose** ≥ 7·0 mmol/L on a different day.

For young children less than 10 years of age in 2010, hospital requested glucose tests were not examined because high glucose results in hospital for young children are more likely to relate to artificial nutritional feeds or parenteral nutrition than to diabetes.

Comparison to hospital diagnosis

People within the HSU population who had a previous hospitalisation with a primary or secondary diagnosis of diabetes (ICD 10 codes Edition 3 E10-E14, and O240-O243) from 1 July 1999 to 30 June 2010 in New Zealand were compared against the laboratory diagnosis of dysglycemia as defined by this study.

Demographic variables

The dysglycemic status for each person within the HSU population was determined by the blood test results. The demographic variables including adjustment for migration and deaths were made in an identical way for both the numerator (people who had at least one glucose or HbA1c blood test or people with dysglycemia) and denominator (HSU population which includes people with dysglycemia or diabetes). Ethnicity was determined as per ethnicity data protocols published by the New Zealand Ministry of Health using the prioritised method.[12] Age was calculated from date of birth with reference to 1 Jan 2010.

Age standardisation

The prevalence proportions were separated into 5-year age groups from <15 to ≥85 for direct age standardisation using the World Health Organization (WHO) World population as the standard.[13] 95% confidence intervals are presented.

Results

There were 1,475,347 people living in the Auckland metropolitan region as defined by the HSU population in June 2010. The estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 was 1,477,600.[14]A total of 4,281,599 glucose and HbA1c blood tests were analysed from 792,588 people who had at least one glycaemia related blood test in the study period. There were 1,458,350 tests performed in laboratories based in hospitals (34% of the total) and 2,823,249 tests performed by community laboratories (66%). There were 38 people who had a glycaemia related blood test but did not have a gender recorded, and all

had age recorded. The proportions of people receiving at least one glucose or HbA1c blood test by age, gender and ethnicity are shown in Tables 1 and 2. The age groups highlighted in yellow are the recommended age ranges for diabetes screening as per New Zealand Cardiovascular Guidelines.[15]

Table 1: Proportion of males receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	15·1%	15·6%	16·1%	10·5%	10·9%	14·3%	14·4%	24,465
15-19	25·9%	23·9%	23·7%	16·9%	17·1%	25·5%	24·2%	12,989
20-24	41·1%	38·5%	36·4%	26·3%	28·3%	38·3%	37·3%	18,590
25-29	44·2%	43·0%	42·2%	29·0%	34·5%	40·2%	39·9%	18,811
30-34	49·9%	51·2%	54·5%	36·5%	40·0%	43·4%	45·8%	20,744
35-39	58·7%	60·5%	66·9%	49·7%	51·7%	51·1%	54·5%	28,010
40-44	66·8%	70·4%	78·0%	58·6%	59·1%	61·7%	64·2%	34,175
45-49	75·1%	77·4%	83·5%	66·8%	68·1%	70·9%	72·5%	38,417
50-54	82·4%	84·8%	87·5%	76·9%	76·4%	79·3%	80·4%	36,440
55-59	88·3%	89·1%	88·2%	79·2%	80·3%	85·2%	85·4%	32,353
60-64	92·5%	90·9%	88·9%	84·4%	86·3%	89·3%	89·2%	30,043
65-69	94·3%	92·1%	87·8%	84·5%	88·2%	92·0%	91·4%	22,206
70-74	95·8%	92·1%	88·6%	87·1%	88·3%	94·2%	93·1%	16,649
75-79	95·1%	92·2%	90·1%	88·3%	85·7%	94·9%	93·9%	11,730
80-84	96·1%	90·6%	89·8%	87·8%	84·7%	96·0%	95·0%	8,276
>85	98·3%	87·6%	87·0%	85·0%	84·7%	95·9%	95·1%	5,670
Total								**359,567**

Note: table order reflects ethnicity priority order; "Other" includes those of European descent.

Table 2: Proportion of females receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	12·9%	12·9%	14·5%	8·8%	8·8%	12·7%	12·5%	20,123
15-19	36·6%	27·4%	29·4%	18·1%	17·7%	33·4%	30·6%	16,855
20-24	59·9%	52·1%	50·3%	32·5%	36·1%	50·3%	50·2%	27,144
25-29	65·8%	64·4%	61·0%	40·6%	47·3%	52·3%	54·9%	31,348
30-34	67·4%	68·4%	70·7%	54·4%	53·3%	58·5%	61·5%	34,129
35-39	69·5%	71·0%	76·7%	61·6%	56·6%	63·0%	65·2%	39,085
40-44	72·2%	75·2%	80·1%	68·1%	63·3%	66·9%	69·2%	41,014
45-49	79·4%	81·2%	85·7%	76·7%	68·3%	71·8%	74·6%	42,334
50-54	84·8%	85·8%	89·1%	81·0%	77·7%	78·5%	80·6%	38,528
55-59	88·6%	88·8%	87·8%	81·4%	83·5%	83·2%	84·3%	33,735
60-64	92·3%	91·4%	88·0%	85·9%	86·4%	86·9%	87·6%	30,489
65-69	94·6%	91·4%	89·2%	86·9%	86·3%	90·3%	90·3%	23,404
70-74	95·2%	93·4%	89·7%	87·7%	87·5%	92·7%	92·3%	18,120
75-79	94·8%	92·3%	89·0%	89·1%	85·8%	94·6%	93·7%	13,754
80-84	95·5%	89·0%	87·8%	87·2%	88·4%	95·6%	94·6%	11,095
>85	97·4%	90·8%	87·3%	88·6%	80·2%	96·1%	95·5%	11,796
Total								**432,953**

The test coverage varies by age, gender and ethnicity. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for diabetes screening had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010. There were a total of 78,828 people with dysglycemia as defined by this study living in the Auckland metropolitan region in 2010 identified by the laboratory results. Crude prevalence was 5·3% overall (with 5·7% males, 5·0% females). Pacific and Indian ethnicities had the highest age standardised prevalence in Auckland metropolitan region. There were 31,282 people in the HSU population who had been discharged from hospital in New Zealand with a discharge diagnosis of diabetes between 1 July 2000 and 30 June 2010. Of these people, 91% (n=28,489) also had laboratory results consistent with dysglycemia defined by this study.

Table 3: Estimated prevalence of dysglycemia in Auckland metropolitan region by gender and ethnicity

Males							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,378	10,078	4,440	2,343	1,911	17,415	40,565
HSU population number	83,473	114,660	41,571	42,358	34,081	392,962	709,105
Crude prevalence (%)	5·2	8·8	10·7	5·5	5·6	4·4	5·7
Age standardised prevalence (%) with 95% confident interval	8·2 (7·9 – 8·4)	11·4 (11·2-11·5)	10·8 (10·6-11·1)	4·6 (4·4-4·7)	6·4 (6·2-6·7)	3·0 (3·0 - 3·1)	4·9 (4·8-4·9)
Females							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,570	11,751	3,738	2,476	1,773	13,952	38,260
HSU population number	89,808	121,935	42,438	53,527	42,583	415,830	766,121
Crude prevalence (%)	5·1	9·6	8·8	4·6	4·2	3·4	5.0
Age standardised prevalence (%) with 95% confident interval	7·0 (6·8-7·2)	11·6 (11·4-11·8)	9·3 (9·1-9·6)	3·9 (3·8-4·0)	4·9 (4·7-5·1)	2·2 (2·1-2·2)	4·1 (4·1-4·2)

Figure 1: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (males)

Figure 2: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (females)

Discussion

This study estimated prevalence of dysglycemia in a consistent manner within a geographically defined population of over 1·4 million, by age, gender and ethnicity based on laboratory results sourced from a comprehensive regional laboratory repository (Figure 1Figure 2). If the data linkage methodology used in this study were implemented in a live electronic population register, one could potentially identify individuals who were yet to be screened for diabetes and people who would probably benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way. We have demonstrated that glycaemia-related blood testing coverage is very high in the Auckland metropolitan region, and apparently higher than previously reported in Ontario, Canada in 2005.[6] In Auckland, more than 85% of men and 84% of women over 55 in 2010 have had one or more glucose or HbA1c blood tests since 2004. Females of child-bearing age (aged 15-49) were also more likely to have glucose or HbA1c blood tests than their male counterparts for comparable age and ethnic groups. Overall, the blood test coverage of females between 15 and 49 years of age was 7·7% higher than males.

Consistent with the New Zealand CVD risk management guideline recommendation to screen Maori, Pacific and Indian people 10 years earlier than others, the age-specific blood test coverage was higher in these ethnic groups than other groups in the age groups between 35 and 45 years for males and between 45 and 55 years for females.[15] Since 34% of blood tests were carried out in hospital laboratories, it was likely that a number of tests were undertaken because of symptoms related to diabetes rather than opportunistic screening for diabetes. Since the rate of hospital admissions increases with advancing age, the relatively high coverage of diabetes testing in the older groups may be in part a result of routine glucose testing for most patients admitted to hospitals.

Consistent with previous reports, the ethnic disparities in prevalence of dysglycemia were alarming.[16] This study demonstrated Pacific and Indian people have the highest age standardised prevalence of dysglycemia (Table 3). Almost one in two Pacific women aged 70-74 had evidence of dysglycemia (Figure 2). . These findings highlight the critical need for both primary and secondary prevention efforts to reduce ethnic disparities in diabetes-related morbidity and mortality. A previously published estimate of diabetes prevalence for the southern part of the region (CMDHB) in 2006/7, was about 20% lower in relative terms (a difference of >5,000 people) than in the current study.[17] The key methodological difference between the studies was the availability of blood test results in the current study, whereas the previous study relied on an algorithm based on hospitalisations, drug treatment and the number of HbA1c tests (without the test results being

available) to estimate diabetes prevalence. Demographic changes; improvement in screening; differences in definitions of diabetes and dysglycemia and a real increase in the underlying diabetes prevalence since 2006/7 are likely to explain the difference of results between the studies.

The HSU population (denominator) was constructed from national routinely collected administrative data; it defined the population at risk and effectively adjusted for migration and deaths. The use of current PHO enrolment and/or evidence of health service contact are pragmatic proxies to indicate that the HSU population residing in the Auckland metropolitan area within the defined period of the study. The novelty and strength of this study was that both the test coverage and the dysglycemic status of each individual in the HSU population in 2010 were determined by the laboratory results in a consistent manner through individual person record linkage using a unique identifier, the encrypted NHI.

The use of the HSU population as the denominator on which to base future population registers for many long-term conditions has many technical and practical advantages in policy making and quality improvement. The HSU population (n=1,475,347) was very similar to the estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 (n=1,477,600).[14] In practical terms, virtually everyone with significant disease who resides in the Auckland metropolitan area is likely to be currently enrolled in a primary care practice and/or have had a contact with publicly funded health services in the year. The way the HSU population was defined means that if identifiable data were used as part of a population register, it can potentially identify any potential performance gaps that a health care provider can address at the individual level. Eligible patients could be readily recalled based on latest contact details from primary care enrolment or from the last health service contact. This is particularly important in a context where the actual care that patients received might be suboptimal.[18] For example, a systematic recall system can theoretically be set up for those people who are yet to be screened using the identical record linkage carried out by this study. As pharmaceutical dispensing data can be linked by NHI in New Zealand, a similar systematic system could also be implemented to monitor the care provision for people who are at high risk of complications. For example, it would be possible to recall those with diabetes and microalbuminuria that were not dispensed an angiotensin-converting enzyme inhibitor or angiotensin II receptor antagonist, or people with poorly-controlled diabetes who may need further clinical review or self-management support. Many chronic care models such as Wagner's emphasised the value of clinical information systems and the role of a population registry to facilitate the provision of systematic proactive care to patients with long term conditions.[19] Indeed, an integrated electronic health record system that contains laboratory results, pharmaceutical use, and utilisation of services has recently been highlighted as critical components to measure the quality of care provided.[20]

Other advantages of the HSU population used in this study include the elimination of numerator-denominator biases highlighted in previous reports.[21,22] Furthermore, the participation of all of the laboratories serving the area in the study, meaning virtually 100% of the laboratory tests performed in the Auckland metropolitan area were included. The long-standing use of the data repository, and its incorporation in day-to-day general practice and secondary care also contributes to the completeness and robustness of the data stored.

This study addressed many of the limitations of common sources of data that are used to estimate diabetes prevalence – these are summarised in Table 4.[1,3,4,23-26] Many traditional epidemiological studies are based on surveys that are subject to selection bias and patient recall biases.[1,4] Self-reported diabetes prevalence estimates are often lower than estimates based on biochemical results.[4] Most epidemiological surveys have relied on one single laboratory measurement, however glucose tolerance tests have limited repeatability and glucose measurements have considerable intra-individual variations.[23,27] While some registers have sourced data from primary care, the quality of input data and consistency of coding could be highly variable.[3,24,28] While the UK NHS Quality and Outcomes Framework (QOF) recommends a systematic approach to diagnose diabetes, primary care providers are not required to provide supporting description on how the diabetes diagnoses are made, other than a record of a diabetes diagnosis for the purpose of the QOF indicator.[29] Indeed, QOF openly acknowledges that there are a substantial number of people who are undiagnosed or misdiagnosed.[29] The ability to keep an up to date record of people with 'diagnosed' diabetes would also be more challenging in places where there is a highly mobile population such as in New Zealand, certain parts of Great Britain and the United States.[30-32] Furthermore, a significant number of blood test results may not be requested by the general practices that are currently responsible for the patients' care. For example, as demonstrated in this study, significant numbers of laboratory tests were carried out in hospitals.

The New Zealand NHI database has identifiable information such as name, address, data of birth, self-reported ethnicity.[33] The NHI number has been used in other settings of proactive care such as immunisation in New Zealand.[33,34] The duplicated NHIs are regularly cleaned and mapped back to the Master NHI. Regular audits are performed and Primary Health Organisations are required to provide their patient registries to the Ministry of Health (MOH) every quarter. Therefore, , applying the methodology used in this study to construct a population register has the potential to enable a systematic approach to medical auditing. The method identifies the population eligible but yet to be screened for diabetes within a defined period or people who might have abnormal diabetes laboratory results who would benefit from proactive follow up as defined by this study. Data security and appropriate access and use of health data across the whole of health system are vital components to enable a population register to succeed. The balance between patient confidentiality and the adaptable use of identifiable health data to enable proactive health services should be vigorously debated. While the rationale to develop such a population register is to improve population health and equity through systematic medical audit, appropriate safeguards should be in place to limit any unintended misuse of possible confidential health data.

Clinicians ideally should have timely access to all the available health information for the group of patients that they are clinically responsible for. However, the capacity and capability required to analyse health data from the whole of health system into clinically meaningful and actionable health information to be available at the point of care are not universally available from all health care providers. Therefore, a central system that can apply the methods of this study has a tremendous potential to review some of the possible quality gaps exist in the current system.Table 4: The limitations of common sources of data used to estimate diabetes prevalence

Sources of data	Limitations
Self-report survey	Selection/ sample bias, patient recall bias, limited sample size
Survey with one laboratory test	Selection bias; cross-sectional measure, poor repeatability with glucose tests, estimates the undiagnosed diabetes based on patient recall or medical

	records, not necessarily unknown to the entire health system
Primary care records	Inconsistency in primary care coding, subject to migration bias, may miss diagnosis at secondary care or other health care providers, limited sensitivity in general
Hospitals	Only identifies those with diabetes who attended hospital, recent changes in ICD coding standards may affect consistency. Major undercount
Pharmaceutical dispensing data	Diet-controlled diabetes would not be captured; adherence is not perfect in the community. Medications may have other indications such as metformin in polycystic ovarian syndrome or may be being used to 'prevent' diabetes
Combination of datasets	Depends on quality of the datasets combined. Needs a unique patient identifier for linkage to avoid double counting. The definition of diagnoses may not be consistent across the datasets
Capture- recapture	Identifies people with diabetes not captured by the system, (note - not undiagnosed diabetes). Assumes list independence, and all individuals have the same probability of being captured by each dataset. The estimates can be influenced by factors that are completely unrelated to diabetes prevalence such as changes in ICD coding standards, or admission threshold, and treatment trends. One cannot identify the individuals.

The definition of dysglycemia used in this study is a pragmatic one which identifies a group of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications and need to be followed up by the health care system for ongoing clinical support and management.[35-38] People with borderline elevated HbA1c (>48mmol/mol) may be offered dietary advice and the HbA1C test may not necessarily be repeated immediately in the "real-world" as it does not change immediate management. Strictly speaking, these people would not yet have met the diagnostic criteria of diabetes. However, they should have follow up tests to confirm or exclude the diagnosis of diabetes. Moreover, the proposed method of this study can be refined further to apply the different diagnostic threshold of HbA1C according to ethnicity or to local recommendations.[39,40]

Another limitation of this study is the imperfect sensitivity as it was based on "real-world" data of relatively short duration, and the way dysglycemia is currently defined the study would not have identified people with dysglycemia or diabetes who were lost to follow-up. However, more than 91% of the HSU population who had a diabetes-related hospitalisation in New Zealand between 1 July 2000 and 30 June 2010 also had laboratory results consistent with the diagnosis. This finding suggests a regional laboratory repository of such duration (community test results for 4 years and hospital test results for 6·5 years) would already capture a substantial proportion of people with diabetes. Many people who had a single elevated glucose test might not be followed up (to get the second test required for diagnosis). This study would also miss people who had diabetes diagnosed by laboratory tests performed outside the Auckland metropolitan area or diagnosed before 2004 and subsequently had had excellent diabetes control. However, these cohorts would be identified in subsequent iterations of the population register if their diabetes control deteriorated in the future. The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

In conclusion, a regional laboratory result repository linked to administrative datasets has the potential to provide highly relevant and consistent information to inform clinical decision making in a comprehensive and timely manner as well as being an excellent epidemiological surveillance tool.

Role of funding source:

This study was conducted as a result of the work undertaken for Counties Manukau District Health Board (CMDHB), New Zealand. WCC, GJ, BOW, DRB, MAWL, and DP were paid employees of CMDHB at the time of the study. Views expressed in this publication are those of the authors and not necessarily those of CMDHB.

Conflicts of interests:

We declare no support from any organisation for the submitted work; BOW had received remuneration from the New Zealand Ministry of Health, as the former National clinical director responsible for sector engagement on population health targets. BOW had received payment for lectures from Novo-Nordisk, AstraZeneca, Sanofi and MSD.

Contribution statements:

WCC designed the study methods, applied approval for access for all the relevant data, undertook literature search, record linkage, cross checking, statistical analysis, and drafted up and revised the paper. He is the guarantor. GJ designed the study methods, and revised the paper. CW designed the study methods, linked the administrative data to construct the health service utilisation population, and revised the paper. BO-W designed the study methods and revised the paper. PLD provided clinical diabetes input and revised the paper. DRB designed the study methods and revised the paper. MAWL undertook record linkage, cross checking, and statistical analysis. DP undertook record linkage and data extraction for cross checking. RJ designed the study methods and revised the paper.

Data Sharing Statement:

No additional data

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TITLE: THE FUTURE OF POPULATION REGISTERS: LINKING ROUTINE HEALTH DATASETS TO ASSESS A POPULATION'S CURRENT GLYCAEMIC STATUS FOR QUALITY IMPROVEMENT

Authors' names

Corresponding author:
WC Chan, Public Health Physician, Counties Manukau District Health Board.
Address: Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand
Email: wingcheuk.chan@cmdhb.org.nz
Phone: + 64 9 2599658
Fax: +64 9 259 9665

Authors' positions and Addresses

Wing Cheuk Chan, FNZCPHM, Public Health Physician, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: wingcheuk.chan@cmdhb.org.nz

Gary Jackson, FNZCPHM, Public Health Physician, Health Partners Consulting Group. PO Box 147209, Ponsonby, Auckland, New Zealand. Email: gary@healthpartnersconsulting.com

Craig Shawe Wright, BSc, Senior Managing Consultant, Sapere Research Group, PO Box 587, Wellington, 6140. Email:cwright@srgexpert.com

Brandon Orr-Walker, FRACP, Clinical Head, Endocrinology and Diabetes Service, Counties Manukau District Health Board, Private Bag 94052, 2240, South Auckland Mail Centre, New Zealand. Email: Brandon.Orr-Walker@middlemore.co.nz

Paul L Drury, FRCP, Clinical Director, Auckland Diabetes Centre, Auckland District Health Board. Greenlane Clinical Centre, PO Box 92189, Auckland, New Zealand. Email: PaulD@adhb.govt.nz

D Ross Boswell, PhD, Clinical Director of Laboratory Services, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email:Ross.Boswell@middlemore.co.nz

Mildred Ai Wei Lee, MSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: Mildred.Lee@middlemore.co.nz

Dean Papa, BSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: j.papa@xtra.co.nz

Rod Jackson, PhD, Professor of epidemiology. School of Population Health, University of Auckland, Auckland, New Zealand. Private Bag 92019, Auckland, 1142, New Zealand. Email: rt.jackson@auckland.ac.nz

Number of tables: 3

Number of figures: 2

Title: The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Abstract:

Objectives: To determine diabetes screening levels and ~~the~~ known glycaemic status of all individuals by age, gender and ethnicity within a defined geographic location in a timely and consistent way to potentially facilitate systematic disease prevention and management.

Design: Retrospective observational study.

Setting: Auckland region of New Zealand.

~~**Population**~~**Participants:** 1,475,347 people who had utilised publicly funded health service in New Zealand and domicile in~~We used an encrypted national health identification number to link multiple routine health datasets to identify almost all individuals eligible to utilise health service in~~ the Auckland region of New Zealand ~~in 2010~~in 2010. The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004.

Outcome measures: ~~The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004.~~ The two outcomes measures were glycaemia-related blood testing coverage (HbA1c, fasting and random glucose and glucose tolerance tests), and the proportions and number of people with known dysglycemia in 2010 using modified ADA and WHO criteria.

Results: ~~There were 1,475,347 people in the health service utilisation population in 2010 in the Auckland region.~~ Within the health service utilisation population, 792,560 people had had at least one glucose or HbA1c blood test in the previous 5.5 years. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,982) in the recommended age groups for diabetes screening had a blood test to assess their glycaemic status. Estimated age-standardised prevalence of dysglycemia was highest in people of Pacific Island ethnicity at 11.4% (95% CI: 11.2%-11.5%) for males and 11.6% (11.4%-11.8%) for females, followed closely by people of Indian ethnicity ~~(~~10.8% (10.6-11.1%) and 9.3% (9.1% to 9.6%). Among the indigenous Maori population the prevalence was 8.2% (7.9%-8.4%) and 7.0% (6.8%-7.2%), while for 'Others' (mainly Europeans) it was 3.0% (3.0-3.1%) and 2.2% (2.1-2.2%).

Conclusion: We have demonstrated that ~~a~~the data linkage between a laboratory repository ~~can be linked to~~ and national administrative datasets ~~to~~ has the potential to provide a systematic and consistent ~~-~~individual level clinical information that are relevant to medical auditing ~~quality improvement,~~ for a large geographically defined population.

Keywords: diabetes mellitus, hyperglycemia, quality improvement, quality indicators, prevalence, epidemiology, health status disparities, mass screening.

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Article summary

Article focus

- This article aims to demonstrate the potential value of data linkage of multiple routine health datasets to determine the diabetes screening levels and the known glycaemic status of all individuals within a defined geographic location to facilitate systematic disease prevention and management.

Key messages

- Glycaemia related blood testing is common. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for cardiovascular risk assessment had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010.
- The prevalence of dysglycaemic status as defined by a consistent definition varies markedly by age and ethnicity.
- If the data linkage methodology used in this study were implemented in a live electronic population register, one ~~could readily~~has the potential to identify individuals who were yet to be screened for diabetes and people who more likely to benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way.

Strengths and Limitations of the study

- This study applied a method that aims to address the common systematic biases seen in many population diabetes prevalence studies such as incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, and misdiagnosis.
- The definition of dysglycaemia included people with confirmed diabetes as well as people who require follow up tests to confirm the formal diagnosis of diabetes.
- The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

Introduction

The number of people with diabetes globally increased by almost 200 million from 1980 to 2008.[1] In the context of a potential "diabetes epidemic", an accurate and timely measure of diabetes prevalence is critical to inform policy making, resource allocation and planning and implementation of interventions to improve the quality of care for the people with diabetes. Moreover, a consistent and systematic way to identify individuals for diabetes screening, follow-up and management is necessary to ensure people with diabetes receive the most appropriate care. Indeed, randomised controlled trials have demonstrated that the use of electronic patient registers, patient and clinician reminders are associated with quality improvement in diabetes management.[2] However, the limitations of existing methods to identify populations with diabetes include incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, misdiagnosis, lack of precision by age, gender or ethnicity, and inadequate adjustments for migrations or deaths.[1,3-6]

Auckland (New Zealand) has an ethnically diverse population of over 1·4 million people. The aim of this study is to use ~~longitudinal~~ laboratory results (between 1 Jan 2004 and 30 Jun 2010) from a regional laboratory repository to estimate glycaemia test coverage and glycaemic status in a geographical defined population in 2010. This study proposes a set of methods that utilise "real-world" routinely collected data in a practical manner that ~~can~~ has the potential to provide critical and succinct information for the responsible clinicians that is robust enough at the individual level for quality improvement as well as estimates at the aggregated population level.

Methods

Date sources

TestSafe is a comprehensive data repository containing all the community and hospital laboratory test results requested in the Auckland metropolitan region in New Zealand since July 2006. Individual patient laboratory tests can be requested by general practitioners, privately or publicly funded specialists, resident medical staff or other allied health workers. Prior to July 2006 only hospital test results and community results that were sent to secondary care clinicians were recorded in the data repository. Fasting glucose, random glucose, 2 hour post glucose load values (standard 75g oral glucose tolerance test OGTT), and HbA1c results from 1 Jan 2004 to 30 Jun 2010 were sourced from the TestSafe repository. The following routine administrative datasets were sourced from the Analytical Services team within the National Health Board of the Ministry of Health (MOH) (formerly known as the New Zealand Health Information service (NZHIS)):

- National Minimum Dataset (hospital events) (NMDS)
- National Non-admitted Patient Collection (outpatients and community visits) (NNPAC)
- Pharmaceutical Collection (PHARMHOUSE)
- Laboratory Claims Collection (note: does not include test results)
- Primary Health Organisation Enrolment Collection
- General Medical Subsidy Data Mart
- National Mortality Collection
- National Immunisation Register.

Data linkage

Virtually all health service users in New Zealand are assigned a unique identifier called National Health Index (NHI). The NHI coverage is estimated to be 98% of the New Zealand population.[7] Additional information regarding the purpose, and the use of NHI is available on the New Zealand Ministry of Health website.[8] All NHIs used in this study were encrypted to protect privacy and confidentiality of health information. Record linkage of various data sources were carried out using encrypted NHIs. Ethical approval was obtained from The New Zealand Northern X Regional Ethics Committee (NTX/10/EXP/153) and access of TestSafe laboratory results was approved by Auckland Regional Information Systems Group (RISG).

Inclusion criteria of the study

The linkage of the available administrative datasets by unique encrypted NHI was undertaken to derive the "health service utilisation (HSU) population". This was defined as New Zealand residents who resided within the boundaries of the three District Health Boards located in the Auckland metropolitan region and received any of the publicly-funded health services in New Zealand between 1 July 2009 and 30 June 2010, namely:

- Currently enrolled in a Primary Health Organisation (PHO) or people who had a health service contact with a PHO,
- Publicly funded inpatient and outpatient secondary care events (including mental health and emergency department contact),
- Any community pharmaceutical dispensing,
- Any community laboratory test (including outside the Auckland metropolitan region) including the ones requested by privately funded health professionals,
- Any immunisation received as indicated by the national immunisation register.

Deceased individuals were excluded from the HSU population using the National Mortality Collection. In New Zealand, PHOs supply general practitioner services and are publicly funded, receiving a capitation payment for each enrolee. PHOs are required to provide a defined set of essential services which include appropriate evidence based screening, risk assessment and the use of recall and reminder systems.[9]

Numerator 1: glycaemic status test coverage

The glycaemic status test coverage by age and ethnicity was estimated as the proportion of the HSU population who had at least one glucose or HbA1c blood test recorded in TestSafe repository from 1 Jan 2004 to 30 Jun 2010. Lab tests with missing results or results with <1mmol/L for glucose test, or <1% (<0mmol/mol) of HbA1c were excluded.

$$\text{The glycaemic status test coverage} = \frac{\text{The number of people who had at least one diabetes blood test in Auckland metro from 1/01/2004 to 30/06/2010}}{\text{Corresponding number of people in the health service utilisation population.}}$$

Definition of dysglycemia

The definition of diabetes recommended by American Diabetes Association in 2010 and the World Health Organization consultation in 2011 was modified for this "real-world" study,[10,11] and termed

"dysglycemia". The operational definition of this study was to identify a cohort of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications rather than only the people who had a confirmed diagnosis of diabetes. This defined cohort should be followed up by the health care system for ongoing clinical support and management. The dysglycemic status was derived directly from the laboratory results recorded in a TestSafe laboratory repository for each person in the HSU population. Duplicated test results with identical lab numbers for the same person were removed. A person was defined to have dysglycemia if they had:

- at least one **HbA1c** test ≥ 6·5% (equivalent to 48 mmol/mol) or
- at least one 2 hour post glucose load ≥ 11·1 mmol/l on a **Glucose tolerance test (GTT)**
- two or more tests of **random glucose** ≥ 11·1 mmol/L and/or **fasting glucose** ≥ 7·0 mmol/L on a different day.

For young children less than 10 years of age in 2010, hospital requested glucose tests were not examined because high glucose results in hospital for young children are more likely to relate to artificial nutritional feeds or parenteral nutrition than to diabetes.

Comparison to hospital diagnosis

People within the HSU population who had a previous hospitalisation with a primary or secondary diagnosis of diabetes (ICD 10 codes Edition 3 E10-E14, and O240-O243) from 1 July 1999 to 30 June 2010 in New Zealand were compared against the laboratory diagnosis of dysglycemia as defined by this study.

Demographic variables

The dysglycemic status for each person within the HSU population was determined by the blood test results. The demographic variables including adjustment for migration and deaths were made in an identical way for both the numerator (people who had at least one glucose or HbA1c blood test or people with dysglycemia) and denominator (HSU population which includes people with dysglycemia or diabetes). Ethnicity was determined as per ethnicity data protocols published by the New Zealand Ministry of Health using the prioritised method.[12] Age was calculated from date of birth with reference to 1 Jan 2010.

Age standardisation

The prevalence proportions were separated into 5-year age groups from <15 to ≥85 for direct age standardisation using the World Health Organization (WHO) World population as the standard.[13] 95% confidence intervals are presented.

Results

There were 1,475,347 people living in the Auckland metropolitan region as defined by the HSU population in June 2010. The estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 was 1,477,600.[14] A total of 4,281,599 glucose and HbA1c blood tests were analysed from 792,588 people who had at least one glycaemia related blood test in the study period. There were 1,458,350 tests performed in laboratories based in hospitals (34% of the total) and 2,823,249 tests performed by community laboratories (66%). There were 38 people who had a glycaemia related blood test but did not have a gender recorded,

and all had age recorded. The proportions of people receiving at least one glucose or HbA1c blood test by age, gender and ethnicity are shown in Tables 1 and 2. The age groups highlighted in yellow are the recommended age ranges for diabetes screening as per New Zealand Cardiovascular Guidelines.[15]

Table 1: Proportion of males receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	15·1%	15·6%	16·1%	10·5%	10·9%	14·3%	14·4%	24,465
15-19	25·9%	23·9%	23·7%	16·9%	17·1%	25·5%	24·2%	12,989
20-24	41·1%	38·5%	36·4%	26·3%	28·3%	38·3%	37·3%	18,590
25-29	44·2%	43·0%	42·2%	29·0%	34·5%	40·2%	39·9%	18,811
30-34	49·9%	51·2%	54·5%	36·5%	40·0%	43·4%	45·8%	20,744
35-39	58·7%	60·5%	66·9%	49·7%	51·7%	51·1%	54·5%	28,010
40-44	66·8%	70·4%	78·0%	58·6%	59·1%	61·7%	64·2%	34,175
45-49	75·1%	77·4%	83·5%	66·8%	68·1%	70·9%	72·5%	38,417
50-54	82·4%	84·8%	87·5%	76·9%	76·4%	79·3%	80·4%	36,440
55-59	88·3%	89·1%	88·2%	79·2%	80·3%	85·2%	85·4%	32,353
60-64	92·5%	90·9%	88·9%	84·4%	86·3%	89·3%	89·2%	30,043
65-69	94·3%	92·1%	87·8%	84·5%	88·2%	92·0%	91·4%	22,206
70-74	95·8%	92·1%	88·6%	87·1%	88·3%	94·2%	93·1%	16,649
75-79	95·1%	92·2%	90·1%	88·3%	85·7%	94·9%	93·9%	11,730
80-84	96·1%	90·6%	89·8%	87·8%	84·7%	96·0%	95·0%	8,276
>85	98·3%	87·6%	87·0%	85·0%	84·7%	95·9%	95·1%	5,670
Total								**359,567**

Note: table order reflects ethnicity priority order; "Other" includes those of European descent.

Table 2: Proportion of females receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	12·9%	12·9%	14·5%	8·8%	8·8%	12·7%	12·5%	20,123
15-19	36·6%	27·4%	29·4%	18·1%	17·7%	33·4%	30·6%	16,855
20-24	59·9%	52·1%	50·3%	32·5%	36·1%	50·3%	50·2%	27,144
25-29	65·8%	64·4%	61·0%	40·6%	47·3%	52·3%	54·9%	31,348
30-34	67·4%	68·4%	70·7%	54·4%	53·3%	58·5%	61·5%	34,129
35-39	69·5%	71·0%	76·7%	61·6%	56·6%	63·0%	65·2%	39,085
40-44	72·2%	75·2%	80·1%	68·1%	63·3%	66·9%	69·2%	41,014
45-49	79·4%	81·2%	85·7%	76·7%	68·3%	71·8%	74·6%	42,334
50-54	84·8%	85·8%	89·1%	81·0%	77·7%	78·5%	80·6%	38,528
55-59	88·6%	88·8%	87·8%	81·4%	83·5%	83·2%	84·3%	33,735
60-64	92·3%	91·4%	88·0%	85·9%	86·4%	86·9%	87·6%	30,489
65-69	94·6%	91·4%	89·2%	86·9%	86·3%	90·3%	90·3%	23,404
70-74	95·2%	93·4%	89·7%	87·7%	87·5%	92·7%	92·3%	18,120
75-79	94·8%	92·3%	89·0%	89·1%	85·8%	94·6%	93·7%	13,754
80-84	95·5%	89·0%	87·8%	87·2%	88·4%	95·6%	94·6%	11,095
>85	97·4%	90·8%	87·3%	88·6%	80·2%	96·1%	95·5%	11,796
Total								**432,953**

The test coverage varies by age, gender and ethnicity. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for diabetes screening had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010. There were a total of 78,828 people with dysglycemia as defined by this study living in the Auckland metropolitan region in 2010 identified by the laboratory results. Crude prevalence was 5·3% overall (with 5·7% males, 5·0% females). Pacific and Indian ethnicities had the highest age standardised prevalence in Auckland metropolitan region. There were 31,282 people in the HSU population who had been discharged from hospital in New Zealand with a discharge diagnosis of diabetes between 1 July 2000 and 30 June 2010. Of these people, 91% (n=28,489) also had laboratory results consistent with dysglycemia defined by this study.

Table 3: Estimated prevalence of dysglycemia in Auckland metropolitan region by gender and ethnicity

Males							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,378	10,078	4,440	2,343	1,911	17,415	40,565
HSU population number	83,473	114,660	41,571	42,358	34,081	392,962	709,105
Crude prevalence (%)	5·2	8·8	10·7	5·5	5·6	4·4	5·7
Age standardised prevalence (%) with 95% confident interval	8·2 (7·9 – 8·4)	11·4 (11·2-11·5)	10·8 (10·6-11·1)	4·6 (4·4-4·7)	6·4 (6·2-6·7)	3·0 (3·0 - 3·1)	4·9 (4·8-4·9)
Females							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,570	11,751	3,738	2,476	1,773	13,952	38,260
HSU population number	89,808	121,935	42,438	53,527	42,583	415,830	766,121
Crude prevalence (%)	5·1	9·6	8·8	4·6	4·2	3·4	5.0
Age standardised prevalence (%) with 95% confident interval	7·0 (6·8-7·2)	11·6 (11·4-11·8)	9·3 (9·1-9·6)	3·9 (3·8-4·0)	4·9 (4·7-5·1)	2·2 (2·1-2·2)	4·1 (4·1-4·2)

Figure 1: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (males)

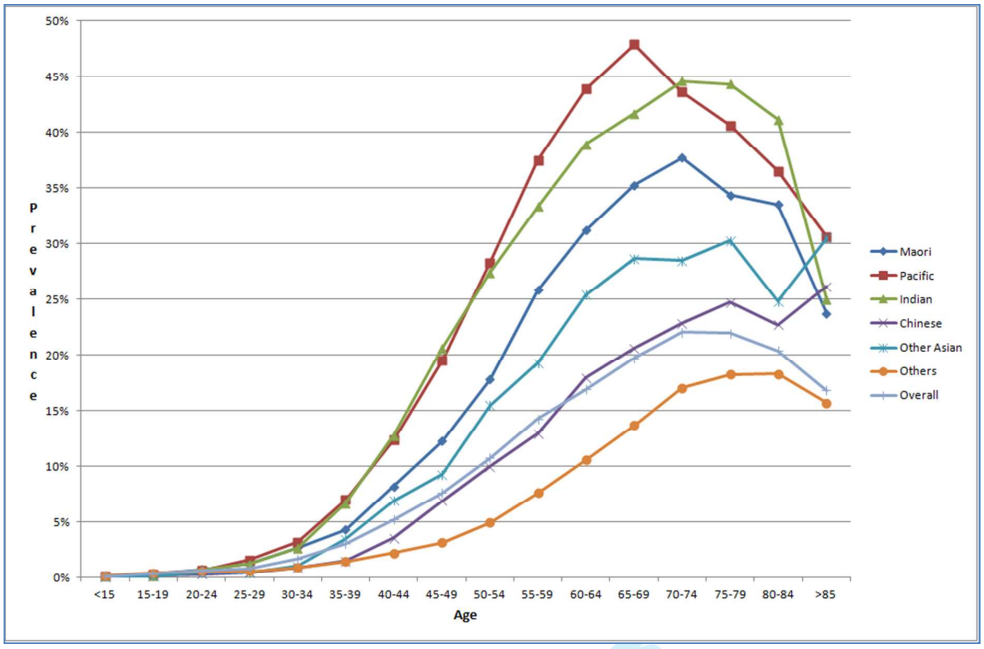
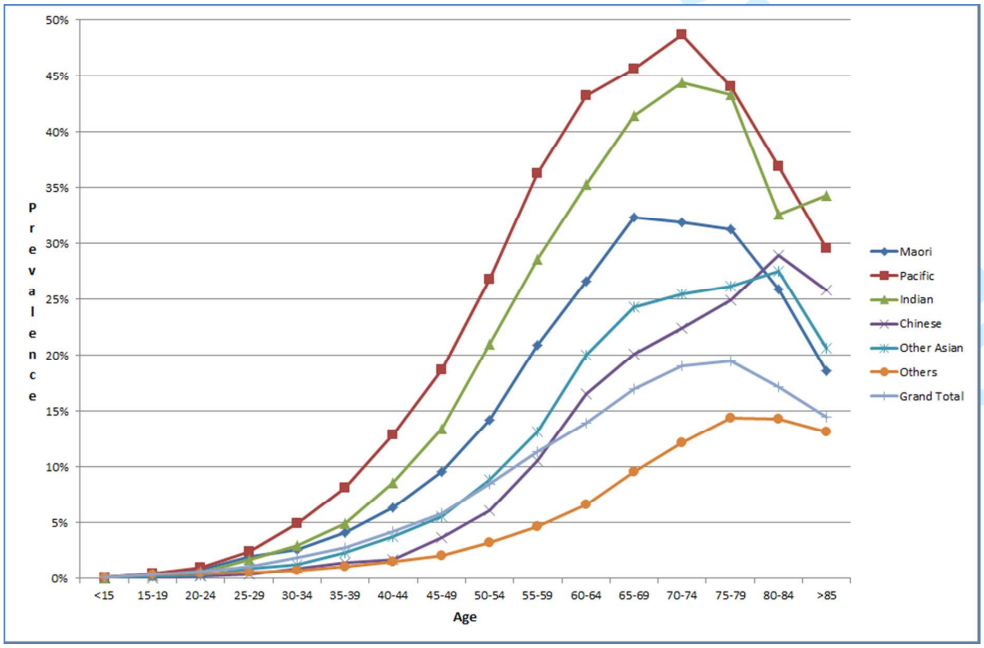


Figure 2: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (females)



Discussion

This study estimated prevalence of dysglycemia in a consistent manner within a geographically defined population of over 1·4 million, by age, gender and ethnicity based on ~~longitudinal~~ laboratory results sourced from a comprehensive regional laboratory repository (Figure 1Figure 2~~&2~~). If the data linkage methodology used in this study were implemented in a live electronic population register, one could ~~readily~~ potentially identify individuals who were yet to be screened for diabetes and people who would probably benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way. We have demonstrated that glycaemia-related blood testing coverage is very high in the Auckland metropolitan region, and apparently higher than previously reported in Ontario, Canada in 2005.[6] In Auckland, more than 85% of men and 84% of women over 55 in 2010 have had one or more glucose or HbA1c blood tests since 2004. Females of child-bearing age (aged 15-49) were also more likely to have glucose or HbA1c blood tests than their male counterparts for comparable age and ethnic groups. Overall, the blood test coverage of females between 15 and 49 years of age was 7·7% higher than males.

Consistent with the New Zealand CVD risk management guideline recommendation to screen Maori, Pacific and Indian people 10 years earlier than others, the age-specific blood test coverage was higher in these ethnic groups than other groups in the age groups between 35 and 45 years for males and between 45 and 55 years for females.[15] Since 34% of blood tests were carried out in hospital laboratories, it was likely that a number of tests were undertaken because of symptoms related to diabetes rather than opportunistic screening for diabetes. Since the rate of hospital admissions increases with advancing age, the relatively high coverage of diabetes testing in the older groups may be in part a result of routine glucose testing for most patients admitted to hospitals.

Consistent with previous reports, the ethnic disparities in prevalence of dysglycemia were alarming.[16] This study demonstrated Pacific and Indian people have the highest age standardised prevalence of dysglycemia (Table 3). Almost one in two Pacific women aged 70-74 had evidence of dysglycemia (Figure 2). ~~The age-specific prevalence of Pacific and Indian people were more than 25% higher in absolute terms across a number of age groups compared to 'others' where the highest age-specific prevalence estimates were below 19% in males, and 15% in females~~. These findings highlight the critical need for both primary and secondary prevention efforts to reduce ethnic disparities in diabetes-related morbidity and mortality. A previously published estimate of diabetes prevalence for the southern part of the region (CMDHB) in 2006/7, was about 20% lower in relative terms (a difference of >5,000 people) than in the current study.[17] The key methodological difference between the studies was the availability of blood test results in the current study, whereas the previous study relied on an algorithm based on hospitalisations, drug treatment and the number of HbA1c tests (without the test results being available) to estimate diabetes prevalence. Demographic changes; improvement in screening; differences in definitions of diabetes and dysglycemia and a real increase in the underlying diabetes prevalence since 2006/7 are likely to explain the difference of results between the studies.

The HSU population (denominator) was constructed from national routinely collected administrative data; it defined the population at risk and effectively adjusted for migration and deaths. The use of current PHO enrolment and/or evidence of health service contact are pragmatic proxies to indicate that the HSU population residing in the Auckland metropolitan area within the defined period of the study. The novelty and strength of this study was that both the test coverage and the dysglycemic status of each individual in the HSU population in 2010 were determined by the ~~longitudinal~~ laboratory results in a consistent manner through individual person record linkage using a unique identifier, the encrypted NHI.

The use of the HSU population as the denominator on which to base future population registers for many long-term conditions has many technical and practical advantages in policy making and quality improvement. The HSU population (n=1,475,347) was very similar to the estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 (n=1,477,600).[14] In practical terms, virtually everyone with significant disease who resides in the Auckland metropolitan area is likely to be currently enrolled in a primary care practice and/or have had a contact with publicly funded health services in the year. The way the HSU population was defined means that if identifiable data were used as part of a population register, it can potentially identify any potential performance gaps that a health care provider can address at the individual level. Eligible patients could be readily recalled based on latest contact details from primary care enrolment or from the last health service contact. This is particularly important in a context where the actual care that patients received might be suboptimal.[18] For example, a systematic recall system can theoretically be set up for those people who are yet to be screened using the identical record linkage carried out by this study. As pharmaceutical dispensing data can be linked by NHI in New Zealand, a similar systematic system could also be implemented to monitor the care provision for people who are at high risk of complications. For example, it would be possible to recall those with diabetes and microalbuminuria that were not dispensed an angiotensin-converting enzyme inhibitor or angiotensin II receptor antagonist, or people with poorly-controlled diabetes who may need further clinical review or self-management support. Many chronic care models such as Wagner's emphasised the value of clinical information systems and the role of a population registry to facilitate the provision of systematic proactive care to patients with long term conditions.[19] Indeed, an integrated electronic health record system that contains laboratory results, pharmaceutical use, and utilisation of services has recently been highlighted as critical components to measure the quality of care provided.[20]

Other advantages of the HSU population used in this study include the elimination of numerator-denominator biases highlighted in previous reports.[21,22] Furthermore, the participation of all of the laboratories serving the area in the study, meaning virtually 100% of the laboratory tests performed in the Auckland metropolitan area were included. The long-standing use of the data repository, and its incorporation in day-to-day general practice and secondary care also contributes to the completeness and robustness of the data stored.

This study addressed many of the limitations of common sources of data that are used to estimate diabetes prevalence – these are summarised in Table 4.[1,3,4,23-26] Many traditional epidemiological studies are based on surveys that are subject to selection bias and patient recall biases.[1,4] Self-reported diabetes prevalence estimates are often lower than estimates based on biochemical results.[4] Most epidemiological surveys have relied on one single laboratory measurement, however

glucose tolerance tests have limited repeatability and glucose measurements have considerable intra-individual variations.[23,27] While some registers have sourced data from primary care, the quality of input data and consistency of coding could be highly variable.[3,24,28] While the UK NHS Quality and Outcomes Framework (QOF) recommends a systematic approach to diagnose diabetes, primary care providers are not required to provide supporting description on how the diabetes diagnoses are made, other than a record of a diabetes diagnosis for the purpose of the QOF indicator.[29] Indeed, QOF openly acknowledges that there are a substantial number of people who are undiagnosed or misdiagnosed.[29] The ability to keep an up to date record of people with 'diagnosed' diabetes would also be more challenging in places where there is a highly mobile population such as in New Zealand, certain parts of Great Britain and the United States.[30-32] Furthermore, a significant number of blood test results may not be requested by the general practices that are currently responsible for the patients' care. For example, as demonstrated in this study, significant numbers of laboratory tests were carried out in hospitals.

The New Zealand NHI database has identifiable information such as name, address, data of birth, self-reported ethnicity.[33] The NHI number has been used in other settings of proactive care such as immunisation in New Zealand.[33,34] The duplicated NHIs are regularly cleaned and mapped back to the Master NHI. Regular audits are performed and Primary Health Organisations are required to provide their patient registries to the Ministry of Health (MOH) every quarter. Therefore, ~~For these reasons~~, applying the methodology used in this study to construct a population register ~~could~~ has the potential to enable a systematic approach to medical auditing. The method identifi~~es~~~~ying~~ the population eligible but yet to be screened for diabetes within a defined period or people who might have abnormal diabetes laboratory results who would benefit from proactive follow up as defined by this study.[33] Data security and appropriate access and use of health data across the whole of health system are vital components to enable a population register to succeed. The balance between patient confidentiality and the adaptable use of identifiable health data to enable proactive health services should be vigorously debated. While the rationale to develop such a population register is to improve population health and equity through systematic medical audit, appropriate safeguards should be in place to limit any unintended misuse of possible confidential health data.

Clinicians ideally should have timely access to all the available health information for the group of patients that ~~one is~~they are clinically responsible for. However, the capacity and capability required to analyse health data from the whole of health system into clinically meaningful and actionable health information to be available at the point of care are not universally available from all health care providers. Therefore, a central system that can apply the methods of this study has a tremendous potential to review some of the possible quality gaps exist in the current system. ~~to allow a more systematic recording of people who had known diabetes according to the biochemical results in a consistent manner.~~

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Table 4: The limitations of common sources of data used to estimate diabetes prevalence

Sources of data	Limitations
Self-report survey	Selection/ sample bias, patient recall bias, limited sample size
Survey with one laboratory test	Selection bias; cross-sectional measure, poor repeatability with glucose tests, estimates the undiagnosed diabetes based on patient recall or medical records, not necessarily unknown to the entire health system
Primary care	Inconsistency in primary care coding, subject to migration bias, may miss

records	diagnosis at secondary care or other health care providers, limited sensitivity in general
Hospitals	Only identifies those with diabetes who attended hospital, recent changes in ICD coding standards may affect consistency. Major undercount
Pharmaceutical dispensing data	Diet-controlled diabetes would not be captured; adherence is not perfect in the community. Medications may have other indications such as metformin in polycystic ovarian syndrome or may be being used to 'prevent' diabetes
Combination of datasets	Depends on quality of the datasets combined. Needs a unique patient identifier for linkage to avoid double counting. The definition of diagnoses may not be consistent across the datasets
Capture- recapture	Identifies people with diabetes not captured by the system, (note - not undiagnosed diabetes). Assumes list independence, and all individuals have the same probability of being captured by each dataset ~~is the same~~. The estimates can be influenced by factors that are completely unrelated to diabetes prevalence such as changes in ICD coding standards, or admission threshold, and treatment trends. One cannot identify the individuals.

The definition of dysglycemia used in this study is a pragmatic one which identifies a group of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications and need to be followed up by the health care system for ongoing clinical support and management.[35-38] People with borderline elevated HbA1c (>48mmol/mol) may be offered dietary advice and the HbA1C test may not necessarily be repeated immediately in the "real-world" as it does not change immediate management. Strictly speaking, these people would not yet have met the diagnostic criteria of diabetes. However, they should have follow up tests to confirm or exclude the diagnosis of diabetes. Moreover, the proposed method of this study can be refined further to apply the different diagnostic threshold of HbA1C according to ethnicity or to local recommendations.[39,40]

Another limitation of this study is the imperfect sensitivity as it was based on "real-world" data of relatively short duration, and the way dysglycemia is currently defined the study would not have identified people with dysglycemia or diabetes who were lost to follow-up. However, more than 91% of the HSU population who had a diabetes-related hospitalisation in New Zealand between 1 July 2000 and 30 June 2010 also had laboratory results consistent with the diagnosis. This finding suggests a regional laboratory repository of such duration (community test results for 4 years and hospital test results for 6·5 years) would already capture a substantial proportion of people with diabetes. Many people who had a single elevated glucose test might not be followed up (to get the second test required for diagnosis). This study would also miss people who had diabetes diagnosed by laboratory tests performed outside the Auckland metropolitan area or diagnosed before 2004 and subsequently had had excellent diabetes control. However, these cohorts would be identified in subsequent iterations of the population register if their diabetes control deteriorated in the future. The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

In conclusion, a regional laboratory result repository linked to administrative datasets ~~can~~ has the potential to provide highly relevant and consistent information to inform clinical decision making in a comprehensive and timely manner as well as being an excellent epidemiological surveillance tool.

Role of funding source:

This study was conducted as a result of the work undertaken for Counties Manukau District Health Board (CMDHB), New Zealand. WCC, GJ, BOW, DRB, MAWL, and DP were paid employees of CMDHB at the time of the study. Views expressed in this publication are those of the authors and not necessarily those of CMDHB.

Conflicts of interests:

We declare no support from any organisation for the submitted work; BOW had received remuneration from the New Zealand Ministry of Health, as the former National clinical director responsible for sector engagement on population health targets. BOW had received payment for lectures from Novo-Nordisk, AstraZeneca, Sanofi and MSD.

Contribution statements:

WCC designed the study methods, applied approval for access for all the relevant data, undertook literature search, record linkage, cross checking, statistical analysis, and drafted up and revised the paper. He is the guarantor. GJ designed the study methods, and revised the paper. CW designed the study methods, linked the administrative data to construct the health service utilisation population, and revised the paper. BO-W designed the study methods and revised the paper. PLD provided clinical diabetes input and revised the paper. DRB designed the study methods and revised the paper. MAWL undertook record linkage, cross checking, and statistical analysis. DP undertook record linkage and data extraction for cross checking. RJ designed the study methods and revised the paper.

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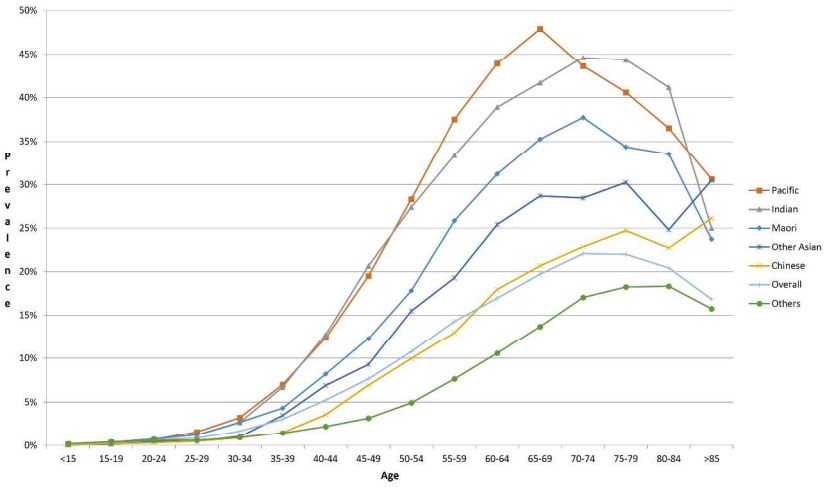

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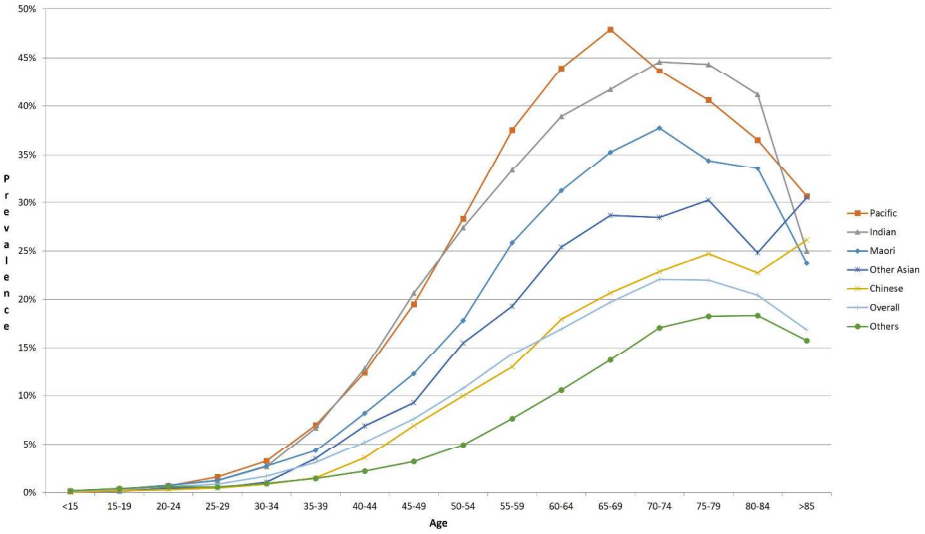

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BMJ Open

The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003975.R2
Article Type:	Research
Date Submitted by the Author:	18-Mar-2014
Complete List of Authors:	Chan, Wing Cheuk; Counties Manukau District Health Board, Population Health Jackson, Gary; Health Partners Consulting Group, Wright, Craig; Sapere Research Group, Orr-Walker, Brandon; Counties Manukau District Health Board, Endocrinology and Diabetes Service Drury, Paul; Auckland District Health Board, Auckland Diabetes Centre Boswell, D; Counties Manukau District Health Board, Laboratory Services Lee, Mildred; Counties Manukau District Health Board, Population Health Papa, Dean; Counties Manukau District Health Board, Population Health Jackson, Rod; University of Auckland, School of Population Health
Primary Subject Heading:	Epidemiology
Secondary Subject Heading:	Diabetes and endocrinology, Evidence based practice, General practice / Family practice, Health informatics, Public health
Keywords:	EPIDEMIOLOGY, General diabetes < DIABETES & ENDOCRINOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

TITLE: THE FUTURE OF POPULATION REGISTERS: LINKING ROUTINE HEALTH DATASETS TO ASSESS A POPULATION'S CURRENT GLYCAEMIC STATUS FOR QUALITY IMPROVEMENT

Authors' names

Corresponding author:
WC Chan, Public Health Physician, Counties Manukau District Health Board.
Address: Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand
Email: wingcheuk.chan@cmdhb.org.nz
Phone: + 64 9 2599658
Fax: +64 9 259 9665

Authors' positions and Addresses

Wing Cheuk Chan, FNZCPHM, Public Health Physician, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: wingcheuk.chan@cmdhb.org.nz

Gary Jackson, FNZCPHM, Public Health Physician, Health Partners Consulting Group. PO Box 147209, Ponsonby, Auckland, New Zealand. Email: gary@healthpartnersconsulting.com

Craig Shawe Wright, BSc, Senior Managing Consultant, Sapere Research Group, PO Box 587, Wellington, 6140. Email:cwright@srgexpert.com

Brandon Orr-Walker, FRACP, Clinical Head, Endocrinology and Diabetes Service, Counties Manukau District Health Board, Private Bag 94052, 2240, South Auckland Mail Centre, New Zealand. Email: Brandon.Orr-Walker@middlemore.co.nz

Paul L Drury, FRCP, Clinical Director, Auckland Diabetes Centre, Auckland District Health Board. Greenlane Clinical Centre, PO Box 92189, Auckland, New Zealand. Email: PaulD@adhb.govt.nz

D Ross Boswell, PhD, Clinical Director of Laboratory Services, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email:Ross.Boswell@middlemore.co.nz

Mildred Ai Wei Lee, MSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: Mildred.Lee@middlemore.co.nz

Dean Papa, BSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: j.papa@xtra.co.nz

Rod Jackson, PhD, Professor of epidemiology. School of Population Health, University of Auckland, Auckland, New Zealand. Private Bag 92019, Auckland, 1142, New Zealand. Email: rt.jackson@auckland.ac.nz

Number of tables: 3

Number of figures: 2

Title: The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Abstract:

Objectives: To determine diabetes screening levels and known glycaemic status of all individuals by age, gender and ethnicity within a defined geographic location in a timely and consistent way to potentially facilitate systematic disease prevention and management.

Design: Retrospective observational study.

Setting: Auckland region of New Zealand.

Participants: 1,475,347 people who had utilised publicly funded health service in New Zealand and domicile inthe Auckland region of New Zealand in 2010. The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004.

Outcome measures: The two outcomes measures were glycaemia-related blood testing coverage (HbA1c, fasting and random glucose and glucose tolerance tests), and the proportions and number of people with known dysglycemia in 2010 using modified ADA and WHO criteria.

Results: Within the health service utilisation population, 792,560 people had had at least one glucose or HbA1c blood test in the previous 5.5 years. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,982) in the recommended age groups for diabetes screening had a blood test to assess their glycaemic status. Estimated age-standardised prevalence of dysglycemia was highest in people of Pacific Island ethnicity at 11.4% (95% CI: 11.2%-11.5%) for males and 11.6% (11.4%-11.8%) for females, followed closely by people of Indian ethnicity 10.8% (10.6-11.1%) and 9.3% (9.1% to 9.6%). Among the indigenous Maori population the prevalence was 8.2% (7.9%-8.4%) and 7.0% (6.8%-7.2%), while for 'Others' (mainly Europeans) it was 3.0% (3.0-3.1%) and 2.2% (2.1-2.2%).

Conclusion: We have demonstrated that the data linkage between a laboratory repository and national administrative datasets has the potential to provide a systematic and consistent individual level clinical information that are relevant to medical auditing for a large geographically defined population.

Keywords: diabetes mellitus, hyperglycemia, quality improvement, quality indicators, prevalence, epidemiology, health status disparities, mass screening.

Article summary

Article focus

- This article aims to demonstrate the potential value of data linkage of multiple routine health datasets to determine the diabetes screening levels and the known glycaemic status of all

individuals within a defined geographic location to facilitate systematic disease prevention and management.

Key messages

- Glycaemia related blood testing is common. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for cardiovascular risk assessment had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010.
- The prevalence of dysglycaemic status as defined by a consistent definition varies markedly by age and ethnicity.
- If the data linkage methodology used in this study were implemented in a live electronic population register, one has the potential to identify individuals who were yet to be screened for diabetes and people who more likely to benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way.

Strengths and Limitations of the study

- This study applied a method that aims to address the common systematic biases seen in many population diabetes prevalence studies such as incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, and misdiagnosis.
- The definition of dysglycaemia included people with confirmed diabetes as well as people who require follow up tests to confirm the formal diagnosis of diabetes.
- The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

Introduction

The number of people with diabetes globally increased by almost 200 million from 1980 to 2008.[1] In the context of a potential "diabetes epidemic", an accurate and timely measure of diabetes prevalence is critical to inform policy making, resource allocation and planning and implementation of interventions to improve the quality of care for the people with diabetes. Moreover, a consistent and systematic way to identify individuals for diabetes screening, follow-up and management is necessary to ensure people with diabetes receive the most appropriate care. Indeed, randomised controlled trials have demonstrated that the use of electronic patient registers, patient and clinician reminders are associated with quality improvement in diabetes management.[2] However, the limitations of existing methods to identify populations with diabetes include incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, misdiagnosis, lack of precision by age, gender or ethnicity, and inadequate adjustments for migrations or deaths.[1,3-6]

Auckland (New Zealand) has an ethnically diverse population of over 1·4 million people. The aim of this study is to use laboratory results (between 1 Jan 2004 and 30 Jun 2010) from a regional laboratory repository to estimate glycaemia test coverage and glycaemic status in a geographical defined population in 2010. This study proposes a set of methods that utilise "real-world" routinely collected data in a practical manner that has the potential to provide critical and succinct information for the responsible clinicians that is robust enough at the individual level for quality improvement as well as estimates at the aggregated population level.

Methods

Date sources

TestSafe is a comprehensive data repository containing all the community and hospital laboratory test results requested in the Auckland metropolitan region in New Zealand since July 2006. Individual patient laboratory tests can be requested by general practitioners, privately or publicly funded specialists, resident medical staff or other allied health workers. Prior to July 2006 only hospital test results and community results that were sent to secondary care clinicians were recorded in the data repository. Fasting glucose, random glucose, 2 hour post glucose load values (standard 75g oral glucose tolerance test OGTT), and HbA1c results from 1 Jan 2004 to 30 Jun 2010 were sourced from the TestSafe repository. The following routine administrative datasets were sourced from the Analytical Services team within the National Health Board of the Ministry of Health (MOH) (formerly known as the New Zealand Health Information service (NZHIS)):

- National Minimum Dataset (hospital events) (NMDS)
- National Non-admitted Patient Collection (outpatients and community visits) (NNPAC)
- Pharmaceutical Collection (PHARMHOUSE)
- Laboratory Claims Collection (note: does not include test results)
- Primary Health Organisation Enrolment Collection
- General Medical Subsidy Data Mart
- National Mortality Collection
- National Immunisation Register.

Data linkage

Virtually all health service users in New Zealand are assigned a unique identifier called National Health Index (NHI). The NHI coverage is estimated to be 98% of the New Zealand population.[7] Additional information regarding the purpose, and the use of NHI is available on the New Zealand Ministry of Health website.[8] All NHIs used in this study were encrypted to protect privacy and confidentiality of health information. Record linkage of various data sources were carried out using encrypted NHIs. Ethical approval was obtained from The New Zealand Northern X Regional Ethics Committee (NTX/10/EXP/153) and access of TestSafe laboratory results was approved by Auckland Regional Information Systems Group (RISG).

Inclusion criteria of the study

The linkage of the available administrative datasets by unique encrypted NHI was undertaken to derive the "health service utilisation (HSU) population". This was defined as New Zealand residents who resided within the boundaries of the three District Health Boards located in the Auckland metropolitan region and received any of the publicly-funded health services in New Zealand between 1 July 2009 and 30 June 2010, namely:

- Currently enrolled in a Primary Health Organisation (PHO) or people who had a health service contact with a PHO,
- Publicly funded inpatient and outpatient secondary care events (including mental health and emergency department contact),
- Any community pharmaceutical dispensing,
- Any community laboratory test (including outside the Auckland metropolitan region) including the ones requested by privately funded health professionals,
- Any immunisation received as indicated by the national immunisation register.

Deceased individuals were excluded from the HSU population using the National Mortality Collection. In New Zealand, PHOs supply general practitioner services and are publicly funded, receiving a capitation payment for each enrolee. PHOs are required to provide a defined set of essential services which include appropriate evidence based screening, risk assessment and the use of recall and reminder systems.[9]

Numerator 1: glycaemic status test coverage

The glycaemic status test coverage by age and ethnicity was estimated as the proportion of the HSU population who had at least one glucose or HbA1c blood test recorded in TestSafe repository from 1 Jan 2004 to 30 Jun 2010. Lab tests with missing results or results with <1mmol/L for glucose test, or <1% (<0mmol/mol) of HbA1c were excluded.

$$\text{The glycaemic status test coverage} = \frac{\text{The number of people who had at least one diabetes blood test in Auckland metro from 1/01/2004 to 30/06/2010}}{\text{Corresponding number of people in the health service utilisation population.}}$$

Definition of dysglycemia

The definition of diabetes recommended by American Diabetes Association in 2010 and the World Health Organization consultation in 2011 was modified for this "real-world" study,[10,11] and termed

"dysglycemia". The operational definition of this study was to identify a cohort of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications rather than only the people who had a confirmed diagnosis of diabetes. This defined cohort should be followed up by the health care system for ongoing clinical support and management. The dysglycemic status was derived directly from the laboratory results recorded in a TestSafe laboratory repository for each person in the HSU population. Duplicated test results with identical lab numbers for the same person were removed. A person was defined to have dysglycemia if they had:

- at least one **HbA1c** test ≥ 6·5% (equivalent to 48 mmol/mol) or
- at least one 2 hour post glucose load ≥ 11·1 mmol/l on a **Glucose tolerance test (GTT)**
- two or more tests of **random glucose** ≥ 11·1 mmol/L and/or **fasting glucose** ≥ 7·0 mmol/L on a different day.

For young children less than 10 years of age in 2010, hospital requested glucose tests were not examined because high glucose results in hospital for young children are more likely to relate to artificial nutritional feeds or parenteral nutrition than to diabetes.

Comparison to hospital diagnosis

People within the HSU population who had a previous hospitalisation with a primary or secondary diagnosis of diabetes (ICD 10 codes Edition 3 E10-E14, and O240-O243) from 1 July 1999 to 30 June 2010 in New Zealand were compared against the laboratory diagnosis of dysglycemia as defined by this study.

Demographic variables

The dysglycemic status for each person within the HSU population was determined by the blood test results. The demographic variables including adjustment for migration and deaths were made in an identical way for both the numerator (people who had at least one glucose or HbA1c blood test or people with dysglycemia) and denominator (HSU population which includes people with dysglycemia or diabetes). Ethnicity was determined as per ethnicity data protocols published by the New Zealand Ministry of Health using the prioritised method.[12] Age was calculated from date of birth with reference to 1 Jan 2010.

Age standardisation

The prevalence proportions were separated into 5-year age groups from <15 to ≥85 for direct age standardisation using the World Health Organization (WHO) World population as the standard.[13] 95% confidence intervals are presented.

Results

There were 1,475,347 people living in the Auckland metropolitan region as defined by the HSU population in June 2010. The estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 was 1,477,600.[14] A total of 4,281,599 glucose and HbA1c blood tests were analysed from 792,588 people who had at least one glycaemia related blood test in the study period. There were 1,458,350 tests performed in laboratories based in hospitals (34% of the total) and 2,823,249 tests performed by community laboratories (66%). There were 38 people who had a glycaemia related blood test but did not have a gender recorded,

and all had age recorded. The proportions of people receiving at least one glucose or HbA1c blood test by age, gender and ethnicity are shown in Tables 1 and 2. The age groups highlighted in yellow are the recommended age ranges for diabetes screening as per New Zealand Cardiovascular Guidelines.[15]

Table 1: Proportion of males receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	15·1%	15·6%	16·1%	10·5%	10·9%	14·3%	14·4%	24,465
15-19	25·9%	23·9%	23·7%	16·9%	17·1%	25·5%	24·2%	12,989
20-24	41·1%	38·5%	36·4%	26·3%	28·3%	38·3%	37·3%	18,590
25-29	44·2%	43·0%	42·2%	29·0%	34·5%	40·2%	39·9%	18,811
30-34	49·9%	51·2%	54·5%	36·5%	40·0%	43·4%	45·8%	20,744
35-39	58·7%	60·5%	66·9%	49·7%	51·7%	51·1%	54·5%	28,010
40-44	66·8%	70·4%	78·0%	58·6%	59·1%	61·7%	64·2%	34,175
45-49	75·1%	77·4%	83·5%	66·8%	68·1%	70·9%	72·5%	38,417
50-54	82·4%	84·8%	87·5%	76·9%	76·4%	79·3%	80·4%	36,440
55-59	88·3%	89·1%	88·2%	79·2%	80·3%	85·2%	85·4%	32,353
60-64	92·5%	90·9%	88·9%	84·4%	86·3%	89·3%	89·2%	30,043
65-69	94·3%	92·1%	87·8%	84·5%	88·2%	92·0%	91·4%	22,206
70-74	95·8%	92·1%	88·6%	87·1%	88·3%	94·2%	93·1%	16,649
75-79	95·1%	92·2%	90·1%	88·3%	85·7%	94·9%	93·9%	11,730
80-84	96·1%	90·6%	89·8%	87·8%	84·7%	96·0%	95·0%	8,276
>85	98·3%	87·6%	87·0%	85·0%	84·7%	95·9%	95·1%	5,670
Total								**359,567**

Note: table order reflects ethnicity priority order; "Other" includes those of European descent.

Table 2: Proportion of females receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	12·9%	12·9%	14·5%	8·8%	8·8%	12·7%	12·5%	20,123
15-19	36·6%	27·4%	29·4%	18·1%	17·7%	33·4%	30·6%	16,855
20-24	59·9%	52·1%	50·3%	32·5%	36·1%	50·3%	50·2%	27,144
25-29	65·8%	64·4%	61·0%	40·6%	47·3%	52·3%	54·9%	31,348
30-34	67·4%	68·4%	70·7%	54·4%	53·3%	58·5%	61·5%	34,129
35-39	69·5%	71·0%	76·7%	61·6%	56·6%	63·0%	65·2%	39,085
40-44	72·2%	75·2%	80·1%	68·1%	63·3%	66·9%	69·2%	41,014
45-49	79·4%	81·2%	85·7%	76·7%	68·3%	71·8%	74·6%	42,334
50-54	84·8%	85·8%	89·1%	81·0%	77·7%	78·5%	80·6%	38,528
55-59	88·6%	88·8%	87·8%	81·4%	83·5%	83·2%	84·3%	33,735
60-64	92·3%	91·4%	88·0%	85·9%	86·4%	86·9%	87·6%	30,489
65-69	94·6%	91·4%	89·2%	86·9%	86·3%	90·3%	90·3%	23,404
70-74	95·2%	93·4%	89·7%	87·7%	87·5%	92·7%	92·3%	18,120
75-79	94·8%	92·3%	89·0%	89·1%	85·8%	94·6%	93·7%	13,754
80-84	95·5%	89·0%	87·8%	87·2%	88·4%	95·6%	94·6%	11,095
>85	97·4%	90·8%	87·3%	88·6%	80·2%	96·1%	95·5%	11,796
Total								**432,953**

The test coverage varies by age, gender and ethnicity. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for diabetes screening had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010. There were a total of 78,828 people with dysglycemia as defined by this study living in the Auckland metropolitan region in 2010 identified by the laboratory results. Crude prevalence was 5·3% overall (with 5·7% males, 5·0% females). Pacific and Indian ethnicities had the highest age standardised prevalence in Auckland metropolitan region. There were 31,282 people in the HSU population who had been discharged from hospital in New Zealand with a discharge diagnosis of diabetes between 1 July 2000 and 30 June 2010. Of these people, 91% (n=28,489) also had laboratory results consistent with dysglycemia defined by this study.

Table 3: Estimated prevalence of dysglycemia in Auckland metropolitan region by gender and ethnicity

Males							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,378	10,078	4,440	2,343	1,911	17,415	40,565
HSU population number	83,473	114,660	41,571	42,358	34,081	392,962	709,105
Crude prevalence (%)	5·2	8·8	10·7	5·5	5·6	4·4	5·7
Age standardised prevalence (%) with 95% confident interval	8·2 (7·9 – 8·4)	11·4 (11·2-11·5)	10·8 (10·6-11·1)	4·6 (4·4-4·7)	6·4 (6·2-6·7)	3·0 (3·0 - 3·1)	4·9 (4·8-4·9)
Females							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,570	11,751	3,738	2,476	1,773	13,952	38,260
HSU population number	89,808	121,935	42,438	53,527	42,583	415,830	766,121
Crude prevalence (%)	5·1	9·6	8·8	4·6	4·2	3·4	5.0
Age standardised prevalence (%) with 95% confident interval	7·0 (6·8-7·2)	11·6 (11·4-11·8)	9·3 (9·1-9·6)	3·9 (3·8-4·0)	4·9 (4·7-5·1)	2·2 (2·1-2·2)	4·1 (4·1-4·2)

Discussion

This study estimated prevalence of dysglycemia in a consistent manner within a geographically defined population of over 1·4 million, by age, gender and ethnicity based on laboratory results sourced from a comprehensive regional laboratory repository (

Figure 1Figure 2). If the data linkage methodology used in this study were implemented in a live electronic population register, one could potentially identify individuals who were yet to be screened for diabetes and people who would probably benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way. We have demonstrated that glycaemia-related blood testing coverage is very high in the Auckland metropolitan region, and apparently higher than previously reported in Ontario, Canada in 2005.[6] In Auckland, more than 85% of men and 84% of women over 55 in 2010 have had one or more glucose or HbA1c blood tests since 2004. Females of child-bearing age (aged 15-49) were also more likely to have glucose or HbA1c blood tests than their male counterparts for comparable age and ethnic groups. Overall, the blood test coverage of females between 15 and 49 years of age was 7·7% higher than males.

Consistent with the New Zealand CVD risk management guideline recommendation to screen Maori, Pacific and Indian people 10 years earlier than others, the age-specific blood test coverage was higher in these ethnic groups than other groups in the age groups between 35 and 45 years for males and between 45 and 55 years for females.[15] Since 34% of blood tests were carried out in hospital laboratories, it was likely that a small number of tests were undertaken because of symptoms related to diabetes rather than opportunistic screening for diabetes. Since the rate of hospital admissions increases with advancing age, the relatively high coverage of diabetes testing in the older groups may be in part a result of routine glucose testing for most patients admitted to hospitals.

Consistent with previous reports, the ethnic disparities in prevalence of dysglycemia were alarming.[16] This study demonstrated Pacific and Indian people have the highest age standardised prevalence of dysglycemia (Table 3). Almost one in two Pacific women aged 70-74 had evidence of dysglycemia (Figure 2). These findings highlight the critical need for both primary and secondary prevention efforts to reduce ethnic disparities in diabetes-related morbidity and mortality. A previously published estimate of diabetes prevalence for the southern part of the region (CMDHB) in 2006/7, was about 20% lower in relative terms (a difference of >5,000 people) than in the current study.[17] The key methodological difference between the studies was the availability of blood test results in the current study, whereas the previous study relied on an algorithm based on hospitalisations, drug treatment and the number of HbA1c tests (without the test results being available) to estimate diabetes prevalence. Demographic changes; improvement in screening; differences in definitions of diabetes and dysglycemia and a real increase in the underlying diabetes prevalence since 2006/7 are likely to explain the difference of results between the studies.

The HSU population (denominator) was constructed from national routinely collected administrative data; it defined the population at risk and effectively adjusted for migration and deaths. The use of current PHO enrolment and/or evidence of health service contact are pragmatic proxies to indicate that the HSU population residing in the Auckland metropolitan area within the defined period of the study. The novelty and strength of this study was that both the test coverage and the dysglycemic

status of each individual in the HSU population in 2010 were determined by the laboratory results in a consistent manner through individual person record linkage using a unique identifier, the encrypted NHI.

The use of the HSU population as the denominator on which to base future population registers for many long-term conditions has many technical and practical advantages in policy making and quality improvement. The HSU population (n=1,475,347) was very similar to the estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 (n=1,477,600).[14] In practical terms, virtually everyone with significant disease who resides in the Auckland metropolitan area is likely to be currently enrolled in a primary care practice and/or have had a contact with publicly funded health services in the year. The way the HSU population was defined means that if identifiable data were used as part of a population register, it can potentially identify any potential performance gaps that a health care provider can address at the individual level. Eligible patients could be readily recalled based on latest contact details from primary care enrolment or from the last health service contact. This is particularly important in a context where the actual care that patients received might be suboptimal.[18] For example, a systematic recall system can theoretically be set up for those people who are yet to be screened using the identical record linkage carried out by this study. As pharmaceutical dispensing data can be linked by NHI in New Zealand, a similar systematic system could also be implemented to monitor the care provision for people who are at high risk of complications. For example, it would be possible to recall those with diabetes and microalbuminuria that were not dispensed an angiotensin-converting enzyme inhibitor or angiotensin II receptor antagonist, or people with poorly-controlled diabetes who may need further clinical review or self-management support. Many chronic care models such as Wagner's emphasised the value of clinical information systems and the role of a population registry to facilitate the provision of systematic proactive care to patients with long term conditions.[19] Indeed, an integrated electronic health record system that contains laboratory results, pharmaceutical use, and utilisation of services has recently been highlighted as critical components to measure the quality of care provided.[20]

Other advantages of the HSU population used in this study include the elimination of numerator-denominator biases highlighted in previous reports as all the demographic variables between the numerator and denominator were recorded in a consistent way.[21,22] Furthermore, the participation of all of the laboratories serving the area in the study, meaning virtually 100% of the laboratory tests performed in the Auckland metropolitan area were included. The long-standing use of the data repository, and its incorporation in day-to-day general practice and secondary care also contributes to the completeness and robustness of the data stored.

This study addressed many of the limitations of common sources of data that are used to estimate known diabetes prevalence – these are summarised in

Table 4.[1,3,4,23-26] Many traditional epidemiological studies are based on surveys that are subject to selection bias and patient recall biases.[1,4] Self-reported diabetes prevalence estimates are often lower than estimates based on biochemical results.[4] Most epidemiological surveys have relied on one single laboratory measurement, however glucose tolerance tests have limited repeatability and glucose measurements have considerable intra-individual variations.[23,27] While some registers have sourced data from primary care, the quality of input data and consistency of coding could be highly

variable.[3,24,28] While the UK NHS Quality and Outcomes Framework (QOF) recommends a systematic approach to diagnose diabetes, primary care providers are not required to provide supporting description on how the diabetes diagnoses are made, other than a record of a diabetes diagnosis for the purpose of the QOF indicator.[29] Indeed, QOF openly acknowledges that there are a substantial number of people who are undiagnosed or misdiagnosed.[29] The ability to keep an up to date record of people with 'diagnosed' diabetes would also be more challenging in places where there is a highly mobile population such as in New Zealand, certain parts of Great Britain and the United States.[30-32] Furthermore, a significant number of blood test results may not be requested by the general practices that are currently responsible for the patients' care. For example, as demonstrated in this study, significant numbers of laboratory tests were carried out in hospitals.

The New Zealand NHI database has identifiable information such as name, address, data of birth, self-reported ethnicity.[33] The NHI number has been used in other settings of proactive care such as immunisation in New Zealand.[33,34] The duplicated NHIs are regularly cleaned and mapped back to the Master NHI. Regular audits are performed and Primary Health Organisations are required to provide their patient registries to the Ministry of Health (MOH) every quarter. Therefore, applying the methodology used in this study to construct a population register has the potential to enable a systematic approach to medical auditing. The method identifies the population eligible but yet to be screened for diabetes within a defined period or people who might have abnormal diabetes laboratory results who would benefit from proactive follow up as defined by this study. Data security and appropriate access and use of health data across the whole of health system are vital components to enable a population register to succeed. The balance between patient confidentiality and the adaptable use of identifiable health data to enable proactive health services should be vigorously debated. While the rationale to develop such a population register is to improve population health and equity through systematic medical audit, appropriate safeguards should be in place to limit any unintended misuse of possible confidential health data.

Clinicians ideally should have timely access to all the available health information for the group of patients that they are clinically responsible for. However, the capacity and capability required to analyse health data from the whole of health system into clinically meaningful and actionable health information to be available at the point of care are not universally available from all health care providers. Therefore, a central system that can apply the methods of this study has a tremendous potential to review some of the possible quality gaps exist in the current system.

Table 4: The limitations of common sources of data used to estimate diabetes prevalence

Sources of data	Limitations
Self-report survey	Selection/ sample bias, patient recall bias, limited sample size
Survey with one laboratory test	Selection bias; cross-sectional measure, poor repeatability with glucose tests, estimates the undiagnosed diabetes based on patient recall or medical records, not necessarily unknown to the entire health system
Primary care records	Inconsistency in primary care coding, subject to migration bias, may miss diagnosis at secondary care or other health care providers, limited sensitivity in general
Hospitals	Only identifies those with diabetes who attended hospital, recent changes in ICD coding standards may affect consistency. Major undercount
Pharmaceutical	Diet-controlled diabetes would not be captured; adherence is not perfect in

dispensing data	the community. Medications may have other indications such as metformin in polycystic ovarian syndrome or may be being used to 'prevent' diabetes
Combination of datasets	Depends on quality of the datasets combined. Needs a unique patient identifier for linkage to avoid double counting. The definition of diagnoses may not be consistent across the datasets
Capture- recapture	Identifies people with diabetes not captured by the system, (note - not undiagnosed diabetes). Assumes list independence, and all individuals have the same probability of being captured by each dataset. The estimates can be influenced by factors that are completely unrelated to diabetes prevalence such as changes in ICD coding standards, or admission threshold, and treatment trends. One cannot identify the individuals.

The definition of dysglycemia used in this study is a pragmatic one which identifies a group of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications and need to be followed up by the health care system for ongoing clinical support and management.[35-38] People with borderline elevated HbA1c (>48mmol/mol) may be offered dietary advice and the HbA1C test may not necessarily be repeated immediately in the "real-world" as it does not change immediate management. Strictly speaking, these people would not yet have met the diagnostic criteria of diabetes. However, they should have follow up tests to confirm or exclude the diagnosis of diabetes, impaired fasting glucose, or impaired glucose tolerance. Moreover, the proposed method of this study can be refined further to apply the different diagnostic threshold of HbA1C according to ethnicity or to local recommendations.[39,40]

Another limitation of this study is the imperfect sensitivity as it was based on "real-world" data of relatively short duration, and the way dysglycemia is currently defined the study would not have identified people with dysglycemia or diabetes who were lost to follow-up. However, more than 91% of the HSU population who had a diabetes-related hospitalisation in New Zealand between 1 July 2000 and 30 June 2010 also had laboratory results consistent with the diagnosis. This finding suggests a regional laboratory repository of such duration (community test results for 4 years and hospital test results for 6·5 years) would already capture a substantial proportion of people with diabetes. Many people who had a single elevated glucose test might not be followed up (to get the second test required for diagnosis). This study would also miss people who had diabetes diagnosed by laboratory tests performed outside the Auckland metropolitan area or diagnosed before 2004 and subsequently had had excellent diabetes control. However, these cohorts would be identified in subsequent iterations of the population register if their diabetes control deteriorated in the future. The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes. Since glycaemia-related blood testing coverage varies by age, gender, and ethnicity as shown in Table 1Table 2, the differential testing coverage could contribute a degree of systematic bias to this study's estimate of dysglycaemia prevalence.

In conclusion, a regional laboratory result repository linked to administrative datasets has the potential to provide highly relevant and consistent information to inform clinical decision making in a comprehensive and timely manner as well as being an excellent epidemiological surveillance tool.

Role of funding source:

This study was conducted as a result of the work undertaken for Counties Manukau District Health Board (CMDHB), New Zealand. WCC, GJ, BOW, DRB, MAWL, and DP were paid employees of CMDHB at the time of the study. Views expressed in this publication are those of the authors and not necessarily those of CMDHB.

Contribution statements:

WCC designed the study methods, applied approval for access for all the relevant data, undertook literature search, record linkage, cross checking, statistical analysis, and drafted up and revised the paper. He is the guarantor. GJ designed the study methods, and revised the paper. CW designed the study methods, linked the administrative data to construct the health service utilisation population, and revised the paper. BO-W designed the study methods and revised the paper. PLD provided clinical diabetes input and revised the paper. DRB designed the study methods and revised the paper. MAWL undertook record linkage, cross checking, and statistical analysis. DP undertook record linkage and data extraction for cross checking. RJ designed the study methods and revised the paper.

Conflicts of interests:

We declare no support from any organisation for the submitted work; BOW had received remuneration from the New Zealand Ministry of Health, as the former National clinical director responsible for sector engagement on population health targets. BOW had received payment for lectures from Novo-Nordisk, AstraZeneca, Sanofi and MSD.

Data Sharing Statement:

No additional data

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Figure 1: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (males)

Figure 2: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (females)

TITLE: THE FUTURE OF POPULATION REGISTERS: LINKING ROUTINE HEALTH DATASETS TO ASSESS A POPULATION'S CURRENT GLYCAEMIC STATUS FOR QUALITY IMPROVEMENT

Authors' names

Corresponding author:
WC Chan, Public Health Physician, Counties Manukau District Health Board.
Address: Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand
Email: wingcheuk.chan@cmdhb.org.nz
Phone: + 64 9 2599658
Fax: +64 9 259 9665

Authors' positions and Addresses

Wing Cheuk Chan, FNZCPHM, Public Health Physician, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: wingcheuk.chan@cmdhb.org.nz

Gary Jackson, FNZCPHM, Public Health Physician, Health Partners Consulting Group. PO Box 147209, Ponsonby, Auckland, New Zealand. Email: gary@healthpartnersconsulting.com

Craig Shawe Wright, BSc, Senior Managing Consultant, Sapere Research Group, PO Box 587, Wellington, 6140. Email:cwright@srgexpert.com

Brandon Orr-Walker, FRACP, Clinical Head, Endocrinology and Diabetes Service, Counties Manukau District Health Board, Private Bag 94052, 2240, South Auckland Mail Centre, New Zealand. Email: Brandon.Orr-Walker@middlemore.co.nz

Paul L Drury, FRCP, Clinical Director, Auckland Diabetes Centre, Auckland District Health Board. Greenlane Clinical Centre, PO Box 92189, Auckland, New Zealand. Email: PaulD@adhb.govt.nz

D Ross Boswell, PhD, Clinical Director of Laboratory Services, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email:Ross.Boswell@middlemore.co.nz

Mildred Ai Wei Lee, MSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: Mildred.Lee@middlemore.co.nz

Dean Papa, BSc, Health Analyst, Counties Manukau District Health Board. Private Bag 94052, South Auckland Mail Centre, 2240, New Zealand. Email: j.papa@xtra.co.nz

Rod Jackson, PhD, Professor of epidemiology. School of Population Health, University of Auckland, Auckland, New Zealand. Private Bag 92019, Auckland, 1142, New Zealand. Email: rt.jackson@auckland.ac.nz

Number of tables: 3

Number of figures: 2

Title: The future of population registers: linking routine health datasets to assess a population's current glycaemic status for quality improvement

Abstract:

Objectives: To determine diabetes screening levels and known glycaemic status of all individuals by age, gender and ethnicity within a defined geographic location in a timely and consistent way to potentially facilitate systematic disease prevention and management.

Design: Retrospective observational study.

Setting: Auckland region of New Zealand.

Participants: 1,475,347 people who had utilised publicly funded health service in New Zealand and domicile inthe Auckland region of New Zealand in 2010. The health service utilisation population was individually linked to a comprehensive regional laboratory repository dating back to 2004.

Outcome measures: The two outcomes measures were glycaemia-related blood testing coverage (HbA1c, fasting and random glucose and glucose tolerance tests), and the proportions and number of people with known dysglycemia in 2010 using modified ADA and WHO criteria.

Results: Within the health service utilisation population, 792,560 people had had at least one glucose or HbA1c blood test in the previous 5.5 years. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,982) in the recommended age groups for diabetes screening had a blood test to assess their glycaemic status. Estimated age-standardised prevalence of dysglycemia was highest in people of Pacific Island ethnicity at 11.4% (95% CI: 11.2%-11.5%) for males and 11.6% (11.4%-11.8%) for females, followed closely by people of Indian ethnicity 10.8% (10.6-11.1%) and 9.3% (9.1% to 9.6%). Among the indigenous Maori population the prevalence was 8.2% (7.9%-8.4%) and 7.0% (6.8%-7.2%), while for 'Others' (mainly Europeans) it was 3.0% (3.0-3.1%) and 2.2% (2.1-2.2%).

Conclusion: We have demonstrated that the data linkage between a laboratory repository and national administrative datasets has the potential to provide a systematic and consistent individual level clinical information that are relevant to medical auditing for a large geographically defined population.

Keywords: diabetes mellitus, hyperglycemia, quality improvement, quality indicators, prevalence, epidemiology, health status disparities, mass screening.

Article summary

Article focus

- This article aims to demonstrate the potential value of data linkage of multiple routine health datasets to determine the diabetes screening levels and the known glycaemic status of all

individuals within a defined geographic location to facilitate systematic disease prevention and management.

Key messages

- Glycaemia related blood testing is common. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for cardiovascular risk assessment had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010.
- The prevalence of dysglycaemic status as defined by a consistent definition varies markedly by age and ethnicity.
- If the data linkage methodology used in this study were implemented in a live electronic population register, one has the potential to identify individuals who were yet to be screened for diabetes and people who more likely to benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way.

Strengths and Limitations of the study

- This study applied a method that aims to address the common systematic biases seen in many population diabetes prevalence studies such as incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, and misdiagnosis.
- The definition of dysglycaemia included people with confirmed diabetes as well as people who require follow up tests to confirm the formal diagnosis of diabetes.
- The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes.

Introduction

The number of people with diabetes globally increased by almost 200 million from 1980 to 2008.[1] In the context of a potential "diabetes epidemic", an accurate and timely measure of diabetes prevalence is critical to inform policy making, resource allocation and planning and implementation of interventions to improve the quality of care for the people with diabetes. Moreover, a consistent and systematic way to identify individuals for diabetes screening, follow-up and management is necessary to ensure people with diabetes receive the most appropriate care. Indeed, randomised controlled trials have demonstrated that the use of electronic patient registers, patient and clinician reminders are associated with quality improvement in diabetes management.[2] However, the limitations of existing methods to identify populations with diabetes include incomplete coverage of the population at risk, inconsistency in the definition of diabetes, selection and patient recall bias, measurement errors, misdiagnosis, lack of precision by age, gender or ethnicity, and inadequate adjustments for migrations or deaths.[1,3-6]

Auckland (New Zealand) has an ethnically diverse population of over 1·4 million people. The aim of this study is to use laboratory results (between 1 Jan 2004 and 30 Jun 2010) from a regional laboratory repository to estimate glycaemia test coverage and glycaemic status in a geographical defined population in 2010. This study proposes a set of methods that utilise "real-world" routinely collected data in a practical manner that has the potential to provide critical and succinct information for the responsible clinicians that is robust enough at the individual level for quality improvement as well as estimates at the aggregated population level.

Methods

Date sources

TestSafe is a comprehensive data repository containing all the community and hospital laboratory test results requested in the Auckland metropolitan region in New Zealand since July 2006. Individual patient laboratory tests can be requested by general practitioners, privately or publicly funded specialists, resident medical staff or other allied health workers. Prior to July 2006 only hospital test results and community results that were sent to secondary care clinicians were recorded in the data repository. Fasting glucose, random glucose, 2 hour post glucose load values (standard 75g oral glucose tolerance test OGTT), and HbA1c results from 1 Jan 2004 to 30 Jun 2010 were sourced from the TestSafe repository. The following routine administrative datasets were sourced from the Analytical Services team within the National Health Board of the Ministry of Health (MOH) (formerly known as the New Zealand Health Information service (NZHIS)):

- National Minimum Dataset (hospital events) (NMDS)
- National Non-admitted Patient Collection (outpatients and community visits) (NNPAC)
- Pharmaceutical Collection (PHARMHOUSE)
- Laboratory Claims Collection (note: does not include test results)
- Primary Health Organisation Enrolment Collection
- General Medical Subsidy Data Mart
- National Mortality Collection
- National Immunisation Register.

Data linkage

Virtually all health service users in New Zealand are assigned a unique identifier called National Health Index (NHI). The NHI coverage is estimated to be 98% of the New Zealand population.[7] Additional information regarding the purpose, and the use of NHI is available on the New Zealand Ministry of Health website.[8] All NHIs used in this study were encrypted to protect privacy and confidentiality of health information. Record linkage of various data sources were carried out using encrypted NHIs. Ethical approval was obtained from The New Zealand Northern X Regional Ethics Committee (NTX/10/EXP/153) and access of TestSafe laboratory results was approved by Auckland Regional Information Systems Group (RISG).

Inclusion criteria of the study

The linkage of the available administrative datasets by unique encrypted NHI was undertaken to derive the "health service utilisation (HSU) population". This was defined as New Zealand residents who resided within the boundaries of the three District Health Boards located in the Auckland metropolitan region and received any of the publicly-funded health services in New Zealand between 1 July 2009 and 30 June 2010, namely:

- Currently enrolled in a Primary Health Organisation (PHO) or people who had a health service contact with a PHO,
- Publicly funded inpatient and outpatient secondary care events (including mental health and emergency department contact),
- Any community pharmaceutical dispensing,
- Any community laboratory test (including outside the Auckland metropolitan region) including the ones requested by privately funded health professionals,
- Any immunisation received as indicated by the national immunisation register.

Deceased individuals were excluded from the HSU population using the National Mortality Collection. In New Zealand, PHOs supply general practitioner services and are publicly funded, receiving a capitation payment for each enrolee. PHOs are required to provide a defined set of essential services which include appropriate evidence based screening, risk assessment and the use of recall and reminder systems.[9]

Numerator 1: glycaemic status test coverage

The glycaemic status test coverage by age and ethnicity was estimated as the proportion of the HSU population who had at least one glucose or HbA1c blood test recorded in TestSafe repository from 1 Jan 2004 to 30 Jun 2010. Lab tests with missing results or results with <1mmol/L for glucose test, or <1% (<0mmol/mol) of HbA1c were excluded.

$$\text{The glycaemic status test coverage} = \frac{\text{The number of people who had at least one diabetes blood test in Auckland metro from 1/01/2004 to 30/06/2010}}{\text{Corresponding number of people in the health service utilisation population.}}$$

Definition of dysglycemia

The definition of diabetes recommended by American Diabetes Association in 2010 and the World Health Organization consultation in 2011 was modified for this "real-world" study,[10,11] and termed

"dysglycemia". The operational definition of this study was to identify a cohort of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications rather than only the people who had a confirmed diagnosis of diabetes. This defined cohort should be followed up by the health care system for ongoing clinical support and management. The dysglycemic status was derived directly from the laboratory results recorded in a TestSafe laboratory repository for each person in the HSU population. Duplicated test results with identical lab numbers for the same person were removed. A person was defined to have dysglycemia if they had:

- at least one **HbA1c** test ≥ 6·5% (equivalent to 48 mmol/mol) or
- at least one 2 hour post glucose load ≥ 11·1 mmol/l on a **Glucose tolerance test (GTT)**
- two or more tests of **random glucose** ≥ 11·1 mmol/L and/or **fasting glucose** ≥ 7·0 mmol/L on a different day.

For young children less than 10 years of age in 2010, hospital requested glucose tests were not examined because high glucose results in hospital for young children are more likely to relate to artificial nutritional feeds or parenteral nutrition than to diabetes.

Comparison to hospital diagnosis

People within the HSU population who had a previous hospitalisation with a primary or secondary diagnosis of diabetes (ICD 10 codes Edition 3 E10-E14, and O240-O243) from 1 July 1999 to 30 June 2010 in New Zealand were compared against the laboratory diagnosis of dysglycemia as defined by this study.

Demographic variables

The dysglycemic status for each person within the HSU population was determined by the blood test results. The demographic variables including adjustment for migration and deaths were made in an identical way for both the numerator (people who had at least one glucose or HbA1c blood test or people with dysglycemia) and denominator (HSU population which includes people with dysglycemia or diabetes). Ethnicity was determined as per ethnicity data protocols published by the New Zealand Ministry of Health using the prioritised method.[12] Age was calculated from date of birth with reference to 1 Jan 2010.

Age standardisation

The prevalence proportions were separated into 5-year age groups from <15 to ≥85 for direct age standardisation using the World Health Organization (WHO) World population as the standard.[13] 95% confidence intervals are presented.

Results

There were 1,475,347 people living in the Auckland metropolitan region as defined by the HSU population in June 2010. The estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 was 1,477,600.[14] A total of 4,281,599 glucose and HbA1c blood tests were analysed from 792,588 people who had at least one glycaemia related blood test in the study period. There were 1,458,350 tests performed in laboratories based in hospitals (34% of the total) and 2,823,249 tests performed by community laboratories (66%). There were 38 people who had a glycaemia related blood test but did not have a gender recorded,

and all had age recorded. The proportions of people receiving at least one glucose or HbA1c blood test by age, gender and ethnicity are shown in Tables 1 and 2. The age groups highlighted in yellow are the recommended age ranges for diabetes screening as per New Zealand Cardiovascular Guidelines.[15]

Table 1: Proportion of males receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	15·1%	15·6%	16·1%	10·5%	10·9%	14·3%	14·4%	24,465
15-19	25·9%	23·9%	23·7%	16·9%	17·1%	25·5%	24·2%	12,989
20-24	41·1%	38·5%	36·4%	26·3%	28·3%	38·3%	37·3%	18,590
25-29	44·2%	43·0%	42·2%	29·0%	34·5%	40·2%	39·9%	18,811
30-34	49·9%	51·2%	54·5%	36·5%	40·0%	43·4%	45·8%	20,744
35-39	58·7%	60·5%	66·9%	49·7%	51·7%	51·1%	54·5%	28,010
40-44	66·8%	70·4%	78·0%	58·6%	59·1%	61·7%	64·2%	34,175
45-49	75·1%	77·4%	83·5%	66·8%	68·1%	70·9%	72·5%	38,417
50-54	82·4%	84·8%	87·5%	76·9%	76·4%	79·3%	80·4%	36,440
55-59	88·3%	89·1%	88·2%	79·2%	80·3%	85·2%	85·4%	32,353
60-64	92·5%	90·9%	88·9%	84·4%	86·3%	89·3%	89·2%	30,043
65-69	94·3%	92·1%	87·8%	84·5%	88·2%	92·0%	91·4%	22,206
70-74	95·8%	92·1%	88·6%	87·1%	88·3%	94·2%	93·1%	16,649
75-79	95·1%	92·2%	90·1%	88·3%	85·7%	94·9%	93·9%	11,730
80-84	96·1%	90·6%	89·8%	87·8%	84·7%	96·0%	95·0%	8,276
>85	98·3%	87·6%	87·0%	85·0%	84·7%	95·9%	95·1%	5,670
Total								**359,567**

Note: table order reflects ethnicity priority order; "Other" includes those of European descent.

Table 2: Proportion of females receiving a glycaemia related blood test in Auckland metropolitan region in 2010

Age	Maori	Pacific	Indian	Chinese	Other Asian	Others	Overall	Absolute number tested
<15	12·9%	12·9%	14·5%	8·8%	8·8%	12·7%	12·5%	20,123
15-19	36·6%	27·4%	29·4%	18·1%	17·7%	33·4%	30·6%	16,855
20-24	59·9%	52·1%	50·3%	32·5%	36·1%	50·3%	50·2%	27,144
25-29	65·8%	64·4%	61·0%	40·6%	47·3%	52·3%	54·9%	31,348
30-34	67·4%	68·4%	70·7%	54·4%	53·3%	58·5%	61·5%	34,129
35-39	69·5%	71·0%	76·7%	61·6%	56·6%	63·0%	65·2%	39,085
40-44	72·2%	75·2%	80·1%	68·1%	63·3%	66·9%	69·2%	41,014
45-49	79·4%	81·2%	85·7%	76·7%	68·3%	71·8%	74·6%	42,334
50-54	84·8%	85·8%	89·1%	81·0%	77·7%	78·5%	80·6%	38,528
55-59	88·6%	88·8%	87·8%	81·4%	83·5%	83·2%	84·3%	33,735
60-64	92·3%	91·4%	88·0%	85·9%	86·4%	86·9%	87·6%	30,489
65-69	94·6%	91·4%	89·2%	86·9%	86·3%	90·3%	90·3%	23,404
70-74	95·2%	93·4%	89·7%	87·7%	87·5%	92·7%	92·3%	18,120
75-79	94·8%	92·3%	89·0%	89·1%	85·8%	94·6%	93·7%	13,754
80-84	95·5%	89·0%	87·8%	87·2%	88·4%	95·6%	94·6%	11,095
>85	97·4%	90·8%	87·3%	88·6%	80·2%	96·1%	95·5%	11,796
Total								**432,953**

The test coverage varies by age, gender and ethnicity. Overall, 81% of males (n= 198,086) and 87% of females (n= 128,983) in the recommended age groups for diabetes screening had a glycaemia related blood test recorded at the regional laboratory repository from 1 Jan 2004 to 30 Jun 2010. There were a total of 78,828 people with dysglycemia as defined by this study living in the Auckland metropolitan region in 2010 identified by the laboratory results. Crude prevalence was 5·3% overall (with 5·7% males, 5·0% females). Pacific and Indian ethnicities had the highest age standardised prevalence in Auckland metropolitan region. There were 31,282 people in the HSU population who had been discharged from hospital in New Zealand with a discharge diagnosis of diabetes between 1 July 2000 and 30 June 2010. Of these people, 91% (n=28,489) also had laboratory results consistent with dysglycemia defined by this study.

Table 3: Estimated prevalence of dysglycemia in Auckland metropolitan region by gender and ethnicity

Males							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,378	10,078	4,440	2,343	1,911	17,415	40,565
HSU population number	83,473	114,660	41,571	42,358	34,081	392,962	709,105
Crude prevalence (%)	5·2	8·8	10·7	5·5	5·6	4·4	5·7
Age standardised prevalence (%) with 95% confident interval	8·2 (7·9 – 8·4)	11·4 (11·2-11·5)	10·8 (10·6-11·1)	4·6 (4·4-4·7)	6·4 (6·2-6·7)	3·0 (3·0 - 3·1)	4·9 (4·8-4·9)
Females							
Ethnicity	**Maori**	**Pacific**	**Indian**	**Chinese**	**Other Asian**	**Others**	**Overall**
Number of people with dysglycemia	4,570	11,751	3,738	2,476	1,773	13,952	38,260
HSU population number	89,808	121,935	42,438	53,527	42,583	415,830	766,121
Crude prevalence (%)	5·1	9·6	8·8	4·6	4·2	3·4	5.0
Age standardised prevalence (%) with 95% confident interval	7·0 (6·8-7·2)	11·6 (11·4-11·8)	9·3 (9·1-9·6)	3·9 (3·8-4·0)	4·9 (4·7-5·1)	2·2 (2·1-2·2)	4·1 (4·1-4·2)

Figure 1: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (males)

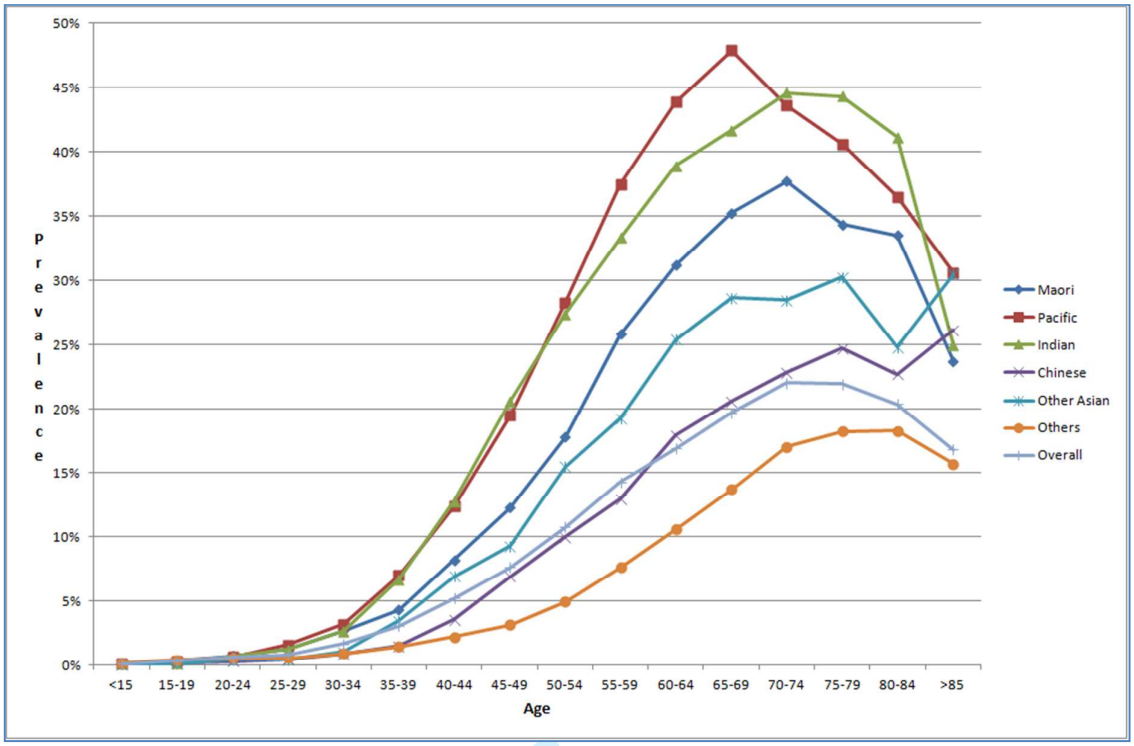
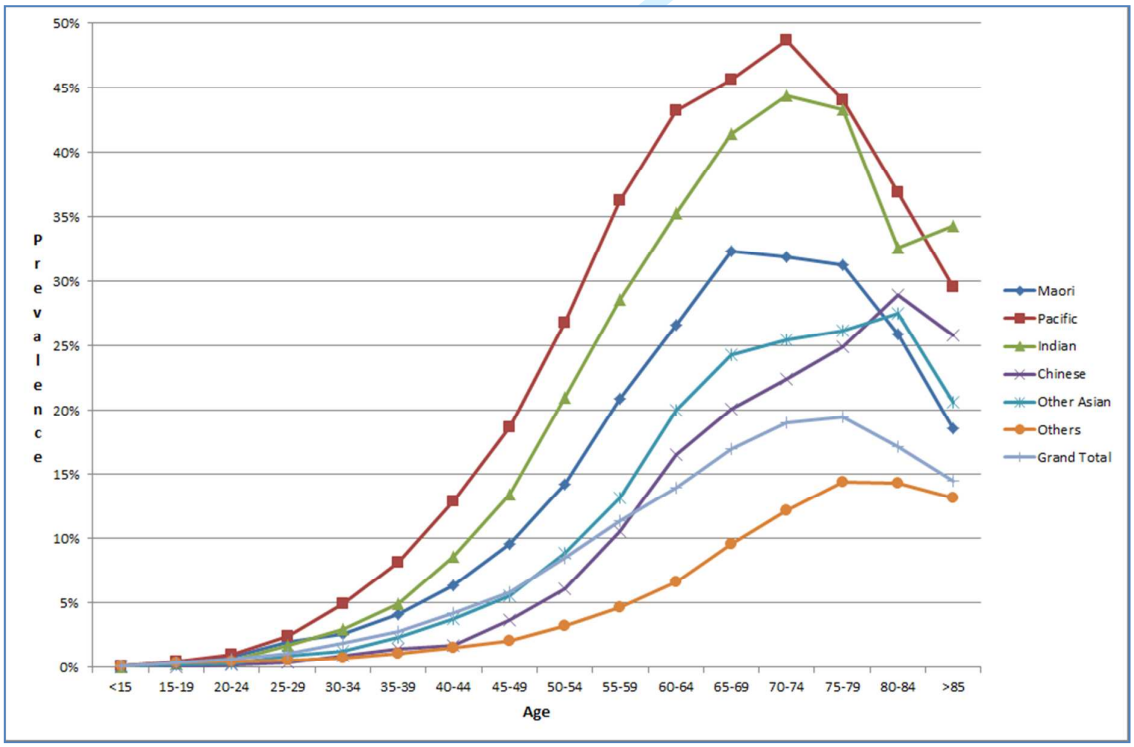


Figure 2: Age specific prevalence of dysglycemia in Auckland metropolitan region in 2010 by ethnicity (females)



Discussion

This study estimated prevalence of dysglycemia in a consistent manner within a geographically defined population of over 1·4 million, by age, gender and ethnicity based on laboratory results sourced from a comprehensive regional laboratory repository (Figure 1Figure 2~~&2~~). If the data linkage methodology used in this study were implemented in a live electronic population register, one could potentially identify individuals who were yet to be screened for diabetes and people who would probably benefit from intensive on-going clinical follow up and management of the cardiovascular risk factors and complications associated with hyperglycaemia in a consistent, comprehensive and timely way. We have demonstrated that glycaemia-related blood testing coverage is very high in the Auckland metropolitan region, and apparently higher than previously reported in Ontario, Canada in 2005.[6] In Auckland, more than 85% of men and 84% of women over 55 in 2010 have had one or more glucose or HbA1c blood tests since 2004. Females of child-bearing age (aged 15-49) were also more likely to have glucose or HbA1c blood tests than their male counterparts for comparable age and ethnic groups. Overall, the blood test coverage of females between 15 and 49 years of age was 7·7% higher than males.

Consistent with the New Zealand CVD risk management guideline recommendation to screen Maori, Pacific and Indian people 10 years earlier than others, the age-specific blood test coverage was higher in these ethnic groups than other groups in the age groups between 35 and 45 years for males and between 45 and 55 years for females.[15] Since 34% of blood tests were carried out in hospital laboratories, it was likely that a small number of tests were undertaken because of symptoms related to diabetes rather than opportunistic screening for diabetes. Since the rate of hospital admissions increases with advancing age, the relatively high coverage of diabetes testing in the older groups may be in part a result of routine glucose testing for most patients admitted to hospitals.

Consistent with previous reports, the ethnic disparities in prevalence of dysglycemia were alarming.[16] This study demonstrated Pacific and Indian people have the highest age standardised prevalence of dysglycemia (Table 3). Almost one in two Pacific women aged 70-74 had evidence of dysglycemia (Figure 2). These findings highlight the critical need for both primary and secondary prevention efforts to reduce ethnic disparities in diabetes-related morbidity and mortality. A previously published estimate of diabetes prevalence for the southern part of the region (CMDHB) in 2006/7, was about 20% lower in relative terms (a difference of >5,000 people) than in the current study.[17] The key methodological difference between the studies was the availability of blood test results in the current study, whereas the previous study relied on an algorithm based on hospitalisations, drug treatment and the number of HbA1c tests (without the test results being available) to estimate diabetes prevalence. Demographic changes; improvement in screening; differences in definitions of diabetes and dysglycemia and a real increase in the underlying diabetes prevalence since 2006/7 are likely to explain the difference of results between the studies.

The HSU population (denominator) was constructed from national routinely collected administrative data; it defined the population at risk and effectively adjusted for migration and deaths. The use of current PHO enrolment and/or evidence of health service contact are pragmatic proxies to indicate

that the HSU population residing in the Auckland metropolitan area within the defined period of the study. The novelty and strength of this study was that both the test coverage and the dysglycemic status of each individual in the HSU population in 2010 were determined by the laboratory results in a consistent manner through individual person record linkage using a unique identifier, the encrypted NHI.

The use of the HSU population as the denominator on which to base future population registers for many long-term conditions has many technical and practical advantages in policy making and quality improvement. The HSU population (n=1,475,347) was very similar to the estimated population of the three Auckland metropolitan District Health Boards from Statistics New Zealand in June 2010 (n=1,477,600).[14] In practical terms, virtually everyone with significant disease who resides in the Auckland metropolitan area is likely to be currently enrolled in a primary care practice and/or have had a contact with publicly funded health services in the year. The way the HSU population was defined means that if identifiable data were used as part of a population register, it can potentially identify any potential performance gaps that a health care provider can address at the individual level. Eligible patients could be readily recalled based on latest contact details from primary care enrolment or from the last health service contact. This is particularly important in a context where the actual care that patients received might be suboptimal.[18] For example, a systematic recall system can theoretically be set up for those people who are yet to be screened using the identical record linkage carried out by this study. As pharmaceutical dispensing data can be linked by NHI in New Zealand, a similar systematic system could also be implemented to monitor the care provision for people who are at high risk of complications. For example, it would be possible to recall those with diabetes and microalbuminuria that were not dispensed an angiotensin-converting enzyme inhibitor or angiotensin II receptor antagonist, or people with poorly-controlled diabetes who may need further clinical review or self-management support. Many chronic care models such as Wagner's emphasised the value of clinical information systems and the role of a population registry to facilitate the provision of systematic proactive care to patients with long term conditions.[19] Indeed, an integrated electronic health record system that contains laboratory results, pharmaceutical use, and utilisation of services has recently been highlighted as critical components to measure the quality of care provided.[20]

Other advantages of the HSU population used in this study include the elimination of numerator-denominator biases highlighted in previous reports as all the demographic variables between the numerator and denominator were recorded in a consistent way.[21,22] Furthermore, the participation of all of the laboratories serving the area in the study, meaning virtually 100% of the laboratory tests performed in the Auckland metropolitan area were included. The long-standing use of the data repository, and its incorporation in day-to-day general practice and secondary care also contributes to the completeness and robustness of the data stored.

This study addressed many of the limitations of common sources of data that are used to estimate known diabetes prevalence – these are summarised in

Table 4~~Table 4~~.[1,3,4,23-26] Many traditional epidemiological studies are based on surveys that are subject to selection bias and patient recall biases.[1,4] Self-reported diabetes prevalence estimates are often lower than estimates based on biochemical results.[4] Most epidemiological surveys have relied on one single laboratory measurement, however glucose tolerance tests have limited repeatability

and glucose measurements have considerable intra-individual variations.[23,27] While some registers have sourced data from primary care, the quality of input data and consistency of coding could be highly variable.[3,24,28] While the UK NHS Quality and Outcomes Framework (QOF) recommends a systematic approach to diagnose diabetes, primary care providers are not required to provide supporting description on how the diabetes diagnoses are made, other than a record of a diabetes diagnosis for the purpose of the QOF indicator.[29] Indeed, QOF openly acknowledges that there are a substantial number of people who are undiagnosed or misdiagnosed.[29] The ability to keep an up to date record of people with 'diagnosed' diabetes would also be more challenging in places where there is a highly mobile population such as in New Zealand, certain parts of Great Britain and the United States.[30-32] Furthermore, a significant number of blood test results may not be requested by the general practices that are currently responsible for the patients' care. For example, as demonstrated in this study, significant numbers of laboratory tests were carried out in hospitals.

The New Zealand NHI database has identifiable information such as name, address, data of birth, self-reported ethnicity.[33] The NHI number has been used in other settings of proactive care such as immunisation in New Zealand.[33,34] The duplicated NHIs are regularly cleaned and mapped back to the Master NHI. Regular audits are performed and Primary Health Organisations are required to provide their patient registries to the Ministry of Health (MOH) every quarter. Therefore, applying the methodology used in this study to construct a population register has the potential to enable a systematic approach to medical auditing. The method identifies the population eligible but yet to be screened for diabetes within a defined period or people who might have abnormal diabetes laboratory results who would benefit from proactive follow up as defined by this study. Data security and appropriate access and use of health data across the whole of health system are vital components to enable a population register to succeed. The balance between patient confidentiality and the adaptable use of identifiable health data to enable proactive health services should be vigorously debated. While the rationale to develop such a population register is to improve population health and equity through systematic medical audit, appropriate safeguards should be in place to limit any unintended misuse of possible confidential health data.

Clinicians ideally should have timely access to all the available health information for the group of patients that they are clinically responsible for. However, the capacity and capability required to analyse health data from the whole of health system into clinically meaningful and actionable health information to be available at the point of care are not universally available from all health care providers. Therefore, a central system that can apply the methods of this study has a tremendous potential to review some of the possible quality gaps exist in the current system.

Table 4: The limitations of common sources of data used to estimate diabetes prevalence

Sources of data	Limitations
Self-report survey	Selection/ sample bias, patient recall bias, limited sample size
Survey with one laboratory test	Selection bias; cross-sectional measure, poor repeatability with glucose tests, estimates the undiagnosed diabetes based on patient recall or medical records, not necessarily unknown to the entire health system
Primary care records	Inconsistency in primary care coding, subject to migration bias, may miss diagnosis at secondary care or other health care providers, limited sensitivity in general
Hospitals	Only identifies those with diabetes who attended hospital, recent changes in

	ICD coding standards may affect consistency. Major undercount
Pharmaceutical dispensing data	Diet-controlled diabetes would not be captured; adherence is not perfect in the community. Medications may have other indications such as metformin in polycystic ovarian syndrome or may be being used to 'prevent' diabetes
Combination of datasets	Depends on quality of the datasets combined. Needs a unique patient identifier for linkage to avoid double counting. The definition of diagnoses may not be consistent across the datasets
Capture- recapture	Identifies people with diabetes not captured by the system, (note - not undiagnosed diabetes). Assumes list independence, and all individuals have the same probability of being captured by each dataset. The estimates can be influenced by factors that are completely unrelated to diabetes prevalence such as changes in ICD coding standards, or admission threshold, and treatment trends. One cannot identify the individuals.

The definition of dysglycemia used in this study is a pragmatic one which identifies a group of people with abnormalities of glucose metabolism, who are at high risk of cardiovascular complications and need to be followed up by the health care system for ongoing clinical support and management.[35-38] People with borderline elevated HbA1c (>48mmol/mol) may be offered dietary advice and the HbA1C test may not necessarily be repeated immediately in the "real-world" as it does not change immediate management. Strictly speaking, these people would not yet have met the diagnostic criteria of diabetes. However, they should have follow up tests to confirm or exclude the diagnosis of diabetes, impaired fasting glucose, or impaired glucose tolerance. Moreover, the proposed method of this study can be refined further to apply the different diagnostic threshold of HbA1C according to ethnicity or to local recommendations.[39,40]

Another limitation of this study is the imperfect sensitivity as it was based on "real-world" data of relatively short duration, and the way dysglycemia is currently defined the study would not have identified people with dysglycemia or diabetes who were lost to follow-up. However, more than 91% of the HSU population who had a diabetes-related hospitalisation in New Zealand between 1 July 2000 and 30 June 2010 also had laboratory results consistent with the diagnosis. This finding suggests a regional laboratory repository of such duration (community test results for 4 years and hospital test results for 6·5 years) would already capture a substantial proportion of people with diabetes. Many people who had a single elevated glucose test might not be followed up (to get the second test required for diagnosis). This study would also miss people who had diabetes diagnosed by laboratory tests performed outside the Auckland metropolitan area or diagnosed before 2004 and subsequently had had excellent diabetes control. However, these cohorts would be identified in subsequent iterations of the population register if their diabetes control deteriorated in the future. The study did not have information related to patients' symptoms or the ability to differentiate type 1 and type 2 diabetes. Since glycaemia-related blood testing coverage varies by age, gender, and ethnicity as shown in Table 1Table 2 ~~& 2~~, the differential testing coverage could contribute a degree of systematic bias to this study's estimate of dysglycaemia prevalence.

In conclusion, a regional laboratory result repository linked to administrative datasets has the potential to provide highly relevant and consistent information to inform clinical decision making in a comprehensive and timely manner as well as being an excellent epidemiological surveillance tool.

Role of funding source:

This study was conducted as a result of the work undertaken for Counties Manukau District Health Board (CMDHB), New Zealand. WCC, GJ, BOW, DRB, MAWL, and DP were paid employees of CMDHB at the time of the study. Views expressed in this publication are those of the authors and not necessarily those of CMDHB.

Conflicts of interests:

We declare no support from any organisation for the submitted work; BOW had received remuneration from the New Zealand Ministry of Health, as the former National clinical director responsible for sector engagement on population health targets. BOW had received payment for lectures from Novo-Nordisk, AstraZeneca, Sanofi and MSD.

Contribution statements:

WCC designed the study methods, applied approval for access for all the relevant data, undertook literature search, record linkage, cross checking, statistical analysis, and drafted up and revised the paper. He is the guarantor. GJ designed the study methods, and revised the paper. CW designed the study methods, linked the administrative data to construct the health service utilisation population, and revised the paper. BO-W designed the study methods and revised the paper. PLD provided clinical diabetes input and revised the paper. DRB designed the study methods and revised the paper. MAWL undertook record linkage, cross checking, and statistical analysis. DP undertook record linkage and data extraction for cross checking. RJ designed the study methods and revised the paper.

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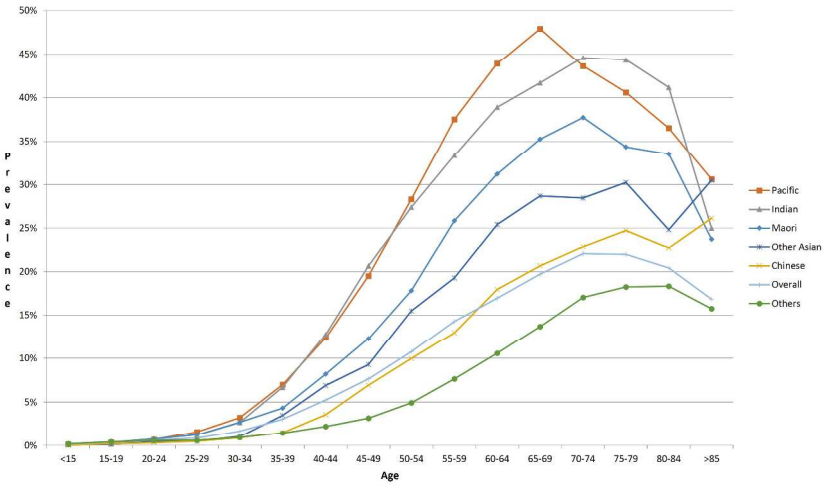

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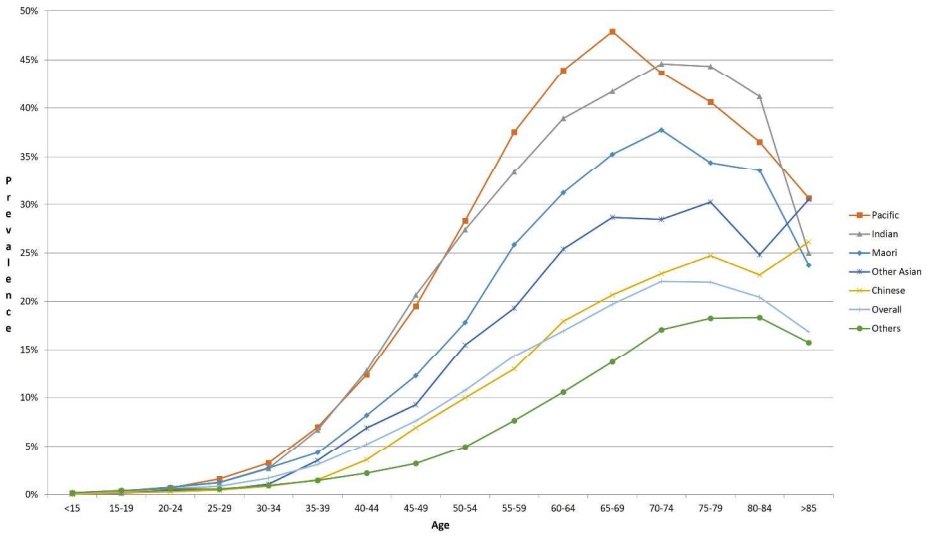

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