The case for an Australian Diabetes Blindness Prevention Initiative

VISION 2020 THE RIGHT TO SIGHT AUSTRALIA

diabetes australia

CENTRE FOR Eye Research Australia

The case for an Australian Diabetes Blindness Prevention Initiative

The problem

> Approximately 1.7 million Australians are estimated to be living with diabetes, and with an additional 280 people developing diabetes every day, this figure is estimated to grow to 2.45 million by 2030.[1]

> Every person with diabetes is at risk of diabetic retinopathy (DR). Diabetes also increases the risk of cataracts and glaucoma.

> Almost everyone with type 1 diabetes and more than 60 per cent of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of diagnosis.

> Diabetic retinopathy is a major cause of vision loss and blindness in working age and older Australians.

> The total indirect annual cost of vision loss associated with diabetic macular oedema (DME), one of the most common manifestations of DR, is estimated to be $2.07 billion. This is more than $28,000 per person with DME.[2]

> Diabetes-related eye disease is often asymptomatic until it reaches an advanced stage and outcomes of late treatment are usually inferior to early intervention.

> Evidence shows that early detection and timely treatment can prevent the majority of diabetes-related vision loss.

> The lack of a coordinated and systematic approach means a significant proportion of Aboriginal and Torres Strait Islander people and non-Indigenous Australians with diabetes do not have an eye examination when required. This is despite ample existing capacity in optometry, ophthalmology and general medical practices to support early detection and treatment.

[1] Diabetes Australia, *Diabetes in Australia*, 2015, www.diabetesaustralia.com.au/diabetes-in-australia (accessed March 2017)

[2] Deloitte Access Economics, *The economic impact of diabetic macular oedema in Australia*, 2015

The solution

A coordinated, national Initiative to:

> Utilise and leverage a "registry" approach using existing registries and databases such as the National Diabetes Services Scheme (NDSS) – which currently has over 1.2 million Australians voluntarily registered – and Communicare to facilitate systematic eye checks for all people with diabetes in Australia.

> Adopt an "opt out" policy linked to NDSS registration and the MyHealth Record so that the vast majority of the current 1.2 million people with diabetes on the NDSS, and all new registrants in the coming year (estimated at over 100,000) will have a MyHealth Record and be included in a coordinated, proactive approach.

> Create systematic contact with people with diabetes who have not had an eye examination and need one. Enable targeted strategies to increase the uptake of eye examinations through effective methods of communication including emails and text messages, social and traditional media and channels.

> Enable better information sharing between members of the healthcare team, so that the results of eye examinations (including retinal photographs and optical coherence tomography scans) can trigger timely ophthalmic treatment and better inform the control of key risk factors (hyperglycaemia, hypertension and hyperlipidaemia) that contribute to the complications of diabetes, including eye disease.

> Enable accurate data on eye examination uptake to be used by Primary Health Networks (PHNs) to coordinate public health resources.

"It is a tragedy that diabetes remains the leading cause of blindness in working age Australians. Other countries have reduced this impact through coordinated diabetes complication prevention programs. We can and should do the same in Australia."

The Hon Judi Moylan AO, President Diabetes Australia

Alignment with Australian Government Policies and International Commitments

This Initiative aligns with Australian Government priorities, including:

> Goal 3 of the *Australian National Diabetes Strategy 2016-2020*, calls for reducing the occurrence of diabetes-related complications and improving quality of life among people with diabetes. Areas for action include:
  - *Consider complication prevention programmes across the health system;*
  - *Promote the uptake of MyHealth Record and explore its role in optimising workflow and better manage complex conditions.*

> The House of Representatives Standing Committee on *Health Inquiry into Chronic Disease Prevention and Management in Primary Health Care (2016)* recommended that the Australian Government:
  - *Commit to providing consistent support and funding for the establishment of PHNs to enable consistent development and support for chronic disease prevention and management;*
  - *Continue to prioritise funding of the evolution and expansion of the MyHealth Record to support improvements in the prevention and management of chronic disease.*

> The *Second Draft of the National Strategic Framework for Chronic Conditions* outlined three objectives:
  - *Focus on prevention for a healthier Australia;*
  - *Engage people with chronic conditions in the management of their own health;*
  - *Target priority populations, including Aboriginal and Torres Strait Islander communities.*

> Chronic disease accounts for around three quarters of the gap in mortality rates between Indigenous and non-Indigenous Australians. The *Closing The Gap Prime Ministers Report 2016* recognised collaboration across governments, the health sector and Aboriginal and Torres Strait Islander people as essential to closing the gap.

> *The Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023* supports:
  - *Accessible interventions with a strong focus on prevention and early intervention;*
  - *Improved regional planning and coordination of health care services across sectors and providers;*
  - *Improving access to primary prevention screening and early detection for Aboriginal and Torres Strait Islander adults;*
  - *Aboriginal and Torres Strait Islander adults have improved access to quality treatment services to manage chronic conditions.*

> The WHO *Universal eye health: a global action plan 2014–2019* endorsed by the Australian Government at the Sixty-sixth World Health Assembly in 2013, urges Member States:
  - *To strengthen national efforts to prevent avoidable visual impairment including blindness through, inter alia, better integration of eye health into national health plans and health service delivery, as appropriate;*
  - *To implement the proposed actions in the global action plan 2014-2019 on universal eye health in accordance with national priorities, including universal and equitable access to services.*

It should also be noted that:

> The Council of Australian Governments Communiqué in December 2015 recommended *"a new approach to integrated community and primary care, with particular focus on a chronic care model for patients at risk of, or with complex and chronic disease, and timeframes for potential implementation."*

> The Prime Minister and Cabinet Reform of Federation Discussion Paper (2015) states: *"There are strong reasons for taking action now to address the challenge of providing better integrated and coordinated care for people with chronic and complex conditions."*

> PHNs have been established *"with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time."*

The scale of the problem

> The current approach to eye examinations for Australians with diabetes is not systematic. As a result, 47 per cent of Aboriginal and Torres Strait Islander people and 22 per cent of non-Indigenous Australians with diabetes are not having an eye examination at the frequency recommended by the National Health and Medical Research Council.[3]

> Diabetic retinopathy is a major cause of vision loss and blindness in working age and older Australians. It causes damage to tiny blood vessels in the retina at the back of the eye. This can seriously affect vision ultimately leading to blindness.

> Diabetes is a progressive condition and a person's risk of developing diabetic retinopathy increases the longer they live with the condition. Almost everyone with type 1 diabetes and more than 60 per cent of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of diagnosis.[4]

> The total indirect annual cost of vision loss associated with diabetic macular oedema (DME), one of the most common manifestations of diabetic retinopathy, is estimated to be $2.07 billion. This is more than $28,000 per person with DME.[5]

Evidence shows that early detection and timely treatment can prevent the majority of diabetes-related vision loss. In fact, diabetes-related blindness can be prevented or delayed in 98 per cent of cases. There are clear international examples of where this has been achieved.

> In Iceland, systematic screening for diabetes-related blindness began in 1980 and by 2005 the condition had been virtually eliminated.

> The United Kingdom has implemented comprehensive screening programs and now, for the first time in more than 50 years, diabetic retinopathy is no longer the leading cause of blindness in England.[6] Poland and Sweden have also significantly reduced rates of diabetes-related blindness and vision impairment.

> In all of these cases, expanded and systematic screening has led to earlier identification of clinical issues, allowing for earlier treatment and intervention which is more likely to be successful.

There is ample existing capacity in optometry, ophthalmology and general medical practices in Australia to serve the eye health needs of all people with diabetes; ***however the lack of coordination poses a major barrier.***

[3] Foreman, J., et al, *The National Eye Health Survey Report 2016*, The Centre for Eye Research Australia and Vision 2020 Australia, 2016

[4] Baker IDI Heart and Diabetes Institute and Centre for Eye Research Australia, *Out of Sight – A Report into Diabetic Eye Disease in Australia*, 2013.

[5] Deloitte Access Economics, *The economic impact of diabetic macular oedema in Australia*, 2015

[6] Liew G et al., *A comparison of the causes of blindness certifications in England and Wales in working age adults (16-64 years), 1999-2000 with 2009-2010*. BMJ Open, 2014

The implementation of systematic retinal photography programs in the United Kingdom, Iceland, Poland and Sweden has dramatically decreased the incidence of vision impairment and blindness from diabetes. For the first time in more than 50 years, DR is no longer the leading cause of blindness registrations in those of working age in England and this has been largely attributed to the introduction of a national diabetic retinopathy screening program.

The rationale for an Australian Diabetes Blindness Prevention Initiative

In Australia, a systematic approach to diabetes blindness prevention would be consistent with the goals of the National Diabetes Strategy, particularly the aim to reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes, especially for high risk groups such as Aboriginal and Torres Strait Islander people.

Furthermore, the National Diabetes Strategy aligns with other current Australian Government priorities, including:

> The eye health priorities outlined in the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss (2005)* and its *Implementation Plan (2014-2016)*;

> Improving the coordination of healthcare through e-health and the My Health Record platform; and

> Strengthening the primary care system through the PHNs.

Together, these Australian Government priorities provide a unique opportunity to introduce a systematic approach to reducing vision impairment and blindness caused by diabetes, tailored to the health needs of Australians and our unique healthcare environment.

The eye health, vision care and diabetes sectors propose that the Australian Government support an Australian Diabetes Blindness Prevention Initiative to reduce vision loss related to diabetes.

The proposed Initiative could:

> Capitalise on the capabilities of existing registries and databases such as the NDSS – which currently has over 1.2 million Australians voluntarily registered – and Communicare to facilitate linking, storing and sharing information between the databases, people with diabetes, PHNs, eye health practitioners, optometrists, general practitioners, specialist diabetes clinicians and other health services.

> Utilise the MyHealth Record with the opportunity to adopt an "opt out" policy for the NDSS database which could enable the vast majority of the current 1.2 million people with diabetes registered, and all new registrants in the coming year (estimated at over 100,000) to have a MyHealth Record including records and images of eye checks and reports.

> Enable the systematic identification of, and contact with, people with diabetes who have not had an eye examination and need one.

> Enable targeted strategies to increase the uptake of eye examinations through effective methods of communication including emails and text messages, social and traditional media and channels.

> Enable better information sharing between members of the healthcare team, so that the results of eye examinations (including retinal photographs) can trigger timely ophthalmic treatment and better inform the control of key risk factors (hyperglycaemia, hypertension and hyperlipidaemia) that contribute to all of the complications of diabetes, including eye and kidney disease.

> Enable accurate data on eye examination uptake to be used by PHNs to coordinate public health resources.

How will it work?

By harnessing strong leadership from experts in the diabetes, eye health and vision care sectors, the Initiative will coordinate and facilitate effective linkages between members of the health care team to ensure improved eye health outcomes for Australians with diabetes. Further, the Initiative will facilitate wider consumer engagement to better identify those not currently engaged with the health care system.

Eye examinations will be provided by optometrists, ophthalmologists and general practitioners (GPs), as is currently the case. However, the Initiative will work to identify ways in which clinicians and services could be supported and encouraged to upload retinal photographs, optical coherence tomography scans, and screening outcomes to MyHealth Records, closing the loop between primary health care teams.

The implementation of the Initiative will have four key elements:

1. Facilitating consumer engagement and consumer-driven demand for system change; registries and promotion to ensure wide uptake and effectiveness.

2. Coordination with PHNs, Health Care Homes, MyHealth Record/Digital Health Agency to facilitate initial linking, storing and sharing of existing databases and information with primary care.

3. Clinical leadership and engagement to facilitate the integration of data, systems and approaches in consultation with clinicians in optometry, ophthalmology, diabetology and GPs.
4. Engagement with systems, the services sector and private sectors to ensure seamless software integration within primary care/clinical practice environment and with the MyHealth Record.

The path to success

The diabetes and eye health sectors, facilitated by Diabetes Australia and Vision 2020 Australia, are seeking to work with the Australian Government to establish and support a limited life Taskforce to lead the development of the Australian Diabetes Blindness Prevention Initiative with an investment cost of $1.5 million ($750,000 per year for two years) from 1 July 2017.

The Taskforce, with a national project manager and small team, will:

> Deliver strong consumer engagement strategies through Diabetes Australia and the network of state and territory diabetes organisations, utilising existing registries, such as the NDSS, to provide systematic recall and reminders for consumers, and increase the uptake of eye checks within recommended timeframes.

> Develop and promote coordinated approaches working with all PHNs to facilitate linking, storing and sharing information between clinicians such as eye health practitioners, optometrists, general practitioners, specialist diabetes clinicians and other health services to ensure regular checks and identification of problems and trigger earlier treatment.

> Work with the Digital Health Agency to optimise the uptake of the MyHealth Record for people with diabetes and eye health including implementing an "opt out" policy for people registered with the NDSS which could enable the majority of the 1.2 million people with diabetes, and all new registrants, to have a MyHealth Record.

> Coordinate the ongoing involvement and support of leading organisations and individuals in the diabetes and eye health sectors including consumers, health professionals and researchers.

The Australian Diabetes Blindness Prevention Initiative will:

> Serve as a flagship for the MyHealth Record system and new Digital Health Strategy by utilising existing data, health information resources and clinical expertise.

> Engage consumers.

> Not require the creation of new funded services.

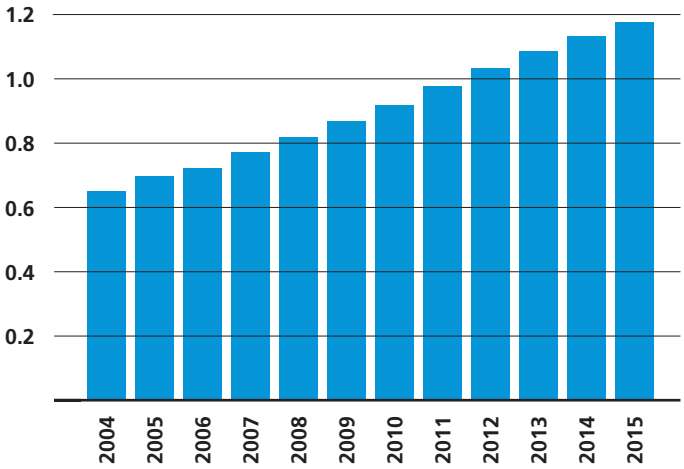
Existing private sector digital health information systems have significant and increasing penetration in the eye health care environment and are well placed for efficient integration with the MyHealth record system.

It is anticipated that tangible improvements in the coordination of eye health care for people with diabetes could be realised in a short timeframe with limited additional investment. This approach may serve as the framework for a systematic approach to comprehensive health care coordination for all Australians with diabetes.

It should be noted that Australia has amongst the world's highest uptake of mobile communications devices (phones and tablets), and has 1.2 million people currently diagnosed with diabetes voluntarily registered to a national database (the NDSS). Every one of these Australians should be able to carry their eye check photograph or report with them on the their mobile device, and access their health records with their health professionals so that early detection and prevention of vision loss and blindness is achieved.

This initiative realises the digital health opportunity to achieve much greater value and better health outcomes from the smart use of existing data and systems.

The number of people (millions) registered with the NDSS, 2004–2015



Benefits summary of this proposal and investment

This initiative realises the digital health opportunity to achieve much greater value and better health outcomes from the smart use of existing data and systems.

Efficient

An integrated approach using the existing services of GPs, optometrists and ophthalmologists, incorporating public, private and not for profit services, for optimal care delivery.

- **Efficiency in existing services undertaking primary care-based prevention with less duplication**
- **Uptake of MyHealth Record, ensuring linkage between members of health care team**
- **Coordination and information sharing amongst health care team members resulting in improved patient outcomes**

Effective

Evidence-based early diagnosis and care according to clinical guidelines.

- **Early detection and treatment**
- **Vision loss and blindness; fewer hospitalisations and reduced risk of associated disability**

Economical

Cost-effective without the need to create new funded services.

- **Return on investment**
- **Health expenditure**

Ethical

Emphasis on rural and remote, Aboriginal and Torres Strait Islander people and vulnerable groups.

- **Health outcomes for 1.7 million Australians**
- **Productivity losses**

Establishment of limited life Taskforce: $1.5 million over two years

Vision 2020 Australia

Recognised by government as the national peak body for eye health and vision care, Vision 2020 Australia leads the collaboration of key government, non-government and private sector stakeholders to improve eye health and vision care in Australia and our region.

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Diabetes Australia

Diabetes Australia is the national body for people with all types of diabetes and those at risk. We are committed to reducing the impact of diabetes in Australia and we work in partnership with consumers, health professionals and researchers.

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Centre for Eye Research Australia

CERA is Australia's leading eye research institute. Our mission is to eliminate the major eye diseases that cause vision loss and blindness and reduce their impact in our community.

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For further information about the case for an Australian Diabetes Blindness Prevention Initiative please contact Vision 2020 Australia CEO Carla Northam or Diabetes Australia CEO, A/Professor Greg Johnson.

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