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Better Outcomes for people with Chronic Disease and Complex Health Conditions

Thank you for the opportunity to comment on the *Better Outcomes for People with Chronic Disease and Complex Health Conditions* discussion paper and to contribute to the work of the Primary Care Advisory Committee.

Diabetes Australia believes there are significant opportunities to strengthen primary care to better support, and improve health outcomes for people with diabetes.

Managing the growing burden of diabetes in terms of increasing prevalence, and serious complications, is the biggest challenge for Australia's health care system.

Diabetes Australia believes that strengthening the ability for the (current) 1.2 million Australians with diabetes to better self manage their condition, stay healthy and out of hospital, remains one of the biggest opportunities to reduce the burden of disease on Australia's health care system.

The Case for Change

Diabetes is the leading global threat to human health and productivity in the 21st century.

Diabetes is a serious and complex metabolic condition which can lead to many costly complications if not well-managed. These include heart attacks, stroke, eye damage and blindness, kidney failure, lower limb amputations, and depression/anxiety/distress.

An estimated 1.7 million Australians currently are affected by diabetes (this includes all types of diabetes) and an additional 280 Australians develop the condition every day.

People with diabetes are already high-end users of health care

Diabetes accounts for around one-third of all preventable hospital admissions with longer than average bed stays. A study of patients in 11 Melbourne hospitals found that, regardless of the reason for their hospitalisation, 24.7 per cent of inpatients had diabetes¹.

Patients with diabetes stay longer in hospital with estimates ranging from 1.0 to 2.8 additional days in hospital².

¹ Bach, L.A., et al. "The high burden of inpatient diabetes mellitus: the Melbourne Public Hospitals Diabetes Inpatient Audit." *Medical Journal of Australia* 2014; 201 (6): 334-338.

² Baker, S.T., et al. "Outcomes for general medical inpatients with diabetes mellitus and new hyperglycaemia." *Medical Journal of Australia* 2008; 188: 340-343.

A staggering 65 per cent of all cardiovascular-related deaths in Australia are people with diabetes. These complications and comorbidities mean many people with diabetes become frequent users of the health system^{3 4}.

More than 15 per cent of frequent users of GPs were recently found to be diagnosed with diabetes. This same review found people who frequently attended a GP were much more likely to see different doctors, with the highest users averaging 4.8 different GPs in a year. This has implications for continuity of care, and effective diabetes management.⁵

Diabetes is forecast to become the highest contributor to the disease burden in Australia by 2017⁶.

In the coming decades, Australia's health system will be defined by its capacity to manage and respond to the challenge of diabetes. Without a comprehensive response, there is every likelihood diabetes will overwhelm our health system and damage national productivity. The size of the problem, coupled with the complexities of the condition and the modifiable risk factors contributing to the type 2 diabetes epidemic, mean responsibility for responding to this challenge rests with all levels of government and spans the entire health system and broader community.

A fundamental shift towards prevention is needed if Australia's health system is to be sustainable.

Optimal Diabetes Management Starts in Primary Care

Our current primary care system was not designed to effectively manage long-term, complex and chronic conditions such as diabetes which require both coordinated multidisciplinary care and self management.

Many diabetes-related complications and hospitalisations could be prevented through a more effective primary care system designed for effective, early intervention to prevent the development of complications.

However, at present, billions of dollars are spent on expensive, hospital treatment for late stage complications where outcomes are often poor. This is less effective and more expensive than investing in preventing complications through improved early access to optimal diabetes care in the primary care setting – with a stronger focus on risk assessment, early treatment and prevention of complications.

Better diabetes management means a better quality of life and decreases the burden on the health system and society.

Optimal management of diabetes in Australia is limited by a fractured health system, funding and professional silos, and great difficulty for consumers to navigate a complex system and find the services and support they need at the right time.

³ 5 Barr, E.L. et al 2007. Risk of cardiovascular and all-cause mortality in individuals with diabetes mellitus, impaired fasting glucose, and impaired glucose tolerance: the Australian Diabetes, Obesity and Lifestyle Study (AusDiab). *Circulation*, 116, 151-7.

⁴ Whitson M, et al. "What can be learned from the impact of diabetes on hospital admissions from routinely recorded data?" *Diabetes Medicine* 2012; 29: 1199-1205.

⁵ National Health Performance Authority 2015, *Healthy Communities: Frequent GP attenders and their use of health services in 2012–13*.

⁶ AIHW *Australia's health 2010*. Canberra, Australian Institute of Health and Welfare.

A person's access to diabetes care varies considerably according to diabetes type and complexity and by service type, setting and location. Service availability differs significantly by region.

Consumers too often find it hard to identify entry points into the care system; next steps in their diabetes management, and ongoing service access.

Person Centred Approach

Achieving real change should start with putting consumers first.

There has been much rhetoric about "patient centred" approaches, but the reality in Australia is that most of the primary care system, services and funding is still provider-centred and provider-driven.

This is still evident in the terminology and focus of the *Better Outcomes for People with Chronic Disease and Complex Health Conditions* discussion paper. For example, the document talks of the need to "engage" consumers in their health care, yet the term "patient" is used throughout much of the paper. The term 'patient' implies the person is a passive recipient of care, rather than an active agent in his or her own self-care. Many people with diabetes do not regard themselves as "patients" in managing their condition and working with health professionals.

Section 1.4 of the discussion paper discusses responsibility of care, with no reference to the responsibility of consumers (as funders/co-funders or more broadly). While governments, NGOs, and private organisations play a role in providing care, it should be recognised that consumers pay for health care and play a pivotal role in their own care.

"Patient" participation is discussed towards the end of chapter 1 (Section 1.6), yet this should be a key principle highlighted from the outset. Any discussion about effective and appropriate care should always begin with the person (and families and carers), and their capacity to self-care and be part of an effective plan/team.

Most of the "transitions" talked about in the paper are provider centric, not person centric. We need to be more focused on life transitions for people with diabetes. For example,

- Child transition to youth to adult where poor transition into the adult health care system can lead to young people "dropping out" of the care system and, too often, early development of serious complications, which are major causes of morbidity and mortality.
- Moving from oral medication to insulin is an important transition for people with type 2 diabetes - yet too often this transition is poorly communicated and poorly managed with unnecessary delays, fear and anxiety, and poor levels of education.
- Older people moving from independent living at home to aged care services where there are often huge breakdowns and significant psychosocial problems.

If we are really serious about person centred care, we need to empower people with confidence and skills to play a key role in their own care.

Self Management and Structured Education

To improve the health outcomes of people with diabetes, we must improve individual's personal management of their condition and empower them to take charge of their own care.

The evidence shows that the best health outcomes come when people with diabetes are informed and empowered in self-management of their diabetes, in partnership with their multidisciplinary healthcare team.

It is estimated that people with diabetes will interact with health professionals for around 6 to 8 hours per year, leaving them to self manage their condition 364 days per year.

The discussion paper has limited reference to improving diabetes education, access to structured self management programs, or generalised self management support. Section 1.6 almost dismisses the need suggesting “there are range of established supports to enable people living with chronic and complex health conditions to better manage their own health care”. The reality is that Australia is lagging behind many other countries in developing and expanding consumer education and structured self-management programs despite the strong evidence base.

Evidence shows that structured patient education can stabilise blood glucose levels, reduce the risk of diabetes related complications, improve quality of life for people with diabetes and their families, and reduce health care costs.

From the time of diagnosis, people with diabetes and their carers should have access to structured diabetes self-management education and support, with access to an annual review and ongoing education and support.

Yet most people with diabetes in Australia are not offered the chance to participate in diabetes education. There is strong evidence of the success of these programs internationally and in Australia we have seen positive results from programs like DAFNE (Dose Adjustment For Normal Eating) for people with type 1 diabetes and DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) for people with type 2 diabetes. Both programs are delivered in group settings with a range of accredited health practitioners including credentialled diabetes educators, dietitians and other health professionals.

The UK health system engages more effectively with people with chronic disease compared to Australia. Only 48 per cent of people with long-term (chronic disease) cases felt engaged in Australia, compared with 69 per cent of people in the United Kingdom.⁷

In the UK, structured self management education is embedded in the primary care system with National guidelines (NICE Quality Standards) recommending that “structured patient education is made available to all people with diabetes at the time of initial diagnosis and then required on an ongoing basis, based on formal, regular assessment of need”. (See *Attachment 1: Taking control: Supporting people to self manage their diabetes*)

Importantly, these guidelines are enforced under the NHS constitution. In addition, outcomes indicators have been set for Clinical Commission Groups in the UK (responsible for commissioning health services) regarding the number of people with diabetes (newly diagnosed) referred to structured education.

There are opportunities to replicate this model in Australia, with the new Primary Health Networks providing the ideal structure to commission the delivery of structured diabetes education in local communities. Based on the UK experience, there is no “one size fits all” model and different education programs are required to suit local community needs.

⁷ McKinsey: *How can Australia improve its primary health care system to better deal with chronic disease? Background paper;* 2015; pg 19.

However national, quality assured standardised diabetes education programs, combining different learning formats and approaches, should be developed to provide a framework for PHNs to commission the most suitable options for their local populations. Well defined service level agreements for diabetes education between PHNs and service providers should be established. It is important to collect meaningful data on the provision and uptake of diabetes education to ensure that the service is delivering what it is intended to deliver.

A key issue regarding the uptake of patient education both in the UK, and in Australia, is that many healthcare professionals do not value, or are unaware of the value of diabetes education programs. GPs are often too busy and there are few incentives to encourage health professionals to refer people to structured diabetes education courses. It is important that health care professionals understand the benefits of education and are able to promote it to people with diabetes. Opportunities exist to utilise the National Diabetes Services Scheme to better link people with diabetes, GPs, and PHNs with structured education. (see details later)

Traditional (health professional led) structured education needs to be supported with other models of education including peer led programs and technology-enabled education programs. Peer support programs can provide significant clinical and psychological benefits by targeting specific behaviours and consumer empowerment. Telephone and face to face peer support programs have shown significant improvements in blood glucose control in people with diabetes.⁸ Online peer support programs can improve knowledge, social support and people's self efficacy.⁹

Driving quality through enrolment, coordination, monitoring and reporting

There are other lessons from the UK in diabetes care. A renewed push to drive improvements in the quality of services for people with diabetes has also seen improvements in health and care outcomes. This has been achieved through the implementation of systematic nation-wide monitoring through the UK's Quality and Outcomes framework, with services audited annually via the National Diabetes Audit. The Primary Health Networks provide a good structure to introduce clear accountability to drive improvements in diabetes care.

For example, ensuring every person diagnosed with diabetes is supported in this way through an Annual Cycle of Care is essential to preventing or delaying diabetes complications. Each PHN should be accountable to ensure that every person with diabetes in their catchment is able to access an Annual Cycle of Care and improvements in diabetes management and health outcomes are achieved.

In addition, PHNs could monitor other key indicators and outcomes of care for people with diabetes. This could include:

- Referrals to structured education for people newly diagnosed with diabetes;
- Regular checks for 'the 9 care processes' (i.e. HbA1c, blood pressure, body mass index, urine microalbumin, creatinine, cholesterol, eye examination, foot examination and smoking status); and
- Emergency admissions for diabetic ketoacidosis.

⁸ Smith S, Soubhi H, Fortin M. Interventions for Improving Outcomes in Patients with Multimorbidity in Primary Care and Community Settings. *Cochrane Collab*; 2012; (5):CD006560 - . doi:10.1136/bmj.e5205.

⁹ Thom DH, Ghorob A, Hessler D, Vore D De, Chen E, Bodenheimer T. Impact of Peer Health Coaching on Glycemic Control in Low-Income Patients With Diabetes: A Randomized Controlled Trial. 2013;137-144. doi:10.1370/afm.1443.

- Key transitions:
 - Youth
 - Insulin commencement
 - Older people transitioning to care

Australia should also create national screening approaches for complications, with targets and goals for PHNs and hospitals to measure and report on the prevention of diabetes-related complications including:

- Eye complications – retinopathy and vision impairment;
- Kidney complications – nephropathy and requirement for dialysis;
- Cardiovascular complications – heart attacks and strokes;
- Foot and limb complications – lower limb amputations;
- Mental health issues – depression, anxiety and distress; and
- Hypoglycaemia.

Diabetes Australia believes Australia should also implement targeted screening and early intervention programs to address priority diabetes complications including a National Diabetes Blindness Prevention program.

There is strong international evidence supporting the success of targeted programs in reducing the impact of diabetes on both the individual and the health system. The United Kingdom, Iceland, Poland and Sweden have all dramatically decreased the incidence of blindness from diabetes, typically to between one third and one fifth of baseline rates. Diabetes Australia strongly believes Australia could and should adopt a systematic approach to early detection and treatment. Further strategies and programs could be developed to address amputation prevention and kidney health. The NDSS database could be used as an active register and coordination tool to facilitate this.

Better data linkages and coordinating care

There are currently 1.2 million people with diabetes voluntarily registered with the National Diabetes Services Scheme (NDSS). In the past 12 months over 100,000 people have newly registered with the NDSS. This includes type 1 diabetes, type 2 diabetes and gestational diabetes. This national database is an important asset that could provide an important coordination and delivery mechanism for targeted early intervention to support the best ongoing self care and health care.

As identified earlier there are opportunities for better linkages between the NDSS and PHN's, to better help PHNs identify, support and monitor health outcomes of diabetes-affected population groups in PHN catchments

There are opportunities to use the NDSS for better consumer connection and coordination through health system by proactively utilising the NDSS database as a service coordination tool to strengthen consumer access to primary health care services.

For example, Section 1.1 discusses options of patient enrollment. The NDSS could be used as a key enabler to identify people with diabetes and used as a tool for enrolment and ongoing care coordination. The NDSS could be cost effectively used as care coordination tool (in combination with e-health) ensuring that every person with diabetes has an “online” care coordinator through NDSS to support the physical care coordination roles created elsewhere.

The need for a multidisciplinary approach and a funding system to encourage this.

Diabetes is a complex condition affecting every part of a person's health. Because of this, effective management needs to focus on a network of care providers rather than individual health providers competing for "control" of the "patient".

This requires a greater consideration of the role played by credentialed diabetes educators (CDEs), dietitians, practice nurses, podiatrists, psychologists, optometrists, pharmacists and other health practitioners. Sometimes, another practitioner is more central to the person with diabetes and diabetes management than the GP.

Currently people with diabetes are entitled to five (5) allied health 20 minute visits annually within the Chronic Disease Management item. This is a hit and miss approach. Many people with diabetes do not see a qualified diabetes educator at all, or only see one for 20 minutes annually. Structured self management education programs are not supported by this funding structure. Many people with diabetes do not access psychological support or counselling. We recommend extending this to 10 allied health visits annually that include at least two CDE visits for people with diabetes.

There is a higher burden of diabetes in regional and remote communities and generally, poorer outcomes. The provision of coordinated multidisciplinary health services to people living in regional, rural and remote areas continues to be problematic for governments. Telehealth is one part of the solution. Medicare rebates and better access to telehealth consultation for diabetes self-management education services to eligible people with diabetes in non-metropolitan areas should be considered further.

Private/public funding and provision.

There is consideration of a greater role for private health insurers in funding and service provision in the primary care sector. This should be carefully considered in the context where historically, different private health insurers have appeared to pick and choose what aspects of primary care they want to support. There is currently a lack of guiding principles balancing the responsibility of insurers to include comprehensive, integrated care with consideration of funding of all essential components, rather than just selected components.

For example, some private health insurers provide some benefits and support for some aspects of diabetes care, often with their own different detailed eligibility rules. From a consumer perspective, it is a lottery as to whether a person can gain supported access to services through private insurance.

Currently there are very few private health insurance funds which support diabetes self-management education services. Some who do, appear to make it difficult for their customers to obtain the rebate specified. When queried, private health funds often respond that they are highly regulated by government about what they can and cannot rebate. Some services, with little evidence of impact on health outcomes, are rebated (various massage services) yet diabetes education services are not rebated, despite being provided by highly skilled specialist health care professionals, with evidence of the benefits.

Funding Models

Diabetes Australia supports consideration of innovative funding models where there is evidence they can contribute to improved outcomes, including improved consumer experience.

The Diabetes Care Project trialled a blended funding model that utilised fee for service, flexible funding based on risk stratification, quality improvement payments and salaried facilitators. Funding levels were tiered by risk, with resources directed to consumers for whom the greatest benefit would be realised

Evaluation of the project suggested that the funding model enabled greater innovation, encouraged a more consumer centred approach to health care and contributed to improved clinical outcomes.¹⁰

We support moves to change the current chronic disease care funding model to incorporate flexible funding for registration with a health care home, payment for quality and funding for care facilitation, targeting resources where they can realise the greatest benefit.

Part of the “enrolment” and registration for diabetes should include “opt out” registration to the National Diabetes Services Scheme to structurally create a much stronger link between the person with diabetes, their general practitioner, and the NDSS as their ongoing diabetes self management support “home” and coordinator.

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¹⁰ McKinsey: *How can Australia improve its primary health care system to better deal with chronic disease? Background paper*, 2015; pg 49.