

NATIONAL DIABETES STRATEGY

Response to the Consultation Paper

May 2015



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- A society that is well informed and values the benefits of health and medical research.
- Greater investment in health and medical research from all sources.
- Ensure Australia captures the benefits of health and medical research.
- Promote Australia's global position in health and medical research.

Elizabeth Foley

CEO & Managing Director

02 9295 8547

elizabeth.foley@researchaustralia.org

www.researchaustralia.org

384 Victoria Street Darlinghurst NSW 2010

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TABLE OF CONTENTS

Introduction	4
Responses to the Questions	5
Goal 1: Reduce the prevalence and incidence of people living with type 2 diabetes	5
Question 1:	5
b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?	5
Question 3:	5
The paper outlines some potential ways to measure Australia’s progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?	5
Goal 2: Promote earlier detection of diabetes	6
Question 4:	6
b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?	6
Goal 3: Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes	6
Question 7:	6
a) Which of the areas for action described for this goal are most appropriate and why?	6
b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?	7
Question 8:	8
a) Please describe any existing programmes, initiatives or activities relevant to this goal that you think are working well and why? (Please indicate if you are aware of an evaluation report and how it may be obtained)	8
Goal 4: Reduce the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups.....	8
Question 12:	8
The paper outlines some potential ways to measure Australia’s progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?	8
Question 13:	8
In relation to the impact of diabetes in Aboriginal and Torres Strait Islander peoples and high risk groups, please describe any barriers in accessing health services and/or education.	8
Goal 5: Strengthen prevention and care through research, evidence and data	9
Question 14:	9
a) Which of the areas for action described for this goal are most appropriate and why?	9
b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?	10
Question 15:	11
a) Please describe any existing programmes, initiatives or activities relevant to this goal that you think are working well and why? (Please indicate if you are aware of an evaluation report and how it may be obtained)	11
Question 16:	11
The paper outlines some potential ways to measure Australia’s progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?	11
Question 17:	11
Please provide any further comments you may have.	11

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RESPONSE TO THE CONSULTATION PAPER

INTRODUCTION

In April 2015 the Department of Health sought feedback on *A Strategic Framework for Action: Consultation paper for the development of the Australian National Diabetes Strategy*. The Consultation Paper was prepared by the National Diabetes Strategy Advisory Group.

The consultation invited the electronic submission of responses to a number of specific questions. The questions, and Research Australia's responses, are reproduced below. Only those questions to which Research Australia provided a response are reproduced.

RESPONSES TO THE QUESTIONS

Goal 1: Reduce the prevalence and incidence of people living with type 2 diabetes

Question 1:

b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?

It is unlikely that there will be a 'one size fits all' solution to reducing the prevalence and incidence of people living with Type 2 diabetes. We know much of what needs to be done to reduce the prevalence and incidence but not enough about which programs can be implemented effectively.

Existing research findings need to be used more effectively to develop potential candidate programs as successful interventions and implement these in a systematic manner and on a sufficient scale to enable them to be properly evaluated as to their clinical effectiveness, cost effectiveness and suitability for implementation in the health care system. This includes looking to what has worked internationally and considering how it could be implemented here.

We also need to develop a national protocol for the assessment of programs to ensure comparability on a range of measures- clinical effectiveness, cost effectiveness and ability to be integrated into practice.

The *Evaluation Report of the Diabetes Care Project* (Australian Government Department of Health, released May 2015) provides a number of recommendations for improving the care of patients with diabetes and these should be pursued.

Measures to reduce diabetes should not be viewed (only) in isolation from other measures to improve health, and Research Australia welcomes the reference in the Consultation Paper to the development of an overall strategic framework for managing chronic diseases. Such an approach provides the opportunity for improvements in health that will reduce the prevalence of a range of chronic diseases with similar causes, including type 2 diabetes, and the opportunity to more efficiently and effectively support diabetes patients with more than one chronic condition. 'One Life', a Finnish umbrella project involving the Brain Association, the Diabetes Association and the Heart Association to promote vascular health is one example of a program designed to address a common underlying health issue associated with several chronic conditions.

http://www.diabetes.fi/en/finnish_diabetes_association/one_life_projects

Question 3:

The paper outlines some potential ways to measure Australia's progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?

Other important measures will be the numbers of people participating in programs and interventions, and changes in the prevalence and incidence of type 2 diabetes among participants compared to non-participants.

Goal 2: Promote earlier detection of diabetes

Question 4:

b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?

As the paper notes, there is a range of measures that can be taken to improve the early detection of diabetes. We need to take a coordinated approach to the trialling and evaluation of different measures to determine which are the most effective. Research can play a role here in identifying and designing both the programs and the evaluation methodologies.

In particular we need research to identify, develop and refine strategies to effectively engage at risk target groups that are not currently being identified or treated early enough.

Goal 3: Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes

Question 7:

a) Which of the areas for action described for this goal are most appropriate and why?

'More frequent patient/GP encounters did not appear to result in better glycaemic control.... Therefore as with the primary care management of elevated blood pressure, there appears to be clear potential to firstly initiate treatment earlier and apply more structured and intensive management to achieve control in those with persistently elevated blood glucose levels.' (Carrington, MJ, Stewart S, Gerber T and Cohen N *Bittersweet findings of blood glucose levels in 467,955 patients in primary care*. June 2105, Baker IDI and Heart Diabetes Institute, Melbourne, Australia)

As the above extract illustrates, just seeing a doctor, even on a regular basis, does not ensure appropriate action is taken. In a similar manner, clear national guidelines are critical, but they need to be integrated into health care practice if they are to be effective and we need new approaches to ensure this occurs.

Clinical guidelines can be re-written and delivered in new formats but what will maximise their usability and ensure they are fit for purpose? Research into the types of language and layout to be used (tables, checklists) and effective formats for delivery (paper, on line, integrated in to software) can guide the development and delivery of guidelines and educational material to both health professionals and individuals with diabetes.

Implementation research

Beyond the better delivery of guidelines, research is needed into new ways to promote the implementation of appropriate actions. For example, as the *Evaluation Report of the Diabetes Care Project* demonstrated there is scope for clinical management software used by GPs to help better manage patients diagnosed with diabetes (although it is not in itself sufficient to bring about real health improvements). Software can incorporate guidelines, flag patients at risk and prompt specific actions including referrals and diarising

future appointments. Researchers can work with the providers of GP software to integrate active patient management and to understand how to better align it with the delivery of care by GPs. Use of this software can also support the collection of data for the Quality Improvement Programs referred to in the Consultation Paper. Again, one of the findings of the *Evaluation Report of the Diabetes Care Project* was that the software is most effective when the input of data was linked to payment. Integrating patient care software with practice administration systems responsible for making appointments and managing payments has the scope to improve the use of the software and the efficiency of GP practices.

Technology utilisation

Research Australia supports the proposal to develop patient engagement and education platforms, remote monitoring technologies and reminder and recall systems. The last few years have seen significant developments in gaming technology and the birth of the health self monitoring industry with 'health apps' and fitness devices that record health performance data and motivate people to persist with behavioural changes like exercise and diet. The application of this technology to support, monitor and motivate behavioural change in individuals with pre-diabetes and diabetes should be explored further.

Examples of current research into technology to change health behaviours include the TaylorActive project <http://www.tayloractive.org.au> and computer games in stroke rehabilitation.

<http://www.georgeinstitute.org.au/news/computer-games-help-stroke-survivors-get-back-on-their-feet>

b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?

Diabetes is associated with significantly higher rates of other diseases, including heart disease, stroke, depression, vision loss and kidney disease. (*Evaluation Report of the Diabetes Care Project*, Figure 1) Any changes to diabetes management need to recognise that patients with diabetes can also have a range of other conditions which may or may not be related to their diabetes. Discrete diabetes programs need to be part of a patient centered response and models of care that adequately address all of a patient's health needs.

As the Consultation Paper notes, it has been estimated that 15 to 35 per cent of public hospital admissions are diabetes-related admissions. Discharge practices and communication to GPs are critical elements of the interchange between primary care and the acute care system which can have a significant bearing on the wellbeing of people with diabetes. Better understanding what information is critical and how it is best conveyed to ensure the appropriate continuation of healthcare is important if we are to better manage and prevent complications.

Barriers to participation

Research into the patient groups and health care providers that are not currently engaging with best practice will help us better understand how to overcome the barriers. Health care practitioners and patients need to be engaged in in the process and encouraged to participate in research.

Systems Improvement

Health services research is needed to guide and inform the changes required in our healthcare system. This includes looking at the payment system and incentives provided to practitioners and patients, and using pilot programs to understand what incentive and reimbursement structures drive the best behaviours and at what cost.

No new program should be funded or implemented without a clear process and methodology for its evaluation.

Question 8:

a) Please describe any existing programmes, initiatives or activities relevant to this goal that you think are working well and why? (Please indicate if you are aware of an evaluation report and how it may be obtained)

The *Diabetes Care Program* was an Australian Government funded 3 year trial program which commenced in 2011. The *Evaluation Report of the Diabetes Care Project* report makes a number of recommendations which are relevant to the development of a National Diabetes Framework.

Goal 4: Reduce the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups

Question 12:

The paper outlines some potential ways to measure Australia's progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?

Research Australia agrees that Quality of life is an important measure. Further research is required to establish appropriate measures, methodologies and tools which can be adopted consistently, and to inform the use of Quality of Life Measures in clinical decision making, program evaluation and policy development.

Question 13:

In relation to the impact of diabetes in Aboriginal and Torres Strait Islander peoples and high risk groups, please describe any barriers in accessing health services and/or education.

It is important to identify which of the barriers that exist to the provision of diabetes services and/or education are specific to diabetes (eg. understanding of the symptoms of the disease) and which are shared with the provision of health services and education more generally in indigenous and remote communities. Consideration needs to be given to patient centred (rather than disease centred) programs and initiatives that recognise the barriers faced by specific indigenous, remote and other high risk groups and seek to address their health needs including, rather than exclusively, diabetes prevention and care.

Goal 5: Strengthen prevention and care through research, evidence and data

Question 14:

a) Which of the areas for action described for this goal are most appropriate and why?

Research Australia supports the identified action of developing an internationally relevant and nationally coordinated research agenda with a wide remit including ‘the basic science of the disease, its social and economic impacts, and appropriate clinical responses’. The development of priority areas is also important and requires input from patients, the health care and research communities and broader community as well as the funding providers.

A key first step is to develop a clear picture of:

- who is currently funding diabetes research;
- what the research is directed; at,
- who is being funded to do it; and
- how much is being spent.

The Research Agenda needs to be cognisant of the existing areas of Australian diabetes research excellence and disciplines where further capability needs to be developed to ensure the Strategy can be delivered.

Data Linking

Research Australia supports the identified action of data linking. As the Consultation Paper notes, there are many existing sources of data, and the potential to make better use of this data for research purposes is enormous. Greater data management and analysis capabilities, the identification and use of new data sources and the linking of data sources are all critical to making better use of data. The *Evaluation Report of the Diabetes Care Project* highlighted how important the systematic collection and linking of data is to the improvement of care for individuals with diabetes.

Data linking needs to serve multiple needs. It should support individual patients and practitioners, ensuring that up to date information about a patient from various sources is available when and where it is needed. It is necessary for effective research, to help understand the extent and nature of the problem, inform research and identify which solutions work. Data linkage is also needed to support the effective monitoring of the performance of the health system in treating and preventing diabetes and understanding the impact of diabetes on patients and the community. Individual data sources cannot provide the richness needed to achieve these objectives; it can only be achieved when numerous data sources are linked.

Data linking needs to make the best possible use of all data sources, including data recorded in individuals’ blood glucose monitors and the proprietary software used by health practitioners. (The study referred to as Research Australia’s response to question 7 made use of de-identified data supplied by the provider of proprietary clinical software which is used by over 17,000 Australian clinicians.) To provide the clearest

picture of the social and economic impacts of diabetes, the linking of data sources needs to incorporate socioeconomic and demographic data.

We need to ensure that data are collected and linked in a manner that supports future expansion and usability- so that, for example, as research identifies further conditions that are diabetes related, health information on these conditions can be included in the research data pool. To achieve this, diabetes data collection and linkage needs to be integrated with a broader health data strategy that emphasises the importance of the interoperability of databases, the reusability of data and the availability of data for research.

b) Are there any additional actions you would you like to see the governments and/or other stakeholders take and why?

The Consultation Paper recognises the need to enhance the skills of the diabetes health workforce. This needs to include action to increase the research skills of the health workforce working with diabetes, particularly primary healthcare providers and diabetes educators; and to provide clinicians with the opportunity and the time to participate in research. Doing so will not only improve the quality and volume of research; it will also facilitate the more rapid implementation of evidence based practice.

More health services research needs to be undertaken to improve the implementation of evidence based care, and we need to build the capacity of the health services research workforce. In particular this will be critical if we are to identify and implement incentive and reimbursement models for health practitioners that lead to better health outcomes for their patients.

In relation to data linking, the Consultation Paper states that ‘Within the recognised legislative and privacy requirements, linking existing data sets, to provide de-identified aggregate data to understand how people develop diseases (including diabetes); how diseases progress under different preventive and treatment strategies; and how health dollars can be more efficiently and effectively focused.’

The Productivity Commission has also recently looked at Australia’s health system and has identified the capacity to make much greater use of data, including through linking of data sources. The Commission has also recognised that the current legislative and regulatory requirements in relation to Privacy are unreasonably restricting our ability to use data for research and other purposes.

‘Political will is often needed to address privacy concerns in a way that allows data to be released. Policy makers need to make trade offs between a high level of confidentiality and the consequences of not making data available. Concealing data can mean that patients receive ineffective (or even harmful) care, adverse effects of drugs go undetected, or significant money is spent on interventions that do not improve health outcomes (rather than on interventions that do). It can also make it difficult to hold health care providers to account for their performance.

Importantly, moving towards releasing more data does not need to mean releasing all data: releasing some data (with appropriate safeguards) is still better than releasing none. As a general principle, the onus should be on those who wish to withhold data to make a strong case for doing so.’¹

¹ Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra. pp.85-86

Research Australia agrees with the Productivity Commission's position that sensible reforms of the current privacy and confidentiality regime are possible which would facilitate better access for research purposes while providing appropriate protection to individuals. Rather than settling for the 'recognised legislative and privacy requirements', Research Australia urges the Panel to support the Productivity Commission's call for reform in this area.

While linking data is critical we also need to ensure that we have the data management capability to undertake the linking effectively and the data analysis capability to make the best use of it. The need for greater capability in this area, preferably through shared infrastructure and resources available to all research groups needs to be recognised as part of a research agenda.

Question 15:

a) Please describe any existing programmes, initiatives or activities relevant to this goal that you think are working well and why? (Please indicate if you are aware of an evaluation report and how it may be obtained)

The Population Health Research Network is well placed to support the linking of data.

Question 16:

The paper outlines some potential ways to measure Australia's progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?

Establishing milestones for the development of a national research agenda and national datasets and using these to measure progress is strongly supported.

While the number of diabetes publications is an important measure, it needs to be augmented with measures of actual impact on healthcare delivery and health outcomes, including the development and success of programs based on research, and the extent to which research influences government policy, including the National Diabetes Strategy.

Question 17:

Please provide any further comments you may have.

Research Australia is supportive of a National Diabetes Strategy and the development of a Diabetes Research Agenda within that Strategy, and provides the following comments in this context.

Embedding research in the health system

One outcome of the development of the research agenda within the Diabetes Strategy should be to better integrate diabetes research into the health system. Participation in research by health providers in all disciplines and settings:

- enables clinicians to more critically appraise new research outcomes;
- lifts the overall standard and quality of care; and

- promotes the more effective and timely translation of research outcomes into practice.

In turn, the engagement of researchers in healthcare delivery helps direct research to the issues that need to be addressed to improve the quality of healthcare. It also provides opportunities for patients to provide input into the direction of research and to participate in research through clinical trials. Research should not be seen as a 'bolt-on' but as a vital and integral part of the health system, and one of the valued activities and products of health services.

Research Australia advocates:

- The creation of more roles in health services across medical, nursing and allied health professions that have a dedicated time and resource allocation to diabetes research (i.e. clinician researcher roles)
- Career structures that support moving between research and health delivery roles, and the provision of support to health care practitioners who are participating in research projects on a short-term temporary basis
- Provision of infrastructure within our health system to support diabetes research, including better support for investigator led and commercial clinical trials
- Programs to fund diabetes research involvement by primary care providers.

Integrated research

The Diabetes Research Agenda needs to coordinate effort across Australia and be informed by research overseas. It should provide a view across different funding agencies (government, philanthropic and private sector), across different fields of research and locations/venues- laboratories, hospitals, primary care, community. Developing this consolidated picture should be a first step to a national research.

At the same time, the agenda needs to retain its links to other research, to avoid the 'siloing' of resources which can lead to duplication of effort and waste. Research Australia notes in particular the reference in the paper to an overall strategic framework for managing chronic diseases. (page 25)

'The National Diabetes Strategy will form part of the Government's overall strategic framework for managing chronic diseases, which recognises the shared health determinants, risk factors and multi-morbidities (i.e. co-occurring diseases) that exist across a broad range of chronic conditions (including heart disease, diabetes and kidney disease). It will also provide an opportunity to consider how best to facilitate coordinated, integrated and multidisciplinary care, improve utilisation of primary healthcare services, and recognise patient needs across the continuum of care.'

Avoiding siloing is particularly important when considering the numerous complications of diabetes, which include heart disease, vascular disease, loss of cognitive function, neuropathy, dental and gum disease, diabetic retinopathy and kidney disease. Research in these areas that is not undertaken under the banner of diabetes research is still important to the wellbeing of individuals with diabetes. Working with researchers in these other areas to understand, for example, the similarities and differences in cognitive decline in older individuals with and without diabetes is important. Similarly, obesity is a causative factor in type 2 diabetes

but is also a factor in a range of other diseases- it makes sense to take a more holistic view of obesity research, particularly when it comes to prevention and effective measures to reduce obesity.

Innovation- turning research into practice

Placing the research agenda within the National Diabetes Strategy creates the legitimate expectation that research outputs will be put to use in the health system and the community more broadly. Research is essentially the creation of knowledge; its application requires an intervening process of applying that knowledge to the creation of new therapies, interventions, drugs, devices and processes that can be implemented in the health system and the general community. This intervening process is innovation.

While there is no clear delineation in practice between when the creation of knowledge ends and the application of knowledge begins, research funding programs do not normally cover the entire innovation process. In the case of non commercial innovation, research funding may extend as far as the conduct of a clinical trial to demonstrate the efficacy of a particular intervention. In most cases, further work will be required to enable the intervention to be adopted into practice. Where and how is this innovation activity to be funded and who will undertake it? This question is not adequately addressed within the Consultation Paper which appears to assume that useful research outcomes will be absorbed into practice through osmosis. The reality is that this happens only rarely, and that when it does occur it takes a long time. The process for commercial innovation and development of a product is better defined but is also subject to significant shortcomings, particularly in the 'proof of concept' stage.

Research Australia submits that the strategy must address the issue of how diabetes research is to be implemented in the health system. Ideally the Strategy will incorporate processes and funding for the innovation activities necessary for diabetes research to improve health outcomes for people living with diabetes. At a minimum it must recognise that innovation activities are a necessary intermediary step and that the Strategy relies on existing programs and funding elsewhere in the research and health systems in this regard.

RESEARCH AUSTRALIA LIMITED

384 Victoria Street Darlinghurst NSW 2010

T +61 2 9295 8546 **ABN** 28 095 324 379

www.researchaustralia.org