The role of diabetes registries to monitor the treatment and complications of diabetes

John A McKnight

Metabolic Unit, Western General Hospital, Edinburgh, Scotland, United Kingdom

Corresponding author: john.mcknight@nhs.net

Introduction

The management of diabetes requires input from many different healthcare professionals and carers, as well as a major input form the patients themselves. There is a strong evidence base for many interventions, a direct link between the risk of complications and many measured parameters, (e.g. HbA1c, BP, cholesterol) and a need for a structure to ensure clinical measures are performed in a timely fashion, without duplication, for all patients. In this modern age of information technology there is an opportunity to develop systems to record and review the core data relating to the care of people with diabetes in a comprehensive diabetes register. This should include the whole population with diabetes in any defined area, be efficient (e.g. automatic collection of data from laboratories) and easy to use as possible and provide some reward (e.g. generation of formatted letters, easy local audit summaries) to those who have to make any extra effort to record data.

Scotland

The health service in Scotland is a National Health Service, free to the whole population. The responsibility for delivering this is through 14 NHS Boards who organise the care for their population. The population of Scotland is 5.3 million. The size of NHS Board areas varies from 21,000 to 122,000. The diabetes care within NHS Boards is supported by Managed Clinical Networks that are multidisciplinary and work across usual NHS boundaries (e.g. primary care and secondary care) to coordinate services.

We have developed a clinical management system and register for Scotland called SCI-Diabetes. This database automatically collects information defined in our core dataset for diabetes from many different systems in the NHS in Scotland, including all primary care IT systems, the NHS Hospital diabetes clinic systems, all the laboratories, from podiatry foot screening and the eye screening digital photography system. This system started around 2001 and took some time to mature into the current form. The data has been robust for the whole population for the last 8 years or so.

The data is analysed to assess the overall performance of the whole service and for each element of the service, with data available;

- for all of Scotland,
- for each of 14 NHS Board areas,
- for individual Primary Care Practices,
- for Hospital Specialist Services
- in a form for the individual patient with for example graphic presentation of an individuals HbA1c for the last 15 or more years.

The national data has been published annually as the Scottish Diabetes Survey (1), the latest report is for 2013 and is available on line.

Scottish Diabetes Survey 2013

In the Scottish Diabetes Survey 2013, we report that:

- There were 268,154 people diagnosed with diabetes in Scotland recorded on local diabetes registers at the end of 2013. This represents 5.0% of the population;
- Crude prevalence of diabetes ranged from 4.34% to 5.80% across NHS Boards;
- 88.2% (236,605) of all people registered with diabetes had type 2 diabetes;
- 10.9% of all registered people had type 1 diabetes. The number of people registered with type 1 diabetes increased from 26,294 in 2006 to 29,261 in 2014;

- 0.85% (2,288) were recorded as having "other" types of diabetes, including maturity onset diabetes of the young (MODY) and those with unknown diabetes type;
- 37.5% of patients with a recorded BMI and type 1 diabetes and 31.8% of those with a recorded BMI and type 2 diabetes were overweight (BMI 25-30 kg/m^2), while 24.8% of those with type 1 and 55.0% of those with type 2 were obese (BMI 30 kg/m^2 or above);
- 88.7% (type 1) and 93.9% (type 2) had an HbA1c recorded in the previous 15 months. Of these, 21.5% and 61.1% had a result < 58mmol/mol (7.5%), the target reported in previous surveys;
- 86.8% of those with type 1 and 94.9% of those with type 2 diabetes had their blood pressure recorded in the previous 15 months. Of these, 47.6% and 33.8% respectively had a systolic BP measurement of ≤ 130/80 mmHg;
- Cholesterol was recorded in 91.0% of patients within the previous 15 months, and the target of ≤5 mmol/l was achieved in 71.3% of those with type 1 and 80.8% of those with type 2 diabetes;
- 23.5% (type 1) and 18.1% (type 2) were current smokers;
- 1,060 (3.6%) of those with type 1 and 23,546 (10.0%) of those with type 2 diabetes have had a myocardial infarction and survived, and 2.6% and 7.3% respectively have undergone cardiac revascularisation;
- 357 (1.2%) of those with type 1 and 1210 (0.5%) of those with type 2 diabetes have a record of having end stage renal failure;
- 86.7% of people with diabetes had had eye screening in the previous 15 months.

Quality Improvement

We now have a good understanding of the challenges facing us in organising care for the increasing number of people with diabetes. The total registered prevalence has increased from 210,000 in 2007 to 268,000 in 2013. Despite this our screening performance improves each year for most parameters and as described above is above 85 % for most measures. Our data can help with future planning. For example we know how many new cases of type 1 and type 2 diabetes occur in each NHS Board area, enabling some planning for new patient education. We can use our system to decrease duplication of work as the data from one element of the service is available to others.

The provision of the reports for each NHS Board is a real driver for improvement and change as the comparison with others in the system stimulates a degree of competition to do better. This applies at all levels of the service. There are many examples where reviewing data has resulted in a change of clinical practice. In 1996 a comparison of the diabetes data between two clinics in NHS Lothian revealed similar data other than the mean cholesterol at one was 5.6 and another 5.1 mmol/l. The 4S trial had been recently published and there was some discussion of the lipid results. Within 6 months the mean result at both clinics had decreased to 5.0 mmol/l. We also have the ability to compare local Primary Care practices or groups. Again comparison with peer groups is of major influence in stimulating change.

In recent years we have been concerned about the control of our patients with type 1 diabetes in Scotland. Through contacts in various countries we have organised an international comparison of HbA1c in 324,000 people with type 1 diabetes from registers in 19 countries. This has stimulated more work locally. We now regularly review the data from each of more than 20 diabetes centres in Scotland and are developing projects using improvement methodology to improve diabetes control in this important group of patients. Our register has also enabled us to identify that a group that is not accessing care (HbA1c and retinopathy screening) in our current service is that aged 19 to 27 years and we are actively investigating ways to address this issue.

Epidemiological Research

The population-based diabetes register, which contains a unique patient identifier used throughout NHS Scotland, has enabled us, through the

Scottish Diabetes Epidemiology Group, to study many other aspects of diabetes in Scotland.

We have studied the effect of Type 2 diabetes on mortality in different socioeconomic groups (SES) (2). Absolute mortality from all causes among people with type 2 diabetes increased with increasing age and socioeconomic deprivation and was higher for men than women. Relative risk for mortality associated with type 2 diabetes was highest for women aged 35–64 years in the least deprived quintile with diabetes duration < 2 years at 4.83 (95% CI 3.15–7.40) and lowest for men aged 65–84 years in the most deprived quintile with diabetes duration ≥ 2 years at 1.13 (1.03–1.24) (2).

In type 1 diabetes the age-adjusted incident rate ratio (IRR) for first CVD event associated compared to the non-diabetic population was higher in women (3.0: 95% CI 2.4–3.8, p,0.001) than men (2.3: 2.0–2.7, p,0.001) while the IRR for all-cause mortality associated with T1DM was comparable at 2.6 (2.2–3.0, p,0.001) in men and 2.7 (2.2–3.4, p,0.001) in women (3). We have therefore shown that the risks of cardiovascular disease and mortality in type 1 diabetes seem to have declined compared to previous studies. We have been able to show that a high percentage of deaths in the under 40 year age group are due directly to diabetes, whereas after the age of 40 cardiovascular disease becomes a major factor.

Further work has focussed on hospital admissions due to diabetes. Diabetes inpatient expenditure accounted for 12% of the total Scottish inpatient expenditure, whilst people with diabetes account for 4.3% of the population (4). Of the modifiable risk factors, HbA1c was the most important driver of cost in type 1 diabetes

People with type 1 diabetes with highest and lowest mean HbA1c values were associated with increased odds of admission (5). The lowest odds of admission were associated withHbA1c 7.7–8.7% (61–72mmol/mol). People with high HbA1c (>10.8%/95mmol/mol) were at particularly high risk (relative risk of 2.8 compared to the lowest risk decile. There is the need to develop effective interventions to reduce this risk.

Women, smokers, those with high HbA1c and those living in more deprived areas have an increased risk of admission to hospital for diabetic ketoacidosis (6). This work highlights that those living in poorer areas of the community with high HbA1c represent a group who might be usefully supported to try to reduce hospital admission.

Linkage has also enabled us to investigate the changing incidence of amputation in our population (8) and to consider the best interval for screening for diabetic retinopathy (9)

Our data has also enabled us to develop a tool to estimate the risk of developing diabetes following hospital admission based on age and a random glucose taken during the admission (7).

Conclusion

An important element of developing a register for people with diabetes is the automatic collection and assimilation of core diabetes data as part of routine clinical care without, or with minimal extra work for front line clinicians.

The rewards for achieving this include the use of up to date clinical data for audit and quality improvement purposes and opportunities for epidemiological research that will in turn influence clinical care.

I would encourage all those involved in diabetes care to develop, support and use a register for their patient group. It has been extremely interesting and rewarding to be involved in this in Scotland.

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