

5. Researching, Registering and Monitoring Diabetes

Unfortunately, even though diabetes is recognised by the Ministry of Health as one of New Zealand's top health priorities, there is insufficient funding for diabetes research to provide the robust evidence required to convince politicians to resource effective diabetes services. Further, there is only a limited database for recording those diagnosed with diabetes. Given those limitations, it is a challenge to design effective service delivery which meets the particular needs of New Zealand's unique population groupings and service delivery providers. Currently, there is no effective resource for monitoring or auditing the effectiveness of the services.

Between 1997 and 1999, approximately \$100 million was allocated for research by the New Zealand Health Research Council. The Council received government grants to fund only 25% of all health research applications but only 1% of the total over three years was spent on clinical and operational research in diabetes services. Lack of adequate researched evidence makes long term planning difficult.

Similar countries, including Australia, are undertaking significant clinical and operational research into diabetes because it is recognised as one of their major health risks.

5.1 Registering Diabetes

In many countries with good healthcare systems, national databases exist for many diseases and can be linked to costs or hospital admission.

A national diabetes register is essential for providing necessary data on diabetes, any changing incidence, prevalence and complications both by region, population, age and ethnicity. With a register it will be much easier to link people with diabetes to the services they need.

Registers not only provide data but they are a tool to assist with ensuring that people on the register have had recommended tests completed and that action is taken if tests are abnormal.

The existing registers required initial funding for set up. After the first year, additional spending for a nurse or other specialist to be employed leading to ongoing cost of around \$100,000 per year per region. A national register is conservatively estimated to cost between 5 and 10 times that amount.

The current accumulation of a register by means of taking the results for yearly GP reviews will only be built up very slowly and there are likely to be variations in uptake of this scheme within districts and between regions.

1. The set up costs for a national register then would be in the order of \$200,000 to \$500,000 in year one.
2. After that, the maintenance and operation of the register would cost around \$1 million per year.

As under current privacy laws, permission would need to be sought and granted, for Diabetes NZ, representing consumers, to be part of the Register Consortium.

5.2 Monitoring Diabetes

Given the current limited health sector resources available, monitoring the effectiveness of existing programmes is very important as it establishes whether what is intended to happen does happen. The model built for this study is a very simple one and has been specified based on available evidence. By building this model into a monitoring tool, it would be possible to monitor the results of new programmes, based on actual trends. As more research evidence becomes available, including better descriptors based on the national database of the register, it will also be possible to specify the behavioural relationship in the model in more detail.

Two groups could have responsibility for updating the model. The Ministry of Health could update for the purposes of enhancing the policy advice of the options, applying the simple model developed in this report to analyse diabetes services in aggregate and to reprioritise as required. An independent agency, such as Diabetes New Zealand, could be given the responsibility of using the model to monitor health outcomes for people with diabetes, to analyse the implications of new evidence as more research is undertaken and to provide a basis for continuing advocacy for appropriate services for those with diabetes.

Further monitoring will be required for specific services once they are implemented. Some aspects of this monitoring will relate to effectiveness of operations and as such will need to be separate from the overall model.

1. The model in this study provides a basis for developing a framework to be used for monitoring purposes
2. A Ministry of Health Consortium with representatives of consumers, the National Diabetes Forum, advisory diabetes experts and Diabetes NZ could use the monitoring tool as a means of advising on options for policy advice and budget bids
3. An independent organisation such as the Audit Office can use the monitoring as a tool for monitoring health outcomes and the implication of new research
4. Further (different) types of monitoring will be required to understand whether services have been successful at targeting and improving access are effective.

5.3 Researching Diabetes

Clearly it would be inappropriate to adopt overseas research results as the precise description of New Zealand behaviours. On the other hand, the risks of waiting for research results in New Zealand is that the health of the people with diabetes will deteriorate. The answer is to develop strategies based on hypothesis developed from international research and then review the results of the strategies after implementation with additional investment.

With so little New Zealand population-based research to date, criteria to set research priorities will be important. Based on this study, it is recommended that an additional four criteria for selecting the immediate areas of research be included in the list of research priorities:

- Using the register to identify the characteristics of those with diabetes and to link services to them
 - Research key characteristics of the population which put them at risk in order to assess increasing risks
 - Adopt research priorities based on overseas evidence with close linkage to good studies already underway in Australia
 - Prioritise on the development of effective services to prevent diabetes or delay complications.
1. It is then recommended that a nationally coordinated strategy of research be adopted and developed for diabetes
 2. There is urgent need for evidence-based research which provides the Ministry of Health with the analysis required to further develop diabetes services.

