

Summary of the National Diabetes Epidemiology Workshop held 10 August 2007

Dr Kirsten Coppel, Senior Research Fellow, Edgar National Centre for Diabetes Research, University of Otago.

Event

A one day National Diabetes Epidemiology Workshop was hosted by the Expert Advisory Group for Diabetes/Cardiovascular Disease Quality Improvement Programme and organised by the Ministry of Health on 10 August 2007. A range of people attended the workshop including diabetes specialists, researchers, general practitioners and diabetes nurse specialists (see Appendix 1).

Objective of Workshop

The objective of the workshop was to seek “a collective view about the best methodology for estimating the prevalence of diagnosed diabetes (included in DHB indicators that monitor access to diabetes care by ethnicity).”

While the objective refers to ‘diagnosed diabetes’ only, there was considerable discussion regarding assessing prevalence of people with undiagnosed diabetes and ‘pre-diabetic’ states.

Description of Workshop

Oral presentations included modeling the national prevalence of diagnosed diabetes (current and predicted numbers), the results of regional prevalence surveys, results from the collation and analysis of routinely collected Get Checked data and examples of established regional and national diabetes registers.

The presentations highlighted the high level of activity around data collection taking place throughout the country, mostly at a regional level. There was only one ‘national’ based register described, the Starbase. This database is based at the

Starship Paediatric Diabetes Service and collates data on type 1 diabetic children from 10 regions throughout New Zealand with a further 3 regions interested in participating. Participation is voluntary. It is used to compare and contrast regional differences in metabolic control and is able to monitor the incidence and prevalence of type 1 diabetes in children for participating regions. Descriptions of other collections of diabetes data included a database established through retinal screening in the Waikato and collations of Get Checked data collected from primary care.

The definition of diabetes was also discussed. A paper presented suggested that glycaemia be considered as a continuous variable rather than dichotomous one. Thus, the term diabetes (at least as it relates to type 2) might be obsolete. Glucose levels just like blood pressure and lipid levels are continuous variables and definitions for type 2 diabetes should be considered in the same way as hypertension and dyslipidaemia, for which 'cut-offs' have changed over time. The suggestion was made that blood glucose testing (and/or HbA1c) would be part of a cardiovascular risk assessment. This would facilitate the capture of data relating to the assessment of blood glucose on a large number of people nationally, in addition to being clinically relevant. The same paper also made a strong case for using HbA1c as a screening test for diabetes.

Issues highlighted from presentations and discussion

A. Why are reliable national diabetes (and 'pre-diabetes') data wanted?

1. Better planning and provision of diabetes services at a DHB level
2. Better monitoring of the diabetes epidemic, including the effect of prevention activities such as the national Healthy Eating Healthy Action initiative
3. Better source data for modeling future predictions (improve external validity)

B. Options for national diabetes data

Diagnosed diabetes

1. Statistical modeling¹ using routinely collected diabetes data eg hospitalisations

¹ Two presentations described different methods for estimating diabetes prevalence. One was a multistate life table model using 02/03 NZ Health Survey estimates of self-reported diabetes and derived mortality hazard ratios. The other was Bayesian modeling using routinely collected diabetes

2. Collation of 'Get Checked' diabetes annual review data
3. National Health Survey – self-reported diabetes²
4. Aggregation of regional prevalence data
5. Not sure if this is part of item 1

Diagnosed and undiagnosed diabetes

1. Collation of cardiovascular risk assessment data
2. National prevalence survey

C. Routinely collected diabetes data

Problems exist with lists of routinely collected data and these include:

1. Not inclusive, in particular, diet only diabetic patients who do no blood glucose monitoring and have not been hospitalised (or hospitalised and diabetes not reported) are likely to be undercounted. The size of this group is unknown. Note: the size of this group can be assessed in some areas from independent lists such as Diabetes Projects Trust in Auckland and Otago Diabetes Register. The Get Checked database has many people with diet controlled diabetes (I can check actual numbers if this is relevant).
2. We had this report from a large MSO (looks very reassuring to me actually, and we have a good assessment of the average HbA1c fall within a year of people on average that go from diet alone to oral – for modeling etc):

“20,963 diabetes patients from 249 practices have had a diabetes review. As at their latest review 5,993 (28.6%) were on diet only. Mean HbA1c for these diet only patients was 6.59% (Sdev 1.02). Mean age was 68.5 years (Sdev 12.8 years). 1297/5993 (21.6%) had an HbA1c > 7% and 684/5993 (11.4%) had an HbA1c >7.5%.”

3. Under-reporting of diabetes in hospitalisation and mortality data.
4. As not all diabetic patients have an annual review, Get Checked data are incomplete.
5. Duplicate National Health Index (NHI) numbers. This was estimated (by Craig Wright, MoH) to be about 8%, that is, about 8% of individuals have more than one unique identifying NHI number.

data (hospitalisations, mortality, pharmaceuticals and Get Checked) linked by the NHI number. A further modeling possibility is an open population capture-recapture methods to estimate disease prevalence using routinely collected data being developed by a PhD student.

² Note: This option was not discussed at the workshop.

6. Undiagnosed diabetic patients will not be counted. The size of this group is unknown, but it is unlikely to be one diagnosed to one undiagnosed as previously thought.

D. Advantages and Limitations of different options to estimate diabetes prevalence³

1. Statistical modeling – Multistate life table

Advantages

- predicts future burdens of disease and can inform health service planning
- current model internally consistent
- results relatively timely
- uses routinely collected data

Limitations

- undiagnosed diabetes and ‘prediabetic’ states not counted
- validity and reliability of output depends on quality of input data

2. Statistical modeling – Bayesian methods or capture recapture methods using routinely collected data

Advantages

- uses data that are collected routinely
- results can be relatively timely

Limitations

- undiagnosed diabetes and ‘prediabetic’ states not counted
- validity and reliability of output depends on quality of input data

3. Get Checked - diabetic patients only

Advantages

- routinely collected data used
- results relatively timely
- also provides assessment of quality of diabetes care

Limitations

- completeness of list depends on diabetic patients attending for an annual review Note: more a problem if count only people who have attended in a

³ Note: The costs of the different options have not been considered.

given year (as MoH does currently). Less a problem if you count anyone who has ever had a check.(though need to allow for those who have died).

- Our assessment was that to do this one would need to pool identifiable patient data at regional level (at least). This allows one to follow cohorts – a proportion of whom move from PHO to PHO and otherwise end up double counted. That is why we are pushing the regional database approaches.
- undiagnosed diabetes and ‘prediabetic’ states not counted
- misclassification of ‘prediabetic’ states as diabetes Note: I do not think this is a large error, and applies to any routine collected data, i.e. not restricted to Get Checked. It is just one of several data validity checks that need to be undertaken where possible for any data set.

I agree – the diagnostic test accuracy is not so fantastic that other uncertainty is a huge problem, and many who are misclassified as diabetes with prediabetes will be classified correctly as diabetes in future. The diabetes diagnosis was just made earlier than it should have been.

4. Cardiovascular risk assessment data – all people above specified age

Advantages

- routinely collected data used
- results relatively timely
- undiagnosed diabetes and ‘prediabetic’ states could be counted

Limitations

- will not include children and young adults
- timeliness may be delayed by the cardiovascular risk assessment screening interval - if the screening interval was 5 years, then it would take 5 years to collate the CV screening data. This is a problem only over the first 5 years, thereafter incident and missed people are added.(but need to allow for those who have died).

5. Prevalence survey – self reported diagnosed diabetes only

[Note, this was not discussed at the workshop]

Advantages

- has been part of the National Health Surveys

- a question about self reported diabetes could be included as part of scheduled National Nutrition Surveys thereby providing nutritional information as well as diabetes information
- able to compare results from previous surveys

Limitations

- response rate could be less than ideal
- self reports may not be accurate
- miss undiagnosed and pre-diabetes

6. Prevalence survey – diagnosed and undiagnosed diabetes and ‘pre-diabetic’ states

Advantages

- provide estimates of prevalence of undiagnosed diabetes and ‘prediabetic’ states, including insulin resistance
- could be part of already scheduled national surveys (eg National Nutrition Survey or Health Survey) as previously done

Limitations

- less than ideal survey response rate, particularly if the oral glucose tolerance test (OGTT) was used.⁴ The use of HbA1c which does not require individuals to fast may give a better response rate.

7. Aggregation of regional diabetes and ‘pre-diabetes’ prevalence data

Advantages

- data already available
- may obviate the need to do a national prevalence survey

Limitations

- a robust method to do this needs to be explored. Although we have already done this in the Diabetes Cohort Study and have a large data processing manual.

⁴ It is worth noting that the response rate for AusDiab was 55.3%. [Dunstan DW, Zimmet PZ, Welborn TA, Cameron AJ, Shaw J, de Courten M, Jolley D, McCarty DJ; Australian Diabetes, Obesity and Lifestyle Study (AusDiab). The Australian Diabetes, Obesity and Lifestyle Study (AusDiab)--methods and response rates. *Diabetes Res Clin Pract.* 2002 Aug;57(2):119-29.]

Conclusion

The workshop objective implies that a robust timely method for estimating the prevalence of diagnosed diabetes is essential for several reasons:

1. planning services
2. assessing coverage Get Checked
3. predicting future diabetes burden

While a definitive consensus was not reached, there appeared to be an agreement that statistical modeling using lists of routinely collect data offered considerable potential. However, there was insufficient time for discussing alternatives or modifications to the Bayesian model such as a possible new open population capture recapture method.

The multistate life table modeling is useful for predicting different future scenarios. A national prevalence survey would provide the most robust estimate of the burden of undiagnosed diabetes and ‘prediabetic’ states. Such information is essential for assessing the overall burden of disease and the results of public health initiatives aimed at reducing diabetes risk. The respondent burden involved in oral glucose tolerance testing was considered to be a major obstacle in achieving a sufficiently high response rate to generate reliable data. It was considered helpful to explore the use of standardised methods of Hba1c as an alternative for this purpose, as well as the possibility of aggregating existing regional prevalence data.

Appendix 1: List of Workshop Attendees

Invitee	Organisation
Barry Taylor	University of Otago
Brandon Orr Walker	Counties Manukau DHB
Brendan Kelly	Ministry of Health
Bronwyn White	Massey University
Chris Cunningham	Massey University
Christine Andrews	Ministry of Health
Christine van Dalen	Massey University
Colin Feek	Ministry of Health
Craig Jeffries	Starship
Craig Wright	Ministry of Health
David Maplesden	Pinnacle PHO
Dean Millar-Coote	Southlink PHO
Erin Holmes	Ministry of Health
Grace Joshy	University of Auckland
Helen Snell	Midcentral DHB
Jim Mann	University of Otago
Kirsten Coppell	University of Otago
Lindsay McTavish	Capital & Coast DHB
Lis Ellison-Loschmann	Massey University
Lucia Bercinkas	Ministry of Health
Martin Tobias	Ministry of Health
Marty de Boer	Hutt Valley DHB
Murray Dears	Diabetes NZ
Nancy Harp	Ministry of Health
Neil Pearce (Chairman)	Massey University
Nic Crook	Lakes DHB
Patricia Metcalf	University of Auckland
Paul Drury	Auckland DHB
Raina Elley	University of Auckland
Rod Jackson	University of Auckland
Ross Lawrenson	Waikato DHB/University of Auckland
Sandy Dawson	Ministry of Health
Stephen Stannard	Massey University
Tim Kenealy	University of Auckland

Appendix 2: List of Presentations

Prevalence of diagnosed diabetes

- Updating the diabetes multistate lifetable model – Martin Tobias
- Estimating diabetes prevalence from the National Administration Data – Craig Wright

Prevalence of diabetes (diagnosed and undiagnosed)

- Estimates of undiagnosed diabetes using HbA1c scores from the Hepatitis Foundatoin Screening Survey 2000 – Erin Holmes
- Undiagnosed diabetes in Northland – Bronwyn White
- Prevalence of newly and previously diagnosed diabetes – Patricia Metcalfe
- Prevalence of diabetes in the Waikato – Ross Lawrenson

Screening Issues

- Screening issues as part of a basic CVD assessment – Rod Jackson

Clinical diabetes

- What diabetes clinicians want and need to know – Paul Drury
- A cohort from Get Checked data – Raina Elley
- Lessons from diabetes, the South Link Experience – Dean Millar-Coote