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**LINKING EXISTING DATABASES TO MONITOR AND
IMPROVE
DIABETES CARE**

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**A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy,
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ABSTRACT

Background

Lack of population based data is a critical problem in diabetes surveillance in New Zealand. This thesis looks at the feasibility, strengths and weaknesses of linking existing databases to create a regional diabetes register in the Waikato.

Methods

Completeness and validity of key databases and agreement between common data items have been studied using the following audits and studies linking multiple data sources:

- A pilot study in a rural town (Taumarunui), linking multiple data sources including the secondary care based Waikato Regional Diabetes Service (WRDS) database and the Get Checked data from primary care.
- A general practice based study in Hamilton, linking primary care data (diagnosis codes, prescriptions, laboratory tests, Get Checked) with the WRDS database.
- Another general practice based study in Rotorua, a town with high Maori population, linking primary care data with deprivation scores.
- Audits using WRDS data and Waikato DHB hospital systems to assess data agreement.
- Retention of patients in the Get Checked programme was examined using Waikato Primary Health's data.
- Three retrospective studies linking the WRDS data with Waikato DHB hospital systems and national mortality data, which looked at hospital admissions, progression of renal disease and mortality.

The studies used several methods of data validation including comparison of datasets, manual search of patient records, direct contact with patients and comparison of data from external sources. Linked datasets were used to identify disparities in prevalence of diabetes, access to diabetes care, diabetes complications and mortality.

Results

- The coverage of the WRDS database was high (86%-91%), but newly diagnosed patients and older patients not needing retinal screening are under-represented. Case identification using primary care systems was high, but the coverage of the “Get Checked” programme (62%-80%) varied depending on practice IT systems, data handling procedures and patient characteristics.
- The Rotorua study shows that diabetes prevalence rises with increasing deprivation among Europeans, but not among Maori.
- Maori and Asian patients were less likely to access retinal screening in Hamilton. Patients aged <40 years, those of Maori or Asian origin, and those with Type 1 diabetes were less likely to be retained in the Get Checked programme with regular checks. Almost all patients had barriers to diabetes care in Taumarunui. Psychological barriers to diabetes care rank highly for all subgroups of ethnicity, age, gender, duration of diabetes and insulin treatment.
- Outcomes analyses showed that compared with Europeans with diabetes, Maori diabetes patients had a significantly higher risk of end-stage renal disease (ESRD), renal admission and renal death (46-fold, seven-fold and four-fold increases, respectively). Maori patients progressed at a significantly faster rate from first hospital admission for chronic renal disease to ESRD. Maori were more likely than Europeans to have diabetes reported on mortality coding. They were also more likely to die from cardiovascular disease, cancer and renal disease [Hazard-ratios 2.31(1.6-3.3), 1.83(1.1-3), and 11.74(4.8-29) respectively].

Discussion

The advantages and the difficulties of linking primary care and secondary care databases to identifying diagnosed diabetes patients, the potential barriers to implementation of a diabetes register and the critical factors for a successful system are discussed. This research has demonstrated the potential of linking databases to monitor diabetes care and outcomes, but implementation would need substantial policy changes and financial backing.

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ABBREVIATIONS

ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
ACR	Albumin-Creatinine Ratio
ANZDATA	Australia and New Zealand Dialysis and Transplant
BMI	Body Mass Index
BP	Blood Pressure
CDC	Center for Disease Control and Prevention
CG	Cockcroft-Gault
C.I	Confidence Interval
CKD	Chronic Kidney Disease
CVD	Cardiovascular Disease
DAR	Diabetes Annual Review
DHAH	Diabetes Heart and Health
DHB	District Health Board
ESRD	End Stage Renal Disease
GDM	Gestational Diabetes Mellitus
GFR	Glomerular Filtration Rate
GP	General Practitioner
HbA _{1c}	Glycosylated Haemoglobin A _{1c}
ICD	International Classification of Diseases
IDCI	Integrated Diabetes Care Initiative
IFG	Impaired Fasting Glucose
IGT	Impaired Glucose Tolerance
IT	Information Technology
LDT	Local Diabetes Team
MDRD	Modification of Diet in Renal Disease
MoH	Ministry of Health
NHI	National Health Index
NMDS	National Minimum Dataset
NZ	New Zealand

NZDep	New Zealand Deprivation
NZHIS	National Health Information Service
NZHS	New Zealand Health Survey
PGL	Pinnacle Group Ltd
PHO	Primary Health Organisation
PMS	Patient Management System
REDIS	Regional Diabetes Information Service
RGPG	Rotorua General Practice Group
SADP	South Auckland Diabetes Project
SAS	Statistical Analysis System
SMR	Standardised Mortality Ratio
WHO	World Health Organization
WPH	Waikato Primary Health
WRDS	Waikato Regional Diabetes Service

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