Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

by

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Bachelor of Arts (BA, Psych)
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Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (Psychology)

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December, 2017
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Acknowledgements

When I was twelve, my much loved Grandmother suddenly and irreversibly lost sight in both eyes. Although I was too young to understand the cause, I certainly understood the impact. For the next fourteen years, my Grandmother continued to live independently and manage her change in circumstances. However, this was only achieved with courage and determination on her part, and daily support and commitment on the part of her loved ones.

This program of PhD research was conducted in her memory and with the aim of preventing avoidable vision loss for others.

I wish to gratefully acknowledge the following people and thank them for sharing their knowledge, friendship, time, expertise and advice freely, to develop and support this PhD candidate.

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List of publications

The following manuscripts published or submitted for publication, form empirical chapters in this thesis. Authorship statements are presented at the beginning of each relevant chapter. A list of other works arising from this program of PhD research (e.g. letters to the editor, conference presentations and posters, non-refereed reports) is presented in Appendix A.

Refereed journal articles


Submitted for publication


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Abstract

Vision loss from diabetic retinopathy (DR), a common diabetes-related complication and leading cause of blindness for working-age adults worldwide, is preventable. Retinal screening is the proven clinical pathway to early DR detection; risk of vision loss can be significantly reduced by timely, appropriate treatment thereafter. Young adults with type 2 diabetes (T2D, 18-39 years) are a burgeoning population at risk of early development and rapid progression of diabetes-related complications, experiencing considerable health burden by mid-life. Younger-onset T2D (i.e. diagnosis before 40 years of age) is also an independent risk factor for development of DR, and low uptake of retinal screening, highlighting young adults with T2D as a priority population for targeted intervention. Despite this, there is a paucity of research exploring underlying factors impacting retinal screening behaviour, and no retinal screening promotion interventions specifically tailored to young adults with T2D.

The aim of this program of PhD research was to develop a public health intervention to promote uptake of retinal screening among young adults with T2D. Objectives were: 1) identify modifiable factors impacting retinal screening behaviour among young adults with T2D, 2) develop an individual-level, theoretically-grounded, psycho-educational retinal screening promotion intervention, tailored to this priority population, and 3) evaluate the effectiveness of the intervention in increasing self-reported uptake of retinal screening and improving modifiable behavioural determinants. A mixed-methods needs assessment (literature review, in-depth interviews, nationally representative survey) identified facilitators, barriers, and modifiable
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psychosocial determinants of retinal screening for this priority population. Utilising intervention mapping as a development framework, these factors were targeted via theoretically-grounded persuasive messages which were embedded in an engaging and contextually-appropriate format (leaflet) and piloted. The leaflet significantly increased knowledge of DR, an important retinal screening facilitator, but not other behavioural determinants. Reduced sample size and real-world constraints curtailed capacity to test intervention effect on the primary outcome. These findings provide an evidence base for clinicians and researchers focussing on young adults with T2D and a template for best-practice, print-based intervention development. Furthermore, in an Australian context, the broad learnings from this program of PhD research lend support to calls for the introduction of a nationally coordinated retinal screening program.
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACBRD</td>
<td>The Australian Centre for Behavioural Research in Diabetes</td>
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<tr>
<td>ADBPI</td>
<td>Australian Diabetes Blindness Prevention Initiative</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>BCT</td>
<td>Behaviour Change Technique</td>
</tr>
<tr>
<td>BMI</td>
<td>Body Mass Index [weight (kg)/height (m²)]</td>
</tr>
<tr>
<td>CERA</td>
<td>Centre for Eye Research Australia</td>
</tr>
<tr>
<td>DR</td>
<td>Diabetic Retinopathy</td>
</tr>
<tr>
<td>DUHREC</td>
<td>Deakin University Human Research Ethics Committee</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HbA1c</td>
<td>Glycated haemoglobin</td>
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<tr>
<td>IM</td>
<td>Intervention Mapping</td>
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<tr>
<td>IMB</td>
<td>Information-Motivation-Behavioural skills model</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>MRC</td>
<td>Medical Research Council</td>
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<tr>
<td>NDSS</td>
<td>National Diabetes Services Scheme</td>
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<tr>
<td>NEHS</td>
<td>National Eye Health Survey</td>
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<tr>
<td>NIHR</td>
<td>National Institute for Health Research</td>
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<tr>
<td>NPDR</td>
<td>Non-proliferative diabetic retinopathy</td>
</tr>
<tr>
<td>OA</td>
<td>Older adults with type 2 diabetes (aged 40+ years)</td>
</tr>
<tr>
<td>QBE</td>
<td>Question Behaviour Effect</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>SAM</td>
<td>Suitability Assessment of Materials</td>
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<tr>
<td>SCM</td>
<td>Social Cognition Model</td>
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<tr>
<td>T1D</td>
<td>Type 1 diabetes mellitus</td>
</tr>
<tr>
<td>T2D</td>
<td>type 2 diabetes mellitus</td>
</tr>
<tr>
<td>VTDR</td>
<td>Vision Threatening Diabetic Retinopathy</td>
</tr>
<tr>
<td>YA</td>
<td>Young adults with type 2 diabetes (aged 18-39 years)</td>
</tr>
</tbody>
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Outline of Thesis

The aim of this program of PhD research was to develop a public health intervention to promote uptake of retinal screening among young adults with type 2 diabetes (T2D, aged 18-39 years). The objectives of this research were to:

- identify modifiable factors impacting retinal screening behaviour among young adults with type 2 diabetes
- develop an individual-level, theoretically-grounded, psycho-educational retinal screening promotion intervention, tailored to young adults with type 2 diabetes
- evaluate the effectiveness of the intervention in increasing self-reported uptake of retinal screening and improving modifiable behavioural determinants.

To achieve these objectives, mixed-methods needs assessment was conducted, comprising literature review, qualitative in-depth interview study and online quantitative survey. Intervention Mapping used as a framework to develop evidence-based, persuasive messages targeting determinants identified in the needs assessment, and embed them in an engaging and relevant retinal screening promotion intervention. Finally, a randomised controlled trial was conducted to evaluate the effectiveness of the intervention.

This thesis comprises six chapters. Chapter 1 (Introduction) describes type 2 diabetes and the unique clinical and self-management challenges faced by young adults living with the condition. The chapter introduces diabetic retinopathy (DR), the vulnerability of young adults with type 2 diabetes to the condition, and the problem of low retinal screening uptake (a crucial pathway to early DR detection) for this priority population, providing a rationale for the program of research.
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Chapter 2 (Literature Review) summarises and critiques the available evidence regarding: research on the priority population, modifiable factors impacting uptake of retinal screening, previous interventions to increase the rate of retinal screening, as well as providing an overview of current ‘best practice’ in developing high quality health behaviour change interventions.

Chapter 3 presents the first empirical study of the thesis (Paper 1: What factors influence uptake of retinal screening among young adults with type 2 diabetes? A qualitative study informed by the Theoretical Domains Framework). The chapter describes the in-depth exploration (via a semi-structured interview study) of individual-level barriers and facilitators to retinal screening behaviour for young adults with T2D, and a systematic comparison with an older-adult comparator group, in order to identify those of greatest salience to the priority population.

Chapter 4 (Paper 2: A tailored intervention to promote uptake of retinal screening among young adults with type 2 diabetes - an intervention mapping approach) describes a mixed-methods study to develop an evidence-based intervention using Intervention Mapping as a development framework. It presents the needs assessment (summarising the literature review and above qualitative study and detailing the methods and findings of a national, online survey), which sought to identify modifiable determinants of retinal screening behaviour to be targeted in a subsequent individual-level retinal screening promotion intervention. It then goes on to describes the process of intervention development: involving a range of key stakeholders throughout the process; consolidation of needs assessment findings; development of logic models and
selection of modifiable behavioural determinants; development of theoretically-grounded intervention content using evidence-based processes; production of an engaging resource; comprehensive pilot and debriefing of the new resource; and, finally, plans for implementation and evaluation.

Chapter 5 (Paper 3: *What is the effect of a tailored leaflet intervention on diabetic retinopathy screening among young adults with type 2 diabetes? A randomised controlled trial*) describes the evaluation of the evidence-based intervention in terms of primary and secondary outcomes. Efforts to address recruitment and attrition challenges are discussed, and implications for future research, including the use of non-conventional evaluation designs are presented for the benefit of future researchers.

Finally, Chapter 6 (*Discussion*) presents an overview of key findings and discusses the contribution of this thesis to current knowledge, in relation to the literature reviewed in Chapter 2. The strengths and limitations of this program of research are discussed, and recommendations made for the future direction of research and clinical practice.
CHAPTER 1. Introduction

This chapter comprises six sections. The first section introduces type 2 diabetes (T2D), followed by section two which focusses on young adults with T2D (aged 18-39 years), who are the priority population in this program of PhD research. Section three introduces diabetic retinopathy (DR), with a focus on the vulnerability of young adults with T2D to early-onset and rapid progression of this common microvascular complication. Section four introduces retinal screening as a proven clinical pathway for early DR detection, presenting evidence of low uptake of retinal screening among young adults with T2D. Section five summarises the case for a tailored, psychosocial, retinal screening promotion intervention, followed by section six which presents a rationale for the program of PhD research.
1.1 Introducing Type 2 Diabetes

_Type 2 diabetes is projected to become the leading cause of disease burden by 2023._

Australian Institute of Health and Welfare, 2010

More than 415 million adults worldwide live with diabetes mellitus; a key focus of the World Health Organisation General Assembly on the prevention and control of non-communicable diseases (International Diabetes Federation, 2015; World Health Assembly, 2013). Characterised by high blood glucose levels (hyperglycaemia) and glucose intolerance, there are two main forms of this chronic condition. The first, Type 1 diabetes (T1D), is an auto-immune condition, characterised by the inability to produce insulin. T1D accounts for 7-12% of diabetes cases, about half of which are diagnosed in childhood / adolescence. The second form, known as type 2 diabetes (T2D), has both modifiable (e.g. obesity) and non-modifiable risk factors (e.g. ethnicity, age), and is characterised by insulin resistance and deficiency. More often diagnosed in adults over the age of 45 years, T2D accounts for 87-91% of diabetes. Other forms of diabetes, such as gestational (diagnosed during and limited to pregnancy), account for 1-3% of diabetes diagnoses (American Diabetes Association, 2014; Ogurtsova et al., 2017).

Persistent hyperglycaemia can lead to both macrovascular (large blood vessel) and microvascular (small blood vessel) complications. The former include stroke, coronary and peripheral artery disease, while the latter includes nephropathy (kidney damage, which can lead to kidney failure), neuropathy (nerve damage, which can lead to amputation) and retinopathy (retinal damage, which can lead to vision loss). A key aim of diabetes self-management is to
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prevent or delay development of diabetes-related complications, and is achieved primarily via achieving and maintaining glycaemic targets, and other risk factors. Diabetes self-management activities include daily blood glucose testing, following a healthy diet, engaging in regular physical activity, daily foot examinations and pharmacological management (such as daily tablets or insulin injections as prescribed to help manage blood glucose levels). Other self-management behaviours which confer health benefits and protect the individual from risk or progression of diabetes complications include weight management and smoking cessation.

Diabetes self-management is underpinned by coordinated and collaborative care from multiple health providers, and periodic screening examinations, such as those conducted for the early detection of eye and foot complications (Victorian Government Department of Human Services, 2007). However, diabetes self-management behaviours can be onerous and unremitting, and an individual’s decision to initiate or maintain them is influenced by many factors including: degree of personal engagement and motivation, level of healthcare support and access, individual, familial, social and cultural factors (Crosby, Kegler, & DiClemente, 2002).

1.1.1 Prevalence of diabetes. Diabetes prevalence has been increasing in recent years, driven by increasing incidence of T2D and closely linked to an ageing population and rise in obesity (Jaacks, Siegel, Gujral, & Narayan, 2016; Mokdad et al., 2000; Ng et al., 2014). Currently 9% of the world’s population (415 million) live with diabetes worldwide; projected to rise to 10% (642 million) by 2040 (Ogurtsova et al., 2017). There are 1.25 million Australians living with
diagnosed diabetes (5% of the population), with T2D representing 86% of all cases (National Diabetes Services Scheme, 2017); in line with global estimates, this proportion is predicted to increase to 10% by 2025 (Magliano et al., 2009).

1.1.2 The economic and psychosocial burden of diabetes. Given the role of diabetes in the development of micro- and macrovascular complications, the condition is a major cause of morbidity and mortality (Leung, Pollack, Colditz, & Chang, 2015; Tancredi et al., 2015) and a source of considerable burden on individuals, their families and the health system worldwide (Huo et al., 2016).

The economic impact of diabetes treatment and related complications is significant, with a recent systematic review estimating 12% (US$673 billion) of all global health expenditure is dedicated to diabetes (International Diabetes Federation, 2015); this is already disproportionate to the prevalence of the condition, and is projected to increase to US$802 billion by 2040 (Ogurtsova, 2017). In Australia, the total annual cost of diabetes treatment was estimated to be $14.6 billion in 2010 with per-person healthcare costs reported to be 2.5 times higher for those with diabetes-related complications versus those without (Lee et al., 2013).

The major proportion of economic cost of diabetes is accounted for by T2D, and includes carer costs and lost workforce productivity, as people with diabetes who are of working-age lose their place in the workforce or retire early (Australian Institute of Health and Welfare, 2013). For example, a recent systematic review of 23 studies, reported that the number of days lost per annum to absenteeism were 5.4-18.1 for an employee with T2D, compared to
3.4-8.7 for an employee without (Breton et al., 2013), increasing the risk of social isolation and economic deprivation (Egede, 2004).

In addition to the economic cost, the psychological burden of managing diabetes is considerable (Young-Hyman & Peyrot, 2012). People living with T2D are twice as likely as those without diabetes to experience depressive symptoms (Ali, Stone, Peters, Davies, & Khunti, 2006), which have been associated with impaired self-management and health behaviours, such as less physical activity, unhealthy diet, not taking medication as prescribed, and smoking (Lin et al., 2004). Further, over one-third (36%) of people with T2D live with diabetes-specific emotional distress (‘diabetes distress’); which includes a range of emotions such as feeling overwhelmed by diabetes management, and fear of diabetes-related complications, the most common being that of vision loss and blindness (Cavan et al., 2017; Perrin, Davies, Robertson, Snoek, & Khunti, 2017; Strain et al., 2014).

Psychological stressors such as depression and diabetes distress are negatively associated with glycaemic outcomes, self-management activities, risk of complications and mortality (Ahola & Groop, 2013; Egede, Ellis, & Grubaugh, 2009; Gonzalez et al., 2008). Furthermore, emerging research has established that people with T2D perceive diabetes-related stigma and judgement from others, which may be negatively associated with psychological well-being, glycaemic outcomes, perceived social support and participation in diabetes self-management education programs (Browne, Ventura, Mosely, & Speight, 2013b; Schabert, Browne, Mosely, & Speight, 2013; Winkley et al., 2015).
1.2 Introducing Young Adults with Type 2 Diabetes

_The principal concern with diabetes diagnosed at a young age is the development of complications at an earlier stage of life._

Song, 2015

Although improved awareness and treatment of T2D have seen declining rates of diabetes-related complications in developed countries (Gregg et al., 2014), the sheer number of people developing the condition, and changes in risk profile, led K.M. Venkat Narayan, an internationally recognised leader in diabetes research, to claim that policy makers are “winning the battle, but losing the war” (Narayan, 2016, p.653). One of the concerns raised by this and other recent landmark papers is the increasing incidence and burgeoning public health burden of younger-onset T2D (i.e. diagnosis <40 years of age; Dabelea et al., 2017; Jaacks et al., 2016; Mayer-Davis et al., 2017; Nadeau et al., 2016; Viner, White, & Christie, 2017; Yeung et al., 2014; Zimmet, Magliano, Herman, & Shaw, 2014).

Average age at diagnosis for most of those who develop younger-onset T2D is 25-35 years, dependent upon country of origin, (Al-Saeed et al., 2016; Li et al., 2015; Sosale et al., 2016; Yeung et al., 2014). Young adults with T2D (aged 18-39 years) are the priority population in this program of PhD research, and have a number of unique clinical and demographic characteristics. These include: long diabetes duration; a severe, progressive phenotype (Viner et al., 2017); greater likelihood of family history of T2D (Benhalima et al., 2011b; Browne, Scibilia, & Speight, 2013a); higher rates of obesity and other health comorbidities (Browne et al., 2013a; Paul et al., 2017); lower rates of clinically therapeutic treatment (Al-Saeed et al., 2016; Wong, Constantino, & Yue, 2015), and greater
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ethnic diversity than the general T2D population (Chen, Magliano, & Zimmet, 2012; Paul et al., 2017).

Both incidence and severity of diabetes-related complications are greater for young adults with T2D in comparison to similar-age adults with T1D and older adults with T2D (aged 40+ years), reducing quality and quantity of life (Constantino et al., 2013; Dabelea et al., 2017; Gregg, Sattar, & Ali, 2016; Harding, Shaw, Peeters, Davidson, & Magliano, 2016; Luk et al., 2014; Song, 2012; Wong et al., 2015). Higher overall mortality rates for young adults with T2D have been confirmed in an Australian context by Wong and colleagues who reported double the mortality risk when compared with their age of onset-matched T1D peers, and an average 15 years lower age at death when compared to those with older-onset T2D (Al-Saeed et al., 2016; Constantino et al., 2013).

1.2.1 Prevalence of younger-onset type 2 diabetes and data limitations in an Australian context. Globally, there is an increasing trend of obesity and decrease in the age of T2D diagnosis (Chen et al., 2012; Jaacks et al., 2016). Prevalence data for younger-onset T2D has typically focussed on paediatric and adolescent populations (Dabelea et al., 2014), with a recent systematic review reporting that, dependent upon study population, geographic region and ethnicity, prevalence rates for T2D in children and adolescents range from 0 - 5,300 per 100,000 population (Fazeli Farsani, van der Aa, van der Vorst, Knibbe, & de Boer, 2013). In Australia, prevalence of T2D for young adults is reported at 3% of the overall Australian T2D population, representing more than 35,000 registrants on Australia’s National Diabetes
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Services Scheme (NDSS, 2017). In contrast to global trends, a recent Australian Institute of Health and Welfare working paper on T2D in Australia’s children and young people (2014) reported no evidence of an increase in incidence of younger-onset T2D, but cautioned that the data, which are derived from a range of sources but predominantly from the NDSS, should be interpreted with caution and are likely to be an underestimate due to data source limitations. In contrast, 12-year follow-up data from the Australian Diabetes, Obesity and Lifestyle study, a longitudinal population based study of over 11,000 adults (Tanamas et al., 2012), provides evidence of a potential increase in incidence of younger-onset T2D in Australia. The study reported that younger people (aged 25-34), gained more weight than any other age group, and that people who were overweight or obese in the study were 2-5 times more likely to have diabetes. An important limitation of Australian data on incidence and prevalence of younger-onset T2D, is that NDSS registration is not compulsory. Health professionals typically register people to enable them to access subsidised products. As young adults with T2D are less likely to use insulin or take insulin injections as recommended (Browne, Nefs, Pouwer, & Speight, 2014; Browne et al., 2013a), benefits of registration may not be apparent. Further, with the relatively recent restriction of access to subsidised glucose monitoring supplies for those with non-insulin-treated T2D

1 The NDSS is an initiative of the Australian Government, administered with the assistance of Diabetes Australia. The NDSS provides subsidised access to products (e.g. syringes needles, blood glucose test strips, insulin pump consumables) and a range of free services (e.g. information, education and advice) to registrants.
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(July 2016), this situation is likely to perpetuate and there is the very real possibility that Australian T2D prevalence data may become increasingly inaccurate over time. Nonetheless, with 86% of Australians with T2D having registered with the NDSS, the service remains the “best available” source to monitor young Australian adults with T2D (Australian Institute of Health and Welfare, 2014).

1.2.2 Barriers to optimal self-management and glycaemic control faced by young adults with type 2 diabetes. Optimal diabetes self-management and glycaemic control are cornerstones in reducing risk of development, or progression, of diabetes-related complications and consequent poor health outcomes. Known clinical and psychosocial barriers to optimal diabetes self-management for young adults with T2D are presented below.

1.2.2.1 Clinical barriers. Clinical barriers include: high rates of physical comorbidity, such as obesity, high blood pressure (hypertension) and high blood cholesterol (hyperlipidaemia) (Browne et al., 2013a; Chowdhury & Lasker, 2002; Koelmeyer, Dharmage, & English, 2016; Sillars, Davis, Kamber, & Davis, 2010); delay in diagnosis of T2D, estimated at twice that of their T1D counterparts (Crume et al., 2016), and misdiagnosis, due to the clinical complexity of younger-onset T2D (Australian Institute of Health and Welfare, 2014; Song, 2012).

Sub-optimal glycemic outcome is characteristic of young adults with T2D, irrespective of country (Benhalima et al., 2011b; Deconinck, Mathieu, & Benhalima, 2017; Hsieh et al., 2014; Quah, Liu, Luo, How, & Tay, 2013; Song & Hardisty, 2007, 2009; Wilmot et al., 2013). Unique barriers faced by young adults with T2D include: emerging adulthood and learning to navigate the health
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system (Amutha et al., 2017), and lack of intensive therapeutic management by clinicians in accordance with evidence-based guidelines, known as clinical inertia (Al-Saeed et al., 2016; Amed et al., 2014; Benhalima et al., 2011a; Constantino et al., 2013; Gregg et al., 2016; Rosenberg, Friedman, & Gurland, 2011; Song, 2012).

For women, T2D during pregnancy provides an additional diabetes self-management challenge and has been associated with poor outcomes for both the mother and baby. For example, T2D during pregnancy has been associated with increased risk of miscarriage or stillbirth, exacerbation of diabetic retinopathy, and a two-fold increase in risk of congenital abnormality (DCCT Research Group, 2000; Errera, Kohly, & da Cruz, 2013; Klingensmith et al., 2016; Singh, Murphy, Hendrieckx, Ritterband, & Speight, 2013; Song, 2012).

1.2.2 Psychosocial barriers. Psychosocial factors play an integral role in diabetes self-management behaviour (Bennett, Conner, & Godin, 2004; Graffigna, Barello, Libreri, & Bosio, 2014; Nam, Chesla, Stotts, Kroon, & Janson, 2011; Skinner et al., 2014). Young adults with T2D face a range of psychosocial barriers, all of which negatively affect optimal diabetes management and have the potential to translate into disengagement with services and loss to medical follow-up (Pyatak, Sequeira, Peters, Montoya, & Weigensberg, 2013).

Compared to their older T2D counterparts, young adults with T2D are characterised by higher levels of diabetes distress and depression (Browne et al., 2013a), lower diabetes self-efficacy (Hessler, Fisher, Mullan, Glasgow, & Masharani, 2011) and impaired quality of life (Sillars et al., 2010). Young adults with T2D report feeling shame and negative judgement for having a condition usually associated with older adulthood (Browne et al., 2013a; Browne et al.,
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2013b), preferring not to disclose their condition, impeding their ability to communicate with, and connect to, important support networks (Auslander, Sterzing, Zayas, & White, 2010; Brouwer et al., 2012).

Young adults with T2D also face unique, stage of life barriers such as work and study commitments, separation from parental care, disrupted routine, lack of time, age-related optimistic bias and perceptions of invulnerability (Arnett, 2000; Australian Institute of Health and Welfare, 2014; Diabetes Australia, 2006; Johnson, Scott-Sheldon, & Carey, 2010; Lapsley & Hill, 2010; Waitzfelder et al., 2011). Identifying obesity as their most important health issue (Nguyen et al., 2014), young adults with T2D are characterised by lack of diabetes-related clinical complications, which typically manifest themselves after 10 years duration, (Dart et al., 2014), reducing the perceived imperative for diabetes self-care.

In an Australian context, the top diabetes self-management barriers cited by young adults with T2D are: lack of motivation or feeling ‘burned out’, lack of time, work/study commitments, denial of diabetes, fear of complications, dissatisfaction and disengagement with existing diabetes education and support services (which they see as catering for older adults), embarrassment about diabetes diagnosis, and lack of support (Browne et al., 2013a; Diabetes Australia, 2006). Importantly for this program of PhD research, psychosocial factors are considered the “most important” barriers for those with younger-onset T2D (McGavock, Dart, & Wicklow, 2015) and many are amenable to change.
1.3 Introducing Diabetic Retinopathy

In patients with type 2 diabetes...duration of diabetes is independently associated with microvascular events and this effect is greater in the younger patients. Zoungas et al, 2014

With increasing prevalence of T2D comes a concomitant increase in diabetes-related complications, the most common of which is diabetic retinopathy (DR, Dirani, 2013; Nentwich & Ulbig, 2015; Sivaprasad, Gupta, Crosby-Nwaobi, & Evans, 2012). Currently, the fifth most common cause of blindness worldwide, and the leading cause of vision loss in working-age adults (Flaxman et al., 2017; Leasher et al., 2016) the condition has significant economic, psychosocial and public health implications (Access Economics, 2004; Fenwick et al., 2012; Rees, Saw, Lamoureux, & Keeffe, 2007; Ting, Cheung, & Wong, 2016).

At its simplest, DR can be classified as having two stages: an asymptomatic, early stage known as ‘background’ or non-proliferative DR (NPDR), which can progress to ‘proliferative’ or vision-threatening retinopathy (VTDR). In the NPDR stage, chronic hyperglycaemia can damage the tiny blood vessels in the retina resulting in bleeding and leakage of fluids, usually without any visual symptoms. In the second, VTDR stage, new blood vessels form on the surface of the retina and further haemorrhage occurs. The most common manifestation of VTDR is known as diabetic macular oedema; vision changes are experienced by the person with diabetes as blurriness, floaters or spots and inability to see central detail, increasing in severity to vision loss or blindness (Fowler, 2008; Stone, Ryan, & Sinclair, 2012).
1.3.1 Prevalence of diabetic retinopathy and major risk factors.

1.3.1.1 General population. Current global prevalence estimates suggest that approximately 30-40% of people with T2D have DR, with rates varying from 10-61% dependent upon country and ethnic group (Cheung, 2010; International Diabetes Federation, 2015; Ruta et al., 2013; Yau et al., 2012).

Development of DR is closely linked to three key risk factors: diabetes duration, blood glucose and blood pressure. As evidence of the importance of the above three factors, prevalence of DR was mapped to each in a recent meta-analysis of pooled data across 35 population-based studies, with a total sample of N=22,896 (Yau et al., 2012). The authors reported that greater prevalence of DR was associated with increased HbA1c (18% vs 51% for <7% vs >9%), and increased blood pressure (31% vs 40% for ≤140/90 vs >140/90), and increased diabetes duration (21% vs 76% for <10 vs ≥20 years).

In Australia, National Health and Medical Research Council guidelines for the management of DR recommend tight management of the two key modifiable risk factors: blood glucose (target HbA1c <7% or <53mmol/mol)\(^2\) and blood pressure (target systolic blood pressure <130mmHg), (Mitchell & Foran, 2008). Duration of diabetes, a non-modifiable risk factor, has the greatest influence beyond 10 years, with DR prevalence estimated to increase to 60% and 90% at 20 and 25 years, respectively (Bhavsar, 2002; Klein, Klein, Moss, Davis, & DeMets, 1984; Wong et al., 2009).

\(^2\) HbA1c, or glycated haemoglobin is an indicator of an individual’s average blood glucose levels during the past 90-120 days.
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Finally, other modifiable behavioural and psychosocial factors linked with development or progression of DR include depression (Nguyen et al., 2010), obesity, alcohol and tobacco use (Kohner et al., 1998; Tyrberg et al., 2017).

1.3.1.2 Young adults with type 2 diabetes. Diabetic retinopathy confers a 20% lifetime risk of blindness for those who develop T2D before 24 years of age (Zimmet et al., 2014), and is the leading cause of blindness in working-age adults (Yau et al., 2012). There is a lack of diabetes-related research on young adults with T2D in general, and this paucity of data extends to ophthalmic research.

A recent systematic review of 84 large, population-based eye studies reported that none specifically examined young adults, with most focussing on ocular conditions related to ageing (e.g. cataract, macular degeneration and glaucoma) and a substantial minority concentrating on paediatric eye conditions (Forward, Hewitt, & Mackey, 2012).

Yet, there is emerging evidence of age-specific changes in eye disease necessitating a shift in focus toward young adults with T2D. For example, a recent comparison of two cycles of United States (US) National Health and Nutrition Examination Survey data over two time periods (1999-2002 & 2005-2008, N=10,489, aged 20+ years) revealed that the prevalence of non-refractive visual impairment over time increased by 21% (1.4% to 1.7%, $p<0.05$), with the greatest change noted in young adults (20-39 years, from 0.6% to 1.0%). Noting that prevalence of diabetes significantly increased over the same time period, the authors concluded that T2D was a likely contributor to non-refractive visual impairment among younger adults (Ko et al., 2012).
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In a reflection of the nascent stage of research on young adults with T2D, population-level prevalence of DR at diagnosis is difficult to determine for those newly diagnosed with T2D, and existing studies often focus on clinical populations (Chowdhury & Lasker, 2002). The existence of high quality medical record data has allowed for ascertainment of DR prevalence for young adults with T2D at 10 year’s duration, where it is largely equivalent to the general population rates reported in a review by Yau et al (34.6%, 2012). For example, a recent analysis of data for 354 Australian adults who had been diagnosed with younger-onset T2D (average age 40 years, average duration 12 years) reported prevalence of any DR at 37% (Constantino et al., 2013).

Unfortunately however, prevalence and severity of DR increases for young adults with T2D from 10 years duration, impacting affected individuals during their busiest and most productive years. For example, Song and Gray (2011), in their recent survey of a UK hospital diabetes register and retinal screening database (N=2,061), reported significantly higher progression to VTDR for the younger-onset T2D cohort (age <40 years) when compared to their older-onset T2D counterparts. Using 10 years duration of T2D as a reference point, the authors demonstrated a significant increase in VTDR at subsequent duration points of 10-20 years (67% vs 55%, p<0.05) and >20 years (84% vs 73%, p<0.05), concluding that the younger-onset T2D cohort were at risk of developing VTDR 20 years earlier than their later onset counterparts (Song & Gray, 2011).

In addition to vulnerability to the three principle DR risk factors noted above (long diabetes duration, suboptimal glycaemic outcomes and hypertension; Okudaira, Yokoyama, Otani, Uchigata, & Iwamoto, 2000; Song &
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Gray, 2011; Tikellis et al., 2008), young adults with T2D experience clustering of demographic, clinical, behavioural and psychosocial DR risk factors which may explain increased DR prevalence for this priority population.

Demographic risk factors which characterise young adults with T2D include: ethnicity, particularly South Asian which is associated with higher DR prevalence (Cheung, 2010; Raymond et al., 2009; Yau et al., 2012); early age of onset, where younger age is positively associated with higher prevalence of DR independent of duration (Cai et al., 2014; Klein R, 1984; Porta et al., 2001; Wong, Molyneaux, Constantino, Twigg, & Yue, 2008) and pregnancy, which is associated with accelerating the development of DR, particularly if other risk factors are present (DCCT Research Group, 2000; Errera et al., 2013; Klein, Moss, & Klein, 1990; Singh et al., 2013; Tarr, Kaul, Wolanska, Kohner, & Chibber, 2012).

Clinical risk factors that characterise young adults with T2D include: hyperlipidaemia, which has been linked to higher prevalence of diabetic macular oedema (Cheung, 2010; Unnikrishnan et al., 2017; Yau et al., 2012); delay in diabetes diagnosis, which can extend time to DR diagnosis (Song, 2012), and lack of aggressive clinical diabetes management, of crucial importance due to aggressive nature of younger-onset T2D (Song & Hardisty, 2010).

Behavioural and psychosocial DR risk factors which characterise the young adults with T2D priority population include: high rates of depression, which has been associated with retinal microvascular changes in young adults (Meier et al., 2014; Silverstein et al., 2015), and low uptake of retinal screening after diabetes diagnosis, which has been associated with higher rates of VTDR (Scanlon 2016).
1.3.2 The economic and psychosocial burden of diabetic retinopathy.

In economic terms, vision loss and blindness exert considerable stress at all levels, with a recent systematic review of 22 studies reporting that people with vision impairment bear almost twice the hospital and care-related expenses annually than those without (Koberlein, Belfus, Schaffert, & Finger, 2013). In an Australian context, economic costs related to vision disorders have been estimated at AUD$9.85 billion, placing vision impairment as the seventh most expensive disorder, ahead of coronary heart disease, diabetes and depression (Taylor, Pezzullo, & Keeffe, 2006). Importantly for this program of PhD research, a recent analysis of US econometric data by Wittenborn and colleagues (2013) reported that the earlier vision loss develops, the greater the cost burden, with more than one-third (US$27 billion) of the total cost of vision loss and eye disorders in the US applied to people aged under 40 years, including US$21.6 billion for young adults aged 18-39 years.

In addition to economic burden, DR has recently been confirmed as an independent risk factor for symptoms of depression (Rees et al., 2016), which has a negative impact on self-management, treatment concordance and glycaemic outcomes (Evans, Fletcher, & Wormald, 2007; Gonzalez et al., 2008; Horowitz, 2004; Rotella & Mannucci, 2013). Fenwick and colleagues summarised the impact of DR on health beliefs and quality of life factors, concluding that vision loss from DR has a negative impact on perceptions of diabetes, personal and romantic relationships, activities of daily living, social and emotional wellbeing, and employment (Fenwick et al., 2011; Fenwick et al., 2012; Rees et al., 2012).
1.4 Introducing Retinal Screening for the Early Detection of Diabetic Retinopathy

The principal aim of diabetes management is to prevent complications and this is even more pertinent in early-onset subjects given the potential for longer disease duration and exposure to adverse risk factors.

Song and Hardisty, 2009

The purpose of screening is for the early detection of an abnormality in order gain a better health outcome than if the disease were diagnosed at a later stage (Cancer Council Australia, 2014). Retinal screening is an effective clinical pathway for the early detection of DR; risk of vision loss can be significantly reduced by timely and appropriate treatment thereafter (Agardh, Agardh, & Hansson-Lundblad, 1993; Arun, Ngugi, Lovelock, & Taylor, 2003). Retinal screening can be conducted via a range of (mostly non-invasive) methods including: direct ophthalmoscopy (examination of the back of the eye (fundus); slit-lamp bio microscopy (examination of the fundus using high-intensity light source in combination with a microscopy); retinal photography; and most recently, the introduction of remote assessment via tele-retinal and mobile retinal screening, which improves accessibility (Ting et al., 2016). Depending on the examination method, dilation drops (mydriasis) may or may not be needed to increase the field of view and examine the retina, optic nerve and associated blood vessels (Hutchinson et al., 2000). In Australia, retinal screening is usually conducted by an optometrist, takes about 40 minutes, and is either free or costs approximately AUD$35 (dependent upon the billing model of the provider).

Recommended retinal screening intervals vary by country, but in Australia, the National Health and Medical Research Council evidence-based
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guidelines for the management of DR recommend screening uptake at diabetes diagnosis, followed by a minimum of every two years thereafter (Mitchell & Foran, 2008). This interval is less frequent than that prescribed for adults with T2D in the UK and US, (American Diabetes Association, 2017; National Institute for health and Care Excellence, 2015).

If DR is detected, timely treatment thereafter, can prevent up to 98% of DR-related vision loss (Ferris, 1993), dependent upon the stage of the condition (Bloomgarden, 2007). For example, the NPDR stage of the condition is often monitored by an ophthalmologist via more regular retinal screening, whereas the VTDR stage often involves laser photocoagulation (where laser burns arrest progression of blood or fluid leakage) or more serious haemorrhage treated with surgery (Tarr et al., 2012).

Although the primary benefit of retinal screening is early detection of asymptomatic DR, early and regular retinal screening also confer a multitude of secondary benefits. For example, a recent systematic review of economic evidence reported that regular screening was effective in terms of years of sight preserved (Jones & Edwards, 2010). Importantly for this program of PhD research, a second, earlier review noted that retinal screening was most cost-effective for the youngest age T2D cohort (<35 years), who have the potential to gain the most quality adjusted life years (Raikou & McGuire, 2003). Recent meta-analyses have confirmed that presence of DR is likely to provide early indication of presence of other diabetes complications such as renal and cardiovascular disease (He, Xia, Wu, Yu, & Huang, 2013; Zhu et al., 2017), both of which are high risk for young adults with T2D (Constantino et al., 2013). Finally, retinal
screening provides opportunity for eye health professionals to educate and motivate patients, with the potential to improving glycaemic outcomes and moderating concern about DR (Rees et al., 2013).

1.4.1 Rates of retinal screening.

1.4.1.1 General population. Retinal screening rates have increased in developed countries over the past two decades due to coordinated initiatives and improvements in technology, which have increased both awareness of the condition and screening accessibility (Wong et al., 2009). For example, in the UK, retinal screening rates two decades ago were less than 50% (National Health Service, 2014). However, following introduction of a national program, rates have risen to 83% (Scanlon, 2017), with DR no longer the leading cause of vision loss in UK working-age adults (Liew, Michaelides, & Bunce, 2014).

Recent findings from the Diabetic Retinopathy Barometer Study, a large-scale survey of 4,340 adults with diabetes, and 2,329 health professionals from 41 countries, provide insight into global trends, with the authors reporting that 79% of adult respondents had screened at least once for DR since being diagnosed with diabetes (Cavan et al., 2017). In an Australian context, general diabetes population retinal screening rates have risen from a median of 48% at the turn of the century (Tapp, Svoboda, Fredericks, Jackson, & Taylor, 2015) to 78% (Foreman et al., 2017), primarily as the result of retinal photography-based DR screening programs and awareness-raising initiatives (Lee et al., 2000; Tapp et al., 2015).

However, high average retinal screening rates conceal pockets of low uptake, with considerable negative impact, as delays in, or non-attendance of,
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eye examinations increase the risk of VTDR when screening is finally initiated (Forster et al., 2013). Demographic groups at risk of low retinal screening include young people with diabetes aged less than 40 years (Moreton, Stratton, Chave, Lipinski, & Scanlon, 2017), Indigenous and minority ethnic groups (Anderson et al., 2003; Tapp et al., 2015).

1.4.1.2 Young adults with type 2 diabetes. Younger age of onset of diabetes is an independent risk factor for uptake of retinal screening, irrespective of country and healthcare system (Bylsma, Le, Mukesh, Taylor, & McCarty, 2004; Gulliford et al., 2010; MacLennan, McGwin, Heckemeyer, & et al., 2014; Owens et al., 2008; Sachdeva, Stratton, Unwin, Moreton, & Scanlon, 2012; Scanlon et al., 2016; Villarroel, Vahratian, & Ward, 2015). This was illustrated in a recent analysis of UK retinal screening programs (N=689,025, Scanlon et al., 2016) which demonstrated that young adults aged 18-34 took the longest time to reach the goal of 80% retinal screening coverage (2 years and 9 months after registration). Further, the authors demonstrated that time from diabetes diagnosis to retinal screening was a significant predictor of DR severity, with those who delayed screening beyond three years four times more likely to have VTDR when they did screen.

Despite the growing incidence of younger-onset T2D and sub-optimal clinical outcomes this group, there is a lack of focussed research examining rates and correlates of retinal screening. As a case in point, Australia’s first National Eye Health Survey which was completed in 2016, excluded all adults with diabetes aged less than 40 years (Foreman et al., 2016), despite prior research suggesting lower retinal screening rates for young adults with T2D. For example,
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A small survey of young Australian adults with T2D (N=49) revealed lower retinal screening rates, when compared to general population, during an equivalent reporting period (55% vs 77% respectively; Diabetes Australia, 2006; Tapp et al., 2004). Absence of contemporary population-level data on retinal screening rates and prevalence of DR for young Australian adults with T2D increases the risk that the needs of this priority population will be neglected in future policy initiatives (Lake, Browne, & Speight, 2018).

It is difficult to report retinal screening rates for young adults with T2D, as data are often specific to ethnic groups, or combine data for young adults with T2D, with their T1D counterparts (Katulanda et al., 2014; MacLennan et al., 2014; Millett & Dodhia, 2006; Orton, Forbes-Haley, Tunbridge, & Cohen, 2013). However, two recent studies from the US and UK confirm that retinal screening rates for youth/young adults with T2D remain below those of their similar aged T1D counterparts and the general diabetes population.

In the US, a comparison of 12,686 youth/young adults aged ≤21 years (57%, n=7,233 T2D) with health insurance (a screening enabler, Jiang et al., 2017) reported that only 42% of those with T2D had screened for DR in the six years since diabetes diagnosis, compared with 65% of their T1D counterparts (Wang et al., 2017). Further, a UK-based analysis of 21,797 people with diabetes (aged ≥12 years, diabetes type not specified), reported an overall retinal screening rate of 82.4%. However, once stratified by age, uptake was significantly lower in the 12-39 year age group (66.6%) than for any other age group (Moreton et al., 2017).
1.5 The Case for Psychosocial Intervention to Promote Retinal Screening for Young Adults with Type 2 Diabetes

Eye complications have a high prevalence in younger-onset type 2 diabetes. Evidence-based behavioural intervention is still lacking in this group and it is one of the most challenging aspects of medicine in my experience.

Song, 2015, personal communication

Globally, public health advocates and policy makers have acknowledged the clinical and psychosocial challenges faced by young adults with T2D. In the absence of suitable existing retinal screening programs (see Chapter 2 for more detail), there is a growing body of literature calling for development of age-appropriate, culturally and contextually sensitive interventions designed to improve diabetes self-management for this priority population (Browne et al., 2014; Delamater et al., 2001; Dunning & Savage, 2013; MacLennan et al., 2014; Marrero et al., 2013; Nadeau et al., 2016; Thanabalasingham & Owen, 2014; Wilmot & Idris, 2014).

Recommendations include: targeted and aggressive clinical management; tailored service delivery, with an early intervention focus; and psychosocial and educational intervention, to assist with health behaviour change (Amed et al., 2014; Quah et al., 2013; Song, 2014; Turner et al., 2015; Twigg & Wong, 2015; Viner et al., 2017; Wilmot & Idris, 2014; Zhang & Ning, 2014). More specifically, recommendations focusing on promoting retinal screening for young adults with T2D argue that in addition to improving knowledge, efforts should be tailored to the priority population and focus on increasing perception of personal risk, and motivation to screen (Leese, Boyle, Feng, Emslie-Smith, & Ellis, 2008; MacLennan et al., 2014; Millett & Dodhia, 2006; Sachdeva et al., 2012; Scanlon et
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al., 2016). These recommendations respond to earlier research which established that many of the barriers to optimal diabetes self-management for young adults with T2D are psychosocial in origin (Diabetes Australia, 2006; McGavock et al., 2015).

To achieve desired health behaviour for a priority population, best-practice interventions deliver psycho-educational and motivational messages which are comprised of theory-based behaviour change techniques (Michie et al., 2013), and which target previously identified behavioural determinants (Michie & Abraham, 2004). Therefore, before any tailored retinal screening interventions can be developed, a clear understanding of the priority population and the factors associated with retinal screening is required.

A range of factors are attributed to optimal diabetes self-management, including knowledge, attitudes, beliefs, social support, cultural and contextual factors, health literacy and health comorbidities (Nam et al., 2011). Despite evidence of the unique clinical and psychosocial characteristics of young adults with T2D, and the challenges faced by emerging adults with regard to diabetes self-management, prior exploration of barriers, facilitators and determinants to this activity have typically been on paediatric T2D (Hanman et al., 2014; St. George et al., 2017) or adults with T2D aged over 40 years (Duckworth et al., 2009; Miller, Pawelczyk, Cheavens, Fujita, & Moss, 2017). This, taken in combination with paucity of research on factors impacting retinal screening for young adults with T2D, highlights a considerable gap in the literature and an imperative for the proposed program of PhD research.
1.6 Conclusion and Objectives

Lower uptake rates for DR screening among younger people ... represent lost opportunity in limiting the progression of DR ...
Those individuals who are least likely to attend diabetic retinopathy screening appointments are those who are at highest risk of developing DR.

Sachdeva et al, 2012

In conclusion, young adults (aged 18-39 years) with T2D are increasing in prevalence worldwide and have distinct clinical and psychosocial needs and characteristics when compared to their older-onset T2D, or age-equivalent T1D counterparts. Younger-onset T2D is an independent risk factor for development of DR. As such, it is crucial to ensure early uptake of retinal screening, the proven clinical pathway to early DR detection and, therefore, prevention of vision loss. Younger age however, is also an independent risk factor for low retinal screening uptake, and young adults with T2D are less likely to screen for DR in a timely fashion post-diabetes diagnosis.

Educational and psychosocial intervention is a recommended pathway to promotion of retinal screening uptake for young adults with T2D. However, there is a paucity of foundation-level data upon which to develop a retinal screening for this under-researched group. Thus, the overall aim of this program of PhD research is to develop a public health intervention to promote uptake of retinal screening among young adults with T2D. The objectives of this research are to:

• identify modifiable factors impacting retinal screening behaviour among young adults with type 2 diabetes
• develop an individual-level, theoretically-grounded, psycho-educational retinal screening promotion intervention, tailored to young adults with T2D
• evaluate the effectiveness of the intervention in increasing self-reported uptake of retinal screening and improving modifiable behavioural determinants

Preferred modes of receiving diabetes self-management education materials targeting young adults with T2D have been explored and include print, web-based and telephone-based options (Dunning & Savage, 2013). However, reaching young adults with T2D in an Australian context is challenging, due to absence of a nationally coordinated retinal screening database and lack of dedicated services or hubs by which to contact this priority population (Australian Institute of Health and Welfare, 2014; Vision 2020 Australia, 2017). Chapter 2 (Literature Review) outlines the predetermined, real-world parameters impacting the current program of PhD research, and the pragmatic solutions to the challenges associated with promoting retinal screening for young adults with T2D.
1.7 References


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Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

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CHAPTER 2. Literature review

This chapter comprises five sections. The first section provides context, positioning this program of PhD research within broader vision and retinal screening promotion initiatives conducted nationally and internationally. The second section summarises current literature on the barriers and facilitators impacting retinal screening behaviour, with emphasis on modifiable, psychosocial factors known to impact young adults with type 2 diabetes (T2D). The third section reviews previous interventions to promote screening for diabetic retinopathy (DR), with an emphasis on those that were conducted within the predetermined parameters of this program of PhD research (i.e. print-based, individual-level). The fourth section discusses evidence-based intervention design, with emphasis on a ‘best practice’ framework (Intervention Mapping, IM), and other theoretically-grounded models. The fifth section concludes with direction for this program of PhD research.
2.1 Context of this Program of PhD Research

Two large-scale and far-reaching initiatives have influenced the direction and scope of this program of PhD research and literature review.

2.1.1 Vision 2020 – The Right to Sight. In response to projected global increase in blindness and visual impairment, the World Health Organisation and partner organisations launched the ‘Vision 2020 – The Right to Sight’ initiative in 1999, with the aim of eliminating avoidable blindness by 2020. In Australia, the federal government supported this initiative with a National Framework for Action to promote Eye Health and Prevent Avoidable Blindness and Vision Loss (Commonwealth of Australia, 2005). In Victoria, the state government’s public health response was the ‘Vision Initiative’, coordinated by Vision 2020 Australia. Vision Initiative activities were multi-focussed, conducted concurrently at the patient/population, provider/practice and healthcare system levels within four pre-specified Victorian local government areas (LGAs), during the period November 2012 – June 2015. Activities included targeted population and health practitioner eye health campaigns; health workforce education; improvement of referral pathways for vision and rehabilitation services, and development of sustainable partnerships with Victorian eye health and vision care providers.

The program of PhD research described in this thesis was funded by Vision 2020 Australia and was a designated Vision Initiative activity. Conducted in a real-world setting as one of a broader suite of initiatives, many study components were predetermined, including intervention focus, eligibility criteria, timeline, intervention format, and delivery medium. Contractual obligations required that the resource be targeted at the individual-level (intervention
focus), be delivered to young adult National Diabetes Services Scheme (NDSS) registrants with T2D who had not previously screened (eligibility criteria) by June 2015 (timeline: 2 years and 7 months). As the NDSS database primarily records registrant postal addresses, the intervention was, by necessity, print-based (intervention format) in a size that could be posted to participants at their street address (delivery medium: leaflet/brochure size).

Importantly for this program of PhD research, the potentially confounding effect of concurrent, multi-focussed eye health initiatives on evaluation outcomes was identified and addressed early, minimising risk of bias. The development and evaluation components of this program of PhD research were conducted nationwide, with residents from the four target Vision Initiative LGAs (who had been exposed to concurrent Vision Initiative activities) excluded from study involvement. Thus, although the study was part of a multicomponent program of eye health awareness raising activities, the intervention was developed and evaluated in a geographically separate location and, as such, this program of PhD research can be considered single-focus, targeted at the patient/population level. Importantly, residents of the four target LGAs were not excluded from receiving the leaflet post-evaluation, as it was distributed state-wide to all eligible NDSS registrants in a mail out timed to coincide with the culmination of Vision Initiative activities in July 2015.
2.1.2 **UK National Institute for Health Research WIDER-EyeS program.**

The National Institute for Health Research (NIHR) commissions research focused on improving health and social care to improve outcomes and reduce costs within the UK National Health Service. In 2015, the NIHR commissioned an evidence synthesis project titled *What Works to Increase Attendance for Diabetic Retinopathy Screening? An Evidence Synthesis (WIDER-EyeS)* (National Institute for Health Research, 2015), with an anticipated completion date of March 2018. The three-phase program of research, which is ongoing, includes:

1. Systematic review of the effectiveness of interventions to increase attendance for retinal screening (Lawrenson et al., 2016).
2. Systematic review of barriers and enablers to DR screening attendance (Graham-Rowe et al., 2016).
3. Integration of findings and development of recommendations regarding the use of specific evidence and theory-based intervention components for future DR screening interventions.
2.2 Factors Impacting Retinal Screening Behaviour

Identifying the expectations, reservations, and barriers of those who underutilize eye care services will help us to understand the needs of this population and better serve them.

Elam & Lee, 2013

Despite clear health and economic benefits, substantial numbers of people with diabetes do not screen for DR (Foreman et al., 2017; Scanlon et al., 2016). Factors impacting retinal screening exist at the patient, provider and system level (Elam & Lee, 2013; Nsiah-Kumi, Ortmeier, & Brown, 2009). A number of studies have used in-depth interviews or focus groups to explore factors at an individual-level (i.e. experiences and practices for the general diabetes population). However, the average age, where reported, is 60 years, offering little insight into the barriers experienced by young adults (Al-Alawi, Al-Hassan, Chauhan, Al-Futais, & Khandekar, 2016; Ellish, Royak-Schaler, Passmore, & Higginbotham, 2007; Hartnett, Key, Loyacano, Horswell, & DeSalvo, 2005; Hipwell et al., 2014; John, Cooper, & Serrant-Green, 2014; Lewis, Patel, Yorston, & Charteris, 2007).

A systematic review of barriers and facilitators to DR screening attendance is underway (Graham-Rowe et al., 2016). In a reflection of advances in behaviour change theory, the authors aim to classify the identified determinants into 14 theoretical ‘domains’ from the Theoretical Domains Framework (Cane, O’Connor, & Michie, 2012). A review of the literature, focusing on factors impacting screening behaviour was conducted in 2013 by the author, and maintained for the duration of the program of PhD research (see Section 4.8.1 for details and findings). In brief, there are currently no published
studies specifically investigating factors impacting retinal screening for young adults with T2D, although one in-depth, qualitative study explored barriers to eye examinations among young adults (aged 18-35 years) in the general population (Shickle et al., 2014).

More broadly, a range of environmental, systemic, demographic, clinical, and psychosocial factors which impact retinal screening behaviour for the general adult diabetes population have been identified. Given the context for this program of PhD research, those factors that cannot be influenced by the proposed intervention (i.e. information leaflet for young adults with T2D) are not included in this review. These include the environmental, systemic and demographic factors.

Examples of environmental retinal screening barriers include lack of transport and remote location/lack of access (Al-Alawi et al., 2016; Gibson, 2014; Kovarik et al., 2016; Lee et al., 2014). Systemic retinal screening barriers include practice management issues including miscommunication/outdated contact details (Lindenmeyer et al., 2014; Strutton, Du Chemin, Stratton, & Forster, 2016), or poorly constructed care pathways (Cavan et al., 2017). Demographic factors negatively impacting retinal screening behaviour which are not included in this review include: younger age (Khan, 2010; Leese, Boyle, Feng, Emslie-Smith, & Ellis, 2008; Maberley, Koushik, & Cruess, 2002; Millett & Dodhia, 2006; Orton, Forbes-Haley, Tunbridge, & Cohen, 2013; Sachdeva, Stratton, Unwin, Moreton, & Scanlon, 2012); socioeconomic status/social deprivation (Brechner et al., 1993; Hwang, Rudnisky, Bowen, & Johnson, 2015; Leese et al., 2008; Orton et al., 2013; Waqar et al., 2012), and low education (Tajunisah, Wong, Tan, Rokiah,
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& Reddy, 2011). Conversely, examples of demographic factors facilitating retinal screening behaviour which are not included are: female gender (Mukamel, Bresnick, Wang, & Dickey, 1999); treatment modality (Moss, Klein, & Klein, 1995) and (in the US), health insurance (Hwang et al., 2015; Jiang et al., 2017; Paksin-Hall, Dent, Dong, & Ablah, 2013).

Clinical and psychosocial factors play a crucial role in retinal screening behaviour (Gibson, 2014; Sikivou, 2000). When asked, individuals often cite multiple clinical factors ranging from lack of DR symptoms to lack of clinician recommendation to screen for DR. Psychosocial factors include knowledge, attitudes, health beliefs, health engagement and mental health (Peyrot et al., 2005; Simmons, Lillis, Swan, & Haar, 2007). Common clinical and psychosocial retinal screening barriers are reported below, with facilitators viewed as the converse of the barrier unless stated otherwise. Where possible, each factor is discussed in relation to young adults with T2D.

2.2.1 Clinical factors.

2.2.1.1 Clinicians’ recommendation to screen for DR. Eighty-five percent of adults with diabetes who participated in the Diabetic Retinopathy Barometer Study (DRBS), a large-scale survey of 4,340 adults with diabetes, and 2,329 health professionals from 41 countries (Cavan et al., 2017), stated that healthcare professionals were their main source of information about diabetes.

Similarly, general practitioner (GP) recommendation has been highlighted as a key retinal screening predictor (Dervan, Lillis, Flynn, Staines, & O'Shea, 2008). This finding was confirmed qualitatively for young people with T2D, who cited supportive relationships with their health professionals as the most
important factor in enabling diabetes self-management (Protudjer, Dumontet, & McGavock, 2014). Direct encouragement (e.g. provision of information on retinal screening and diabetes-related complications, and follow-up of referrals), is a commonly cited determinant of retinal screening (Al-Alawi et al., 2016; Hwang et al., 2015; John et al., 2014; Lee et al., 2000; Lewis et al., 2007). Despite this, only 50% of DRBS participants reported receiving information about DR from their GP (Cavan et al., 2017).

Clinical inertia, defined as “health professional’s failure to act, or intensify treatment, when clinically indicated” (Osataphan, Chalermchai, & Ngaosuwan, 2017, p.267) is a related concept, which impacts young adults with T2D who rely on GPs as a major source of diabetes management information (Browne, Scibilia, & Speight, 2013a; Diabetes Australia, 2006). Two recent cross-sectional surveys suggest that lack of GP knowledge or confidence may underlie lack of GP encouragement to initiate retinal screening. A survey of 430 Australian GPs (Ting et al., 2011) reported that only 29% had read the National Health and Medical Research Council guidelines on management of DR (Mitchell & Foran, 2008), and 75% did not routinely conduct retinal screening themselves; with 86% citing lack of confidence in their ability to detect DR. Despite this, a recent survey of 598 GPs in the Australian state of Victoria found that only half (53%) of those surveyed referred patients to an eye care provider for DR screening at diagnosis of T2D, taking an average 3.1 years from time of diabetes diagnosis to do so (Papa, Fenwick, Rees, Lamoureux, & Finger, 2016).

Researchers have suggested additional factors may contribute to a disproportionate level of clinical inertia for young adults with T2D, such as:
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Clinician lack of knowledge, or uncertainty regarding appropriate therapeutic management of younger-onset T2D (i.e. diagnosis before 40 years of age), and the misconception that young adults with T2D, aged 18-39 years, are at low risk of complications (Song, 2015; Zafar, Stone, Davies, & Khunti, 2014; Zou et al., 2017). Irrespective of the cause, the outcome (low retinal screening uptake) remains the same, with demonstrated adverse clinical outcomes (Al-Saeed et al., 2016; Owen, 2016).

2.2.1.2 Recent diabetes diagnosis. Recent diabetes diagnosis (or short diabetes duration) is often cited as a barrier to retinal screening, possibly due to demands of psychological and lifestyle adjustment (Beeney, Bakry, & Dunn, 1996; Gregg et al., 2010; Rubin & Peyrot, 2012; van Eijk, Blom, Gussekloo, Polak, & Groeneveld, 2012); conversely, longer duration of diabetes is a key predictor of retinal screening (Moss et al., 1995).

Young adults are vulnerable to delay in retinal screening uptake as demonstrated in an analysis of age versus time from registration to first screen, recently conducted by Scanlon et al. (2016). In their assessment of 394,309 people referred to seven UK-based DR screening programs, Scanlon and colleagues demonstrated that young adults (aged 18-34) are the least likely age group to initiate retinal screening in a timely manner, with 80% coverage not achieved for this age group until 2 years and 9 months post-registration (proxy for diabetes diagnosis). This is a considerable period considering that screening guidelines in the UK recommend retinal screening uptake from diabetes diagnosis (National Institute for health and Care Excellence, 2015).
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2.2.1.3 Absence or presence of DR symptoms. The asymptomatic nature of early DR results in a lack of connection between the individual’s physical experience and the clinical imperative to screen for DR, lowering perception of need and personal risk (Ellish et al., 2007; Klein & Klein, 2006; Lee et al., 2000; Moss et al., 1995; Murgatroyd, MacEwen, & Leese, 2006; van Eijk et al., 2012). In an Australian context, lack of symptoms was the most highly cited reason for not engaging in retinal screening, closely followed by lack of knowledge (86% and 83% respectively, Sikivou, 2000).

The asymptomatic nature of early DR is particularly relevant for young adults with T2D as diabetes-related clinical complications typically manifest themselves after 10 years duration (Dart et al., 2014; Delamater, Jacquez, & Patino-Fernandez, 2009). Providing insight into the beliefs of young adults, Shickle et al. (2014) reported that a dominant view expressed by focus group participants (N=43, aged 18-35 years) was that eye disease was an issue for older people and that eye examinations were only necessary if symptoms appeared. Conversely, presence of DR or experience of vision loss are key retinal screening predictors (Dervan et al., 2008; Ellish et al., 2007; Hartnett et al., 2005; Saadine, Fong, & Yao, 2008), with 65% of optometrists who participated in the DRBS reporting that most individuals presented for retinal screening when visual problems had already occurred (Cavan et al., 2017).

2.2.1.4 Competing health demands. Diabetes is a chronic condition and the presence of other, often chronic, medical comorbidities, can complicate and take precedence over diabetes self-care and engagement in screening (Kovarik et al., 2016; Lee et al., 2000). Despite often being unaffected by diabetes-related
complications in the early stages of the condition (Dart et al., 2014), young adults with T2D are characterised by health comorbidities (of which obesity is generally the primary concern), and complex healthcare needs (Auslander, Sterzing, Zayas, & White, 2010; Nguyen et al., 2014; Sillars, Davis, Kamber, & Davis, 2010). For example, in their in-depth exploration of barriers to diabetes self-management for US adolescents with T2D (N=10, aged 14-19 years) and their parents, Auslander and colleagues (2010) reported that all participants had at least one health comorbidity, and that both parents and adolescents cited health comorbidities as a key barrier to optimal self-management, which is a predictor of DR risk (Auslander et al., 2010).

In an Australian context, Koelmeyer, Dharmage, and English (2016) reported a range of statistically significant physical and health-related comorbidities correlated with diabetes diagnosis in their young adult male cohort (N=11,075, aged 18-49 years), including obesity, depression, anxiety, high cholesterol and high blood pressure. The latter is of greatest concern as it is both an independent risk factor for DR and negative associated with retinal screening uptake (Sachdeva et al., 2012).

2.2.2 Psychosocial factors.

2.2.2.1 Knowledge. In general, most people living with diabetes know of the connection between diabetes and vision loss, and that eyes should be examined (Cavan et al., 2017; Hall, Hall, Kok, Mallya, & Courtright, 2016; Hussain et al., 2016; Kovarik et al., 2016). However, knowledge of two factors crucial to retinal screening behaviour (Zhang et al., 2007): DR (as a condition or complication of diabetes), and of the role of retinal screening as a prevention
and detection measure, is often lacking (Cavan et al., 2017; John et al., 2014; Moss et al., 1995). These include lack of knowledge of the asymptomatic nature of early DR, confusion between screening for DR and a standard vision-related eye examination, and lack of awareness of DR status, all of which are important screening barriers (Dervan et al., 2008; Gibson, 2014; Hipwell et al., 2014; Klein & Klein, 2006; Lee et al., 2000; Peng, 2010; van Eijk et al., 2012).

Two factors closely related to knowledge are: diabetes self-management education, and low health literacy (an individual’s ability to obtain, process, and act appropriately on basic health information; Mackert, Donovan, Mabry, Guadagno, & Stout, 2014). Participation in diabetes self-management education is an important retinal screening predictor (Elam & Lee, 2013; Lewis et al., 2007; Moss et al., 1995; Murray & Shah, 2016; van Eijk et al., 2012; Yamashita, Kart, & Noe, 2012). Despite this, participation is low overall for people with diabetes, and has been identified as significantly lower for younger adults (Li et al., 2014). Explanation given for low participation in structured diabetes education by almost two-thirds (63%) of 149 young adults with T2D surveyed by Browne et al. (2013a) and in qualitative studies, were that participants felt they had “different” healthcare needs from “older” adults, and that current education programs were not age-appropriate (Browne et al., 2013a; Diabetes Australia, 2006; Savage, Dabkowski, & Dunning, 2009).

Recent research has associated low health literacy with negative diabetes self-management outcomes (Bailey et al., 2014; Beard, Clark, Hurel, & Cooke, 2010; Boren, 2009; Fransen, von Wagner, & Essink-Bot, 2012; Paduch et al., 2017), and an important retinal screening barrier (Sikivou, 2000). The issue of
health literacy is particularly important for people living with diabetes because of the need to adequately interpret clinical markers such as HbA1c and blood pressure readings (Williams, Baker, Parker, & Nurss, 1998), which are risk indicators for diabetes-related complications, including for DR.

Young adults with T2D and those at high risk of the condition are characterised by low general and health literacy (Cha, Umpierrez, Kim, Bello, & Dunbar, 2013; Gregg, Sattar, & Ali, 2016). An important step in addressing low health literacy involves ensuring appropriate readability and suitability of individual-level health information resources (Bartholomew Eldredge et al., 2016). Despite this, many existing materials are written at literacy levels above the skills of the target population (Ryan et al., 2014). Excessively complex textual content has been demonstrated to apply to eye health resources, with a recent review of readability of printed DR information materials reporting an average Flesch-Kincaid readability score of 10.1 which is equivalent to a tenth-grade reading level (Muir & Lee, 2010), and well above the eighth-grade acceptability threshold (Doak, Doak, & Root, 1996).

2.2.2.2 Anticipated regret. Anticipated regret, the belief about whether feelings of guilt or regret will result from inaction, has been demonstrated to moderate the intention-behaviour relationship (Abraham & Sheeran, 2003). Vision loss from DR is the diabetes complication of greatest concern to affected individuals (Strain et al., 2014) and fear of vision loss if screening was not conducted, has been cited as a facilitator by people living with diabetes (Hartnett et al., 2005).
2.2.3 Risk perception. In a recent systematic review of how people living with T2D perceive their risk of diabetes-related complications, the authors reported mixed findings, including: overestimation and underestimation of risk, or absence of correlation between perceived and actual risk, dependent upon population and diabetes-related complication (Rouyard, Kent, Baskerville, Leal, & Gray, 2017). Once refined to studies which focused on eye complications however, the authors reported underestimation of risk and higher optimistic bias. As both of these characteristics are disproportionately represented during young adulthood, there is strong likelihood of risk perception being an important retinal screening barrier for young adults with T2D (Lapsley & Hill, 2010; Nguyen et al., 2014; Reyes-Velazquez & Sealey-Potts, 2015; Turner et al., 2015).

2.2.4 Fatalism. Young adults with T2D are more likely than their older-onset T2D counterparts to have a family history of the T2D (Zeitler, Chou, Copeland, & Geffner, 2015). Recent qualitative research with youth with T2D suggested that family history may contribute to a sense of fatalism regarding the inevitability of diabetes complications (Turner et al., 2015). Consequently, researchers have advocated for interventions to provide educational and psychosocial support and assist young adults to both appreciate and cope with the complication risk associated with T2D, including increasing the perception of need for retinal screening (Browne, Nefs, Pouwer, & Speight, 2014; MacLennan, McGwin, Heckemeyer, & et al., 2014; Turner et al., 2015; Zhang & Ning, 2014).

2.2.5 Depression, diabetes-specific distress and stigma. Prevalence of depression among adults with T2D is almost twice as high as in the general population (Ali, Stone, Peters, Davies, & Khunti, 2006), and is associated with low
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participation in diabetes self-care of which screening for DR is one aspect (Sumlin et al., 2014). Diabetes-specific distress, a separate psychological construct which entails a range of negative emotions specific to living with and managing diabetes (e.g. feeling overwhelmed by diabetes, fear for the future and risk of complications, guilt about getting ‘off-track’ with diabetes self-management), also impacts upon diabetes self-management and is associated with sub-optimal glycemic control (Ducat, Philipson, & Anderson, 2014).

Younger age is independently associated with high rates of depressive symptoms and diabetes-specific distress (Anderson et al., 2011; Berge, Bauer, Eisenberg, Denny, & Neumark-Sztainer, 2013; Browne et al., 2014; Browne et al., 2013a; Chittleborough, Winefield, Gill, Koster, & Taylor, 2011; Hessler, Fisher, Mullan, Glasgow, & Masharani, 2011; Stoop et al., 2014) and has been linked to greater emotional distress at diabetes diagnosis, when compared to older adults (Beeney et al., 1996). Despite this, only a small proportion of those with younger-onset T2D receive appropriate therapeutic intervention, (Silverstein et al., 2015) indicating that these (untreated) factors are likely to negatively impact diabetes self-care, and retinal screening behaviour to a greater extent among this priority population.

Relatedly, people living with T2D report perceived and experienced stigma and fear of negative judgement (Browne, Ventura, Mosely, & Speight, 2013b; Winkley et al., 2015), an emotion particularly pertinent for young adults with T2D who perceive additional burden for having a condition commonly associated with obesity and older adulthood (Browne et al., 2013a; Savage et al., 2009).
Perception of stigma has been associated with low health literacy (Mackert et al., 2014) and reported as a barrier to non-attendance at diabetes self-management education (Winkley et al., 2015). For example, in-depth interviews with youth/young adults living with T2D in Australia and overseas revealed a reluctance to disclose their condition, preventing opportunity to seek or receive peer and family support, self-management education, and adequate healthcare support (Browne et al., 2013b; Protudjer et al., 2014).

\textbf{2.2.2.6 Fear of DR screening, diagnosis and/or treatment.} Fear of the DR screening procedure (particularly consequences of pupil dilation drops), diagnosis, and/or of treatment are commonly cited screening barriers (Elam & Lee, 2013; Ellish et al., 2007; Lewis et al., 2007; Luckie et al., 2007; Murgatroyd et al., 2006; Strutton et al., 2016; Walker et al., 1997). The potential negative effects of fear arousal, including denial and avoidance, necessitate careful consideration when designing health behaviour interventions, in order to encourage people to consider acting to minimise the threat of DR, as opposed to message rejection (Ruiter & Kok, 2012).

\textbf{2.2.2.7 Engagement in diabetes self-care.} Those most engaged in their diabetes self-care are also most likely to screen for DR (Ellish et al., 2007; Müller, Lamoureux, Bullen, & Keeffe, 2006). In their exploration of factors associated with never attending retinal screening, Strutton and colleagues (2016) highlighted denial of diabetes and disengagement with diabetes care as important considerations, particularly as those who had not screened for DR “represented a vulnerable group of patients” (Strutton et al., 2016, p.5). Younger age has been associated both with fear of disclosure of T2D and consequent lack
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of engagement with their diabetes self-management, with young adults with T2D reporting key barriers being lack of motivation and feeling “burned out” (Brouwer et al., 2012; Ellish et al., 2007; Müller et al., 2006; Nguyen et al., 2014; Savage et al., 2009; Wilmot & Idris, 2014).

2.2.2.8 Practical obstacles. Practical obstacles (e.g. lack of time, cost, competing commitments) are commonly cited screening barriers for the general diabetes population (Ellish et al., 2007; Hartnett et al., 2005; Hipwell et al., 2014; John et al., 2014; Lewis et al., 2007; Lu et al., 2016) and have considerable impact on young adults with diabetes. For example, Moss et al. (1995) compared 1,298 people with diabetes (type not defined) stratified by age at diagnosis (n=765 <30 years, n=533 ≥30 years). The authors reported that a higher proportion of the younger-onset group cited time and cost as reasons for not screening, compared to their older counterparts (23% vs 11% for lack of time, 30% vs 12% for cost), (Moss et al., 1995).

Adults with diabetes who have never attended screening cited competing commitments, including work and childcare, as key reasons for non-attendance (Sachdeva et al., 2012; Strutton et al., 2016). As lack of time and financial considerations are commonly cited life-stage factors known to impact diabetes self-management for young adults with T2D in Australia (Australian Institute of Health and Welfare, 2014; Diabetes Australia, 2006), it is reasonable to expect these factors to impact upon retinal screening uptake.
2.2.3 **The importance of understanding context.** The barriers cited above indicate that young adults with T2D are a high-need group facing multiple, complex clinical and psychosocial barriers to diabetes self-care, which are likely to also be relevant to the uptake of retinal screening for the early identification of DR.

However, not all barriers may apply to retinal screening behaviour in a given priority population. For example, a recent mixed-methods needs assessment conducted to identify barriers to DR screening for people living with diabetes in Sub-Saharan Africa (Hall et al., 2016), reported that adults with T2D from this region were not impacted by diabetes-related stigma, an emerging issue gaining credence as a barrier to diabetes self-management (Browne et al., 2013b; Joachim & Acorn, 2000; Savage et al., 2009; Schabert, Browne, Mosely, & Speight, 2013; Winkley et al., 2015).

This finding was contrary to expectations, and highlights the importance of exploring cultural and contextual factors for a given priority population. Drawing direct comparison with the Australian experience (Browne et al., 2013b), Hall and colleagues (2016) reported that rather than conceal their diabetes diagnosis, participants wore identifying stickers with pride, observing that “in a continent with a high prevalence of a more stigmatising disease such as HIV/AIDS, it may be a relief to ... have a more socially acceptable explanation for their chronic illness” (Hall et al., 2016, p.12).
2.3 Interventions to Promote Retinal Screening

Our projections indicate a serious picture of the future national diabetes burden in youth ... To prevent future human suffering and health care costs, effective interventions for the prevention of diabetes-related complications should be available to all youth with diabetes.

Imperatore et al (2013)

Interventions to promote retinal screening can be categorised broadly into three areas of focus: patient/population, practitioner/provider or healthcare system. Patient/population-focussed interventions include programs to increase awareness of DR and promote self-management among people with diabetes, including the use of prompts/reminders. Provider-focussed interventions include educational programs designed to improve clinician adherence to clinical guidelines, as well as to improve the quality and flexibility of their clinical practice. Healthcare system-level interventions include programs designed to reduce barriers and improve access to healthcare delivery (e.g. telemedicine), as well as large-scale implementation of registration and recall systems.

A systematic review of interventions to promote screening for DR identified 48 studies published between 1980 and May 2005 (Zhang et al., 2007). Of those, 10 targeted patient/population (Anderson et al., 2003; Basch, Walker, Howard, Shamoon, & Zybert, 1999; Clark, Snyder, Meek, Stutz, & Parkin, 2001; Gross, Cataruozolo, & Mitofsky, 1999; Halbert, Kwan-Moon, Nichol, & Legorreta, 1999; Lafata, Baker, Divine, McCarthy, & Xi, 2002; Maliszewski, Dennis, & Coyd, 1988; Prela, Smilie, McInerney, Harwell, & Helgerson, 2000; Varroud-Vial et al., 1999; Vinker, Shpiz, Elhayany, & Nakar, 2003), four targeted
practitioner/providers, 19 targeted healthcare systems, and 15 were multi-focussed.

A second systematic review of interventions to promote screening for DR is underway and a protocol has been published (Lawrenson et al., 2016). In a reflection of advances in intervention design theory and successful application in other health behaviour change areas (e.g. diet and physical activity; Greaves et al., 2011), the review protocol states that a key is to identify the specific components of existing retinal screening programs associated with intervention effectiveness. To achieve this, the authors propose to classify intervention content into theoretically-grounded “active ingredients” or behaviour change techniques (BCT), defined as “observable, replicable and irreducible component(s) of an intervention designed to alter or redirect causal processes that regulate behaviour” (Michie et al., 2013, p.82).

For this program of PhD research, a literature search was conducted to update the review by Zhang et al (i.e. from 2005 to 2017). Thirteen studies (9 randomised controlled trials (RCT) and four non-randomised), and one companion paper (Jones, Walker, Schechter, & Blanco, 2010), were identified (see Additional file for search strategy and summary of findings). Of the 13 studies, nine targeted patient/population (Bush et al., 2014; Gabbay et al., 2006;  

3 See Zhang et al 2007 for a list of non-patient/population level interventions, beyond the scope of this review.

4 See Section 4.4.3.2 for detail on use of the same approach in this program of PhD research.
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Judah et al., 2017; Lian et al., 2013; Murray & Shah, 2016; Pizzi et al., 2015; Walker, Schechter, Caban, & Basch, 2008; Weiss et al., 2015; Zangallli et al., 2016), two targeted practitioner/providers (Newman, Cummings, Doherty, & Patel, 2012; Zwarenstein et al., 2014) and two targeted healthcare systems (Jani et al., 2017; Olayiwola, Sobieraj, Kulowski, St.Hilaire, & Huang, 2011). Consistent with Zhang et al. (2007), relative risk (RR) with 95% confidence interval (CI) is used as a measure of effect for both randomised and non-randomised designs. In this review, RR was defined as the ratio of the probability of retinal screening occurring, and was calculated as screening rate post-intervention divided by screening rate at baseline (Deeks, 2002).

2.3.1 Synthesis of study findings. Overall, most of the retinal screening promotion interventions achieved statistically significant increases in retinal screening, supporting the assertion by Zhang et al. (2007) that a variety of interventions are effective in promoting the behaviour. Also consistent with the earlier systematic review, (Zhang et al., 2007), quality of studies varied with some missing key data such as length of follow-up, mean age of participants at baseline, clarity of participant screening status (i.e. whether the participants had never screened for DR, or instead, were overdue), and randomisation procedure (for RCTs).

As the context of this program of PhD research is grounded at the patient/population level, the focus from here on is on the 19 studies targeting patients or populations (10 identified by Zhang et al 2007; 9 from the update review), Table 1. Of those, 16 studies reported a modest, statistically significant increase in retinal screening (11 RCTs, 5 five non-randomised
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designs\textsubscript{14,16-19}\textsuperscript{5}. Relative risk ranged from 1.02 (CI 0.94-1.10, Prela et al., 2000) to 2.63 (CI 2.01-3.45, Gabbay et al., 2006) for RCTs, and 1.08 (CI 1.07-1.09, Murray & Shah, 2016) to 1.80 (CI 1.59-2.03, Vinker et al., 2003) for non-randomised designs.

\textsuperscript{5} Subscript numbers represent studies listed in Table 1 below
# Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

Table 1: Study characteristics, intervention effects and relative risk for patient-level retinal screening interventions

<table>
<thead>
<tr>
<th>Primary author (year)</th>
<th>Sample size</th>
<th>Intervention / Control conditions</th>
<th>Length of follow up (weeks)</th>
<th>Mean age at baseline</th>
<th>Relative risk (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Randomised controlled trial designs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Anderson a (2003)</td>
<td>132</td>
<td>Intervention: letter and personalised follow up phone call. Control: letter only</td>
<td>52</td>
<td>54.8</td>
<td>1.86 (1.28 - 2.69)</td>
</tr>
<tr>
<td>2. Basch a (1999)</td>
<td>280</td>
<td>Intervention: three part education program to increase knowledge of DR and personalised telephone outreach. Control: meal planning booklet</td>
<td>26</td>
<td>54.7</td>
<td>2.01 (1.48 - 2.73)</td>
</tr>
<tr>
<td>5. Halbert a (1999)</td>
<td>19,523</td>
<td>Intervention: multiple educational material and reminders to increase awareness of retinal screening. Control: single reminder</td>
<td>52</td>
<td>N/R</td>
<td>1.05 (1.01 - 1.08)</td>
</tr>
<tr>
<td>6. Judah b (2017)</td>
<td>1,051</td>
<td>Intervention A: mailed invitation letter plus 10 pound voucher if attend retinal screening appointment. Intervention B: mailed invitation letter with 1:100 chance to win £1,000. Control: usual care (mailed invitation letter)</td>
<td>12</td>
<td>N/R</td>
<td>Intervention A: 0.70 (0.35 - 1.39)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Intervention B: 0.42 (0.18 - 0.98)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Combined A&amp;B: 0.56 (0.34 - 0.92)</td>
</tr>
</tbody>
</table>
## Table 1: Study characteristics, intervention effects and relative risk for patient-level retinal screening interventions (Cont.)

<table>
<thead>
<tr>
<th>Primary author (year)</th>
<th>Sample size</th>
<th>Intervention / Control conditions</th>
<th>Length of follow up (weeks)</th>
<th>Mean age at baseline</th>
<th>Relative risk (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Randomised controlled trial designs (Cont.)</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>8. Lian(^b) (2013)</td>
<td>2,593</td>
<td>Intervention: small copayment (~£4.90). Control: no cost</td>
<td>N/R</td>
<td>64</td>
<td>0.93 (0.90 – 0.96)</td>
</tr>
<tr>
<td>9. Pizzi(^b) (2015)</td>
<td>356</td>
<td>Intervention A: mailed personalised letter with educational brochure; Intervention B: Int. A plus ≤ 3 phone calls. Control: usual care (standardised reminder letter)</td>
<td>12</td>
<td>61</td>
<td>Intervention A: 0.90 (0.63 – 1.28) Intervention B: 1.41 (1.05 – 1.8)</td>
</tr>
<tr>
<td>10. Prela(^a) (2000)</td>
<td>6,546</td>
<td>Intervention: direct mail reminder. Control: no reminder</td>
<td>26</td>
<td>N/R</td>
<td>1.02 (0.94 - 1.10)</td>
</tr>
<tr>
<td><strong>Other research designs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Clark(^a) (2001, pre-post)</td>
<td>370</td>
<td>Comprehensive diabetes management education program</td>
<td>52</td>
<td>64</td>
<td>1.49 (1.29 - 3.64)</td>
</tr>
</tbody>
</table>
**Table 1: Study characteristics, intervention effects and relative risk for patient-level retinal screening interventions (Cont.)**

<table>
<thead>
<tr>
<th>Primary author (year)</th>
<th>Sample size</th>
<th>Intervention / Control conditions</th>
<th>Length of follow up (weeks)</th>
<th>Mean age at baseline</th>
<th>Relative risk (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other research designs (Cont.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Gross	extsuperscript{a} (1999, pre-post)</td>
<td>100</td>
<td>Survey on receipt of preventive care from hospitalised patients</td>
<td>26</td>
<td>N/R</td>
<td>0.32 (0.02 - 5.01)</td>
</tr>
<tr>
<td>16. Maliszewski	extsuperscript{a} (1988, pre-post)</td>
<td>338</td>
<td>Education program to increase patient awareness of retinal screening</td>
<td>52</td>
<td>N/R</td>
<td>1.78 (1.50 - 2.12)</td>
</tr>
<tr>
<td>17. Varroud-Vial	extsuperscript{a} (1999, pre-post)</td>
<td>505</td>
<td>Cooperation program between healthcare specialists and patient feedback/education</td>
<td>52</td>
<td>61.9</td>
<td>1.12 (1.02 - 1.22)</td>
</tr>
<tr>
<td>18. Vinker	extsuperscript{a} (2003, pre-post)</td>
<td>420</td>
<td>Written reminder plus phone calls to increase patient awareness of retinal screening</td>
<td>52</td>
<td>65.8</td>
<td>1.80 (1.59-2.03)</td>
</tr>
<tr>
<td>19. Murray	extsuperscript{b} (2016, other)</td>
<td>45,212</td>
<td>Attendance at any diabetes self-management education without assessment of content or quality</td>
<td>N/A</td>
<td>76</td>
<td>1.08 (1.07-1.09)</td>
</tr>
</tbody>
</table>

	extsuperscript{a}Studies contained in Zhang et al systematic review (2007, n=10),

	extsuperscript{b}Studies post-Zhang et al systematic review (i.e. published 2005 onward, n=9).

N/R: not reported, N/A: not applicable, BCT: behaviour change technique, BA: behavioural activation
2.3.1.1 Patient/population level interventions that achieved increased retinal screening. Interventions with largest effect were those that utilised the most resources (generally through personalised contact), although cost-effectiveness analyses were not reported. Examples of effective, intensive interventions include:

- utilisation of multi-lingual link-workers for bookings, reminders and recall (Bush et al., 2014; RR 2.55, CI 2.1-3.1),
- care planning and coordination by nurse case manager in conjunction with self-management education (Gabbay et al., 2006; RR 2.63, CI 2.01-3.45),
- community health worker implementation of educational manuals designed to assist people with T2D to identify and address screening barriers and formulate action plans (Weiss et al., 2015; RR 2.58, CI 1.91-3.48), and
- printed education materials combined with telephone outreach (Basch et al., 1999; RR 2.01, 1.48-2.73).

In contrast, studies that reported modest, but statistically significant increases in retinal screening did not include personalised contact. Typically, such interventions comprised print-based reminders or educational brochures with RR ranging from 1.02 (CI 0.94-1.10) to 1.13 (CI 1.04-1.23), (Burnett et al., 1998; Halbert et al., 1999; Lafata et al., 2002; Prela et al., 2000). The study closest in design to the leaflet intervention proposed in this program of PhD research (due to the context of the project, see Section 2.1) involved a direct mail reminder, which was sent to US adults with diabetes, identified through medical claims data. The authors reported a modest, statistically significant increase in eye examination medical claims by the intervention group in the
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Three months following receipt of the flyer (19.4% vs 17.2%; RR 1.13, CI 1.01-1.26), (Prela et al., 2000). However, this was not sustained six months post-intervention and did not influence eye examination rates in people who had not screened for DR in the previous two years. However, it is likely that the didactic content of the letter (Figure 1) may not have tapped into the cognitive, psychosocial or contextual factors associated with the decision to screen.

Figure 1: Direct mail interventions (L: Lafata et al, 2002; R: Prela et al, 2000)

More broadly, although detail of text-based content was often sparse or non-existent in the literature, those printed interventions that were published were limited in scope (Lafata et al., 2002; Prela et al., 2000), as exemplified in Figure 1. Descriptions provided in the remaining studies indicated that text-based interventions were typically in the form of letters, brochures or leaflets. Content was didactic in nature, focusing almost completely on improving...
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awareness and knowledge of DR to prompt the recipient to either initiate or reprise screening for DR. For example, content ranged from appointment only information (Lafata et al., 2002) or directive prompts such as ‘Get regular eye exams’ (Anderson et al., 2003; Prela et al., 2000), to education-based content outlining the condition, the retinal screening process, or emphasising the importance of eye examinations (Pizzi et al., 2015).

Importantly for this program of PhD research, the most effective, print-based interventions relied on individuals to be registered on an existing database, either with an eye health practitioner, or with a centralised, system, such as the UK national screening program (Scanlon, 2017). As young adults with T2D may not yet experience the age-related refractive changes that often prompt a first visit to an eye health practitioner, and no national retinal screening program exists in Australia, reliance on existing databases is not an option in this program of PhD research, necessitating utilisation of alternate data sources to optimise reach.

2.3.1.2 Patient/population level interventions that did not achieve increased retinal screening. Of the four patient/population level studies that did not achieve statistically significant increases in screening rates for participants, three were RCTs6,8,9 and one had a non-randomised design15. Relative risk ranged from 0.32 (Gross et al., 1999; CI 0.02-5.01) to 0.93 (Lian et al., 2013; CI 0.90 0.96). Interestingly, two of the interventions explored the effect

6 Subscript numbers represent studies listed in Table 1.
of cost of screening as a facilitator/barrier, providing insight into the possible
cognitive processes underlying the behaviour.

For example, one study (evaluating the effect of two incentives: one small
and fixed, i.e. guaranteed £10; one larger and probabilistic, i.e. 1:100 chance to
win £1,000) on screening attendance reported that participants offered either
incentive were less likely to screen than control participants who received an
invitation letter only (RR 0.56, CI 0.34-0.92), (Judah et al., 2017). The authors
concluded that, in this case, an extrinsic reward may reinforce the view that
screening is unpleasant.

Conversely, a Hong Kong study, which explored the impact of a small co-
payment by patients (~£4.90) on screening attendance, reported payment was
also associated with lower screening uptake when compared to free access (RR
0.93, CI 0.90–0.96), (Lian et al., 2013). Notably, uptake for both groups was high
(82.4% and 88.5%, respectively, p<.001) in a country where a small co-payment is
typical. These findings suggest that financially-based incentive strategies
(regardless of whether they are framed in terms of financial gain or loss) have
the potential to discourage individuals from screening. Furthermore, there is
little available evidence to support the use of incentives to promote retinal
screening uptake in young adults with T2D.

A recent systematic review by Yu et al. (2016), which examined the use of
incentives in 26 studies, reported that the studies “almost exclusively” targeted
discouraging unhealthy behaviours, and no studies which focussed on diabetes.
As such, the authors were unable to determine the utility of incentives strategies
encouraging uptake of positive health behaviours for young adults.
2.3.2  **Factors impacting intervention effectiveness or interpretation.** In their review, Zhang et al. (2007) reported a range of characteristics related to the effectiveness of interventions. For example, interventions were less likely to succeed if they were conducted outside metropolitan areas or with minority populations, and more likely to succeed if they were multi-focussed, involved multidisciplinary collaborations or were conducted in healthcare systems equipped with a computerised database. However, given that most interventions were found to be effective in promoting retinal screening, three additional factors relevant to this program of PhD research, but not explicitly raised by Zhang et al. (2007), need to be considered, and are described below.

**2.3.2.1 Participant eligibility criteria: lapsed vs never screened.** The first factor with the potential to impact intervention success is choice of target group eligibility criteria. Although the 19 patient-level studies reviewed in this section shared the same assessable outcome (i.e. screening for DR), 13 studies employed broad eligibility criteria which included those who had previously screened, but who had not done so within a pre-defined interval, which was commonly 12 months (hereafter ‘lapsed’). Only three studies specified use of the stricter eligibility criteria of never screened for DR since their diabetes diagnosis (Bush et al., 2014; Halbert et al., 1999; Judah et al., 2017); (eligibility criteria could not be determined for three studies; Clark et al., 2001; Murray & Shah, 2016; Vinker et al., 2003).

Past behaviour is a strong predictor of future behaviour (Ouellette & Wood, 1998) and once initiated, screening is generally sustained (Lee et al., 2000; Zhang et al., 2007). Consequently, retinal screening intervention
evaluations that include ‘lapsed’ participants risk inflation of intervention effect, as the lapsed participant may have always intended to screen for DR. Usage of the stricter criteria (i.e. only those who had never screened), although arguably of greater economic and social benefit to the population (Raikou & McGuire, 2003), is likely to impact the study on multiple levels, from recruitment, through to evaluation, as those who have never screened, by definition, have not engaged with the behaviour and are likely to either be resistant to the behaviour, or face an accumulation of barriers which impede the behaviour (Moreton, Stratton, Chave, Lipinski, & Scanlon, 2017; Scanlon et al., 2016; Strutton et al., 2016; Zhang et al., 2007).

Interestingly, two of the three studies using the stricter criteria reported low or negative effect (Halbert et al., 1999; Judah et al., 2017). The third study, which employed healthcare staff from the same cultural and language background as the target group to encourage screening attendance, demonstrated significant improvements, reinforcing the finding that personalised interaction is a valuable contributor to intervention success, and an important imperative to address literacy, cultural and language retinal screening barriers faced by minority populations (Bush et al., 2014).

2.3.2.2 Question-behaviour-effect. The second factor with the potential to impact intervention success is the potentially confounding effect of the pre-intervention survey on screening behaviour. Known as Question-Behaviour-Effect (QBE), this phenomenon is supported by a body of literature, which posits that the act of asking questions and measuring intentions about a specific behaviour
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influences the performance of that behaviour (Dholakia, 2010; Spangenberg et al., 2012).

Considering that most interventions to promote screening for DR achieved statistically significant increases in retinal screening, and that QBE effects have been demonstrated in other socially desirable behaviours (Ayres et al., 2013; Conner, Godin, Norman, & Sheeran, 2011; Godin, Germain, Conner, Delage, & Sheeran, 2013; Godin, Sheeran, Conner, & Germain, 2008), it is interesting to note that only one study accounted for this phenomenon (Walker et al., 2008). They did so by using a Solomon group design, which assigns participants at random to a combination of four pre-test/intervention groups, and allows the examination of both the intervention and the interaction of pre-test items (Solomon, 1949). If pre-test sensitisation, or QBE, is present, the effect would be expected to be larger in the ‘pre-test plus intervention’ group than in the ‘no pre-test plus intervention’ group. The study, which also cross-validated self-report of retinal screening behaviour with medical records, reported no pre-intervention effect between those who completed and did not complete the pre-intervention questionnaire (RR 1.73 and 1.74, respectively, p=.97), with the authors concluding that QBE was not present (Walker et al., 2008). However, as all participants in this study had previously screened, the sensitivity of the study to detect a QBE may have been reduced, in comparison to effect of QBE on those who had never screened.
2.3.2.3 Standards of reporting and intervention design In the past decade, several clear, systematic intervention design and reporting frameworks have been proposed (Hoffmann et al., 2014; Moher et al., 2010). Despite this, sub-optimal intervention design and reporting continue to impact upon the quality and evaluation of DR screening interventions.

The current literature review was impeded by a lack of published detail on whether screening barriers/facilitators relevant to the priority population were explored prior to intervention development, and whether those factors were targeted explicitly using theoretically-grounded BCT. For example, in their description of a successful education program to increase DR screening, Basch et al. (1999) did not report whether the resources in their tailored, multi-component education intervention were based on an earlier, comprehensive exploration of barriers and facilitators within the priority population (Walker et al., 1997). Considering the proximity of publications and the similar characteristics of study participants (African Americans with diabetes enrolled from New York City medical centres), it is highly likely that this was the case, and clear specification of this prior needs assessment would have added to the strength of the study findings.

Furthermore, some researchers do not appear to have incorporated advances in intervention design theory into their interventions. For example, a recent large-scale, cluster RCT involving 5,048 Canadian GPs and 179,833 people with diabetes reported that various printed educational messages targeting clinicians, and companion patient-targeted memos, were ineffective in increasing patient screening rates (Zwarenstein et al., 2014). However, as acknowledged by
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the authors, the lack of impact may reflect the fact that the message content was not evidence-based (i.e. “not based on a prior assessment of barriers to screening”, p.8), concluding that targeted barriers may not have been relevant to the study population. Indeed, examination of the published patient-targeted memo (Figure 2) shows it to be didactic in nature, focusing solely on commonly known barriers of knowledge and cost, rather than psychosocial, cognitive and contextual factors associated with screening behaviour among the target population.

Figure 2: Patient memo (Zwarenstein et al, 2014)
In summary, a broad range of interventions have been successful in promoting DR screening, and patient-level, print-based materials generally report small-to-moderate positive effect. However, there are several limitations of these studies, which are likely to have contributed to the success of these interventions. Importantly for this program of PhD research, none of the studies reviewed targeted young adults with T2D and the mean age of participants (where reported in Table 1) was 63 years (range 55 - 76 years).

In contrast to ‘best practice’ health behaviour intervention development, none of the intervention studies reported investigating antecedent psychosocial and cognitive factors to inform the content of the intervention, and few targeted or assessed change in known screening determinants (e.g. beliefs, attitudes, risk perception or knowledge). Further, only one of the studies described above (Judah et al., 2017) specifically nominated utilisation of theoretically-derived BCT as a behaviour change strategy, although many used commonly identifiable techniques, such as improving knowledge, goal setting and planning, and providing information about health consequences (Basch et al., 1999; Gabbay et al., 2006; Weiss et al., 2015). Thus, it is expected that a text-based intervention containing tailored, evidence-based message content that reflects a thorough understanding of the target cohort (including existing barriers and determinants), and which addresses the above shortcomings, is likely to be more effective than earlier interventions in promoting uptake of DR screening.
2.4 Changing Health Behaviour

_The evidence that behaviour is the dominant element in successful management of diabetes is so overwhelming that we tend to ignore it._

Gale, 2004

Health behaviours are defined as “behaviour patterns, actions and habits that relate to health maintenance, to health restoration and to health improvement” (Delamater et al., 2009, p.3). They have the capacity to impact an individual’s health positively or negatively (Abraham, Kelly, West, & Michie, 2009). At an individual level, modifiable determinants include knowledge, intention, risk perception, self-efficacy, perceived norms, health beliefs and attitudes (Abraham, Conner, Jones, & O’Connor, 2008). Programs designed to change or enhance health-promoting behaviours and reduce the risk or impact of disease, are known as health behaviour change interventions. Evidence suggests that behaviour change interventions are effective across a broad range of health behaviours (Michie & Abraham, 2004a).

2.4.1 The evolving use of social cognition models in health behaviour change intervention development. Health behaviour change interventions based on theory and theoretical constructs are, generally, more effective than those with no explicit theoretical basis (Gage et al., 2004; Hampson et al., 2000). Historically, a number of social cognition models (SCMs) have been used to account for variations in health behaviour and to inform and evaluate health behaviour change interventions (Serlachius & Sutton, 2009). In general, SCMs predict and explain health behaviour, specifying modifiable antecedents or determinants of behaviour change which can be targeted in a
behaviour change intervention. Examples of application of such models within diabetes include: understanding perceptions of the role of self-monitoring of blood glucose for adults with T2D who had improved glycaemic control, via the Common Sense Model (Tanenbaum et al., 2015); identification of factors predicting concordance with retinal screening recommendations via the Health Belief Model (Sheppler, Lambert, Gardiner, Becker, & Mansberger, 2014); development of a physical activity promotion intervention for adults with T2D, informed by the Theory of Planned Behaviour (Avery et al., 2016), and development of a 5-week self-management program for adult with T2D based on Social Cognitive theory (Steed et al., 2005).

However, in many instances, effect sizes are small (Hardeman et al., 2002; Johnson, Scott-Sheldon, & Carey, 2010). For example, a recent meta-synthesis of 62 meta-analyses of a diverse range of more than 1,000 behaviour change interventions reported a small-to-moderate effect size for the broad range of interventions ($d=0.08-.045$, 95% CI)$^7$ and a moderate effect for those focussed on ‘improving participation in health services’ ($d=0.35$, 95% CI), (Johnson et al., 2010). Of interest to this program of PhD research, is the conclusion by Johnson and colleagues that younger age is a risk factor for efficacy across a range of health behaviour change interventions, with the authors suggesting that increased risk-taking behaviour and perceptions of invulnerability underlie this phenomenon.

$^7d =$ weighted mean effect size (positive for improvements in the outcome studied and negative for impairments).
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Although individual SCMs and the theoretical constructs that underpin them have guided research and intervention development, and formed the basis of numerous effective interventions, various conceptual and pragmatic limitations have been raised by scholars in the field. A common observation is that individual SCM models differ in the specification of mechanisms or pathways by which behaviour can be changed, and individual SCMs are restricted to the regulatory mechanisms that explain behaviour within their own paradigm (Ogden, 2003). For example, Abraham (2015) highlighted limitations of the Theory of Planned Behaviour (TPB) in intention formation and intervention development, arguing that TPB does not specify all processes by which intention can be influenced, and that TPB does not provide information on when and how to target specific mechanisms (Abraham, 2015).

Real-world health behaviours are complex and nuanced, and use of one specific SCM may overlook or omit relevant regulatory processes or determinants that might have been included had another SCM been selected (Michie & Abraham, 2004b).

2.4.1.1 Information-Motivation-Behavioural skills model. An alternate model proposed by leading scholars is an integrated approach which allows for identification of change mechanisms without reliance on any one specific psychological theory (Abraham, 2015; Bartholomew Eldredge et al., 2016). The Information-Motivation-Behavioural skills (IMB) model, developed by Fisher and Fisher (1992), has utility for this purpose (Figure 3). The IMB model posits that although information is a key element in changing behaviour, increasing knowledge and awareness of a behaviour is not sufficient in itself, and requires
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the integration of motivational and skills elements to ensure behaviour change. In essence, an individual who is well-informed relevant to the target health behaviour, personally and socially motivated to perform the behaviour, and who has the appropriate behavioural skills, will be more likely to initiate and maintain the target health behaviour (Fisher, Fisher, & Harman, 2003).

Figure 3: Information-Motivation-Behavioural skills model

Use of the IMB model in behaviour change research requires identification of behavioural determinants in each of the three key areas, which can then be targeted in a subsequent intervention. The model can be used as the foundation for quantitative surveys, with items based on each of the three categories.

Increasingly used with chronic conditions, the IMB has been validated in a model of diabetes self-care behaviours (Osborn & Egede, 2010) and medication adherence (Mayberry & Osborn, 2014). Of particular interest to this program of PhD research is that greater diabetes knowledge, and higher personal and social motivation was associated with performing diabetes self-care behaviours in a sample of 130 adults with T2D from a US medical clinic (Osborn & Egede, 2010). Unfortunately, the lack of consideration of behavioural skills in the study limits our understanding of the application of the IMB model in a diabetes context. More recently, Mayberry & Osborn (2014) demonstrated that IMB elements
explained 41% of the variance in diabetes medication adherence, identifying modifiable determinants for future interventions.

IMB studies among young adults have identified determinants of the uptake of sexual health and screening behaviours such as human papillomavirus vaccination (Perez, Cruess, & Strauss, 2016), HIV self-testing (Brown, Carballo-Diéguez, John, & Schnall, 2016), condom use (Camilleri, Kohut, & Fisher, 2015), and breast cancer screening (Wells, Shon, McGowan, & James, 2017). Considering that studies focussing on correlates to health promoting behaviours for young people have found that knowledge is a weaker correlate than social cognitive determinants, such as attitudes, self-efficacy, risk perception and intentions (Abraham, Krahe, Dominic, & Fritsche, 2002; Bengel, Belz-merk, & Farin, 1996; DiClemente, 1991), identification of motivational and skill factors are an important issue for the priority population (Browne et al., 2013a), and an important element for this program of PhD research.

2.4.2 Guidance for health behaviour change intervention development, implementation, and reporting. In response to acknowledged deficiencies in descriptions of existing health behaviour change interventions and evaluations, guidance has been published on ‘best practice’ development, piloting, implementation, and standardised reporting. For example, Davidson et al. (2003) augmented the CONsolidated Standards of Reporting Trials (CONSORT) statement to include consideration of components unique to behavioural medicine research and, similarly, the TREND group published guidelines for Transparent Reporting of Evaluations with Non-randomised designs (Des Jarlais, Lyles, Crepaz, & Group, 2004). Both initiatives
were supported by scientific reporting guidance for authors (Hoffmann et al., 2014) and journal editors (Albrecht, Archibald, Arseneau, & Scott, 2013) developed by consensus by expert workgroups formed in response to an identified need.

More broadly, Craig et al. (2008) updated UK Medical Research Council (MRC) guidance on developing and evaluating complex health behaviour change interventions, outlining core intervention processes and components. These include: use of good quality evidence from a range of sources, use of psychological theory to identify modifiable behavioural determinants and to select appropriate BCT; use of causal modelling to understand the pathways between the behavioural determinants, the intervention and the desired outcome; and selection of evaluation design appropriate to priority population characteristics and context.

Health behaviour change intervention development theory and practice have also advanced with regard to classification of intervention content and utilisation of systematic frameworks to identify and target underlying psychological mechanisms of a specific health behaviours.

**2.4.2.1 Classification of intervention content: establishing a common language.** A welcome advance in the health behaviour change field, which addresses some of the limitations noted in Section 2.4.1, was the development of a 26-item classification system or behaviour change taxonomy, providing standardised descriptions of intervention content. Twenty-six theory-based behaviour change techniques (BCT) used in health behaviour change
interventions were identified, synthesised from six SCM and theoretical frameworks (Abraham & Michie, 2008).

In their influential work, the authors argued that use of commonly defined, theory-linked BCTs in future interventions would establish a common language and understanding of intervention content, providing opportunity for comparison across interventions, behavioural domains and research teams, as well as enhancing effectiveness and intervention fidelity. Since publication, the taxonomy has been used widely in intervention design, reporting, and evidence synthesis (Michie et al., 2011a). However, as noted by the authors, the original 26-item taxonomy was not exhaustive and since then, behaviour-specific BCT taxonomies (e.g. smoking cessation and physical activity; Michie et al., 2011b; Michie, Hyder, Walia, & West, 2011c) and a cross-behaviour 93-item taxonomy of BCT have been developed, expanding scope and application (Michie et al., 2013).

Shared classification of content via theory-based BCTs (including for interventions to increase attendance for DR screening, Lawrenson et al., 2016), are fundamental to the science of health behaviour change, and prospective inclusion of BCTs are recommended for diabetes-related interventions (Presseau et al., 2015). However it must be noted that the development of BCT taxonomies are is still evolving, with a recent analysis of 40 published interventions reporting that 80 of the 93 BCTs were identified in each intervention, suggesting that, in the interest of parsimony, further refinement of the 80 frequently observed BCTs was warranted (Abraham et al., 2015).
2.4.2.2 Intervention Mapping: a systematic framework for health behaviour change intervention development. Encompassing the MRC elements noted above, Bartholomew and colleagues (1998; 2001) developed a formal, systematic process for building interventions known as Intervention Mapping (IM), to assist program developers to apply ‘best practice’ guidance to the development of real-world health behaviour change problems. Using this framework, program developers were encouraged to adopt a problem-solving approach, using a theory-informed, in-depth needs assessment to explore underlying behavioural determinants specific to the problem, population and context, to be systematically targeted in an intervention tailored to the characteristics and context of the priority population (Bartholomew Eldredge et al., 2016). In order to ensure that a wide range of change mechanisms were considered, program developers using IM were advised to draw upon a range of theoretical constructs in preference to utilisation of a specific SCM; an approach recommended by leading scholars (Abraham, 2015; Davis, Campbell, Hildon, Hobbs, & Michie, 2015), with the challenge being to find “the best theory or combination of theoretical constructs” to address the problem at hand (Bartholomew Eldredge et al., 2016).

The IM framework comprises six iterative steps (Figure 4). Core activities in Step 1 include the formation of a multidisciplinary project planning team, detailed needs assessment to explore and identify individual-level behavioural (e.g. attitudes, knowledge, self-efficacy, cultural beliefs) and environmental determinants, development of a causal logic model of the problem depicting the
proposed relationship between problem and determinants, and clear statement of program goals.

In Step 2, the program planner specifies expected outcomes and Performance Objectives for the desired behaviour, develops a causal logic model of change depicting the proposed relationship between the determinants, the change methods and desired outcome, and constructs matrices of Change Objectives (CO) comprising determinants (columns) and Performance Objectives (PO, rows). Step 3 involves all aspects of program design, including development of program themes and components in collaboration with members of the priority population, selection of theory and evidence-based change methods and selection of practical intervention delivery application. Step 4 focuses on program production, including planning and drafting all content, pre-testing and refinement of the program with broad stakeholder input. Planning and design for program implementation is conducted in Step 5, starting with program adoption, planning for implementation and ensuring program maintenance. Finally, the program is evaluated in Step 6, including assessment of program fidelity, outcome, process and economic evaluation.
<table>
<thead>
<tr>
<th>Step 1: Logic model of the problem</th>
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<tbody>
<tr>
<td>Establish and work with a planning group</td>
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<tr>
<td>Conduct a needs assessment to create a logic model of the problem</td>
</tr>
<tr>
<td>Describe context for the intervention including the population, setting, and community</td>
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<tr>
<td>State program goals</td>
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<thead>
<tr>
<th>Step 2: Program outcomes and objectives; logic model of change</th>
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<tbody>
<tr>
<td>State expected outcomes for behaviour and environment</td>
</tr>
<tr>
<td>Specify Performance Objectives for behavioural and environmental outcomes</td>
</tr>
<tr>
<td>Select determinants for behavioural and environmental outcomes</td>
</tr>
<tr>
<td>Construct matrices of Change Objectives</td>
</tr>
<tr>
<td>Create logic model of change</td>
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</tbody>
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<tr>
<th>Step 3: Program design</th>
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<tbody>
<tr>
<td>Generate program themes, components, scope and sequence</td>
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<tr>
<td>Choose theory- and evidence-based change methods</td>
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<tr>
<td>Select or design practical applications to deliver change methods</td>
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<tr>
<th>Step 4: Program production</th>
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<tr>
<td>Refine program structure and organisation</td>
</tr>
<tr>
<td>Prepare plans for program materials</td>
</tr>
<tr>
<td>Draft message, materials and protocols</td>
</tr>
<tr>
<td>Pre-test, refine and produce materials</td>
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<tr>
<th>Step 5: Program implementation plan</th>
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<tbody>
<tr>
<td>Identify potential program users (implementers, adopters and maintainers)</td>
</tr>
<tr>
<td>State outcomes and Performance Objectives for program use</td>
</tr>
<tr>
<td>Construct matrices of Change Objectives for program use</td>
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<tr>
<td>Design implementation interventions</td>
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<tr>
<th>Step 6: Evaluation plan</th>
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<tr>
<td>Write effect and process evaluation questions</td>
</tr>
<tr>
<td>Develop indicators and measures for assessment</td>
</tr>
<tr>
<td>Specify the evaluation design</td>
</tr>
<tr>
<td>Complete evaluation plan</td>
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</table>

www.interventionmapping.com

*Figure 4: The six steps of Intervention Mapping*
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Intervention mapping has been used widely to guide the development of health behaviour change interventions at the patient/population, practitioner/provider and healthcare system levels, in a variety of contexts and with a range of populations (Bartholomew Eldredge et al, 2016). A core IM process cited as a major strength is the involvement of stakeholders (particularly the priority population and public involvement), which facilitates production of an intervention which is tailored and therefore relevant to the needs and characteristics of the priority population (Fernandez et al., 2009; Greaves et al., 2016; Willems et al., 2017; Wolfers, de Zwart, & Kok, 2012). This feature of IM is particularly important to this program of PhD research, as a recent meta-analytic review of text-based health behaviour change interventions, demonstrated that (in comparison to control conditions) tailored interventions, which match content to previously identified theoretically-grounded determinants from a behaviour change theory or model, have a greater impact on the target health behaviour (Noar, Benac, & Harris, 2007).

Previous IM-based interventions promoting screening uptake at the patient/population level have focussed on: breast and cervical cancer (Byrd et al., 2012; Fernandez, Gonzales, Tortolero-Luna, Partida, & Bartholomew, 2005; Highfield et al., 2015; Hou, Fernandez, Baumler, & Parcel, 2002; Vernon et al., 2008), colorectal cancer (Vernon et al., 2011), hepatitis B (Van Der Veen, Van Empelen, & Richardus, 2012) and utilisation of sexual health service by young people (Newby et al., 2017; Theunissen et al., 2013; Wolfers et al., 2012).

Although IM is a widely-used, positive advance in the development of health behaviour change interventions and the multitude of studies using the
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framework appears to endorse its utility, the framework has been critiqued for a lack of guidance on how to apply BCT and behaviour change methods for complex interventions in a coherent format (Lloyd, Logan, Greaves, & Wyatt, 2011). In addition, there exist a number of limitations to formulation of evidence-based conclusions of the overall effectiveness.

The first is lack of published evidence of the effectiveness of IM-based interventions. This was highlighted in a recent systematic review of evaluation trials of IM-based disease prevention interventions, which identified 168 IM-based studies describing the development of health promotion or disease prevention interventions, but only 22 studies evaluating such interventions (Garba & Gadanya, 2017).

The second limitation is poor quality of reporting of existing evaluation studies. Although each of the 22 studies successfully identified determinants of the uptake of the target behaviours, only five compared the IM-based program to control groups, with each reporting statistically significant increases in percentage uptake of the target disease prevention behaviour, including for screening (range: 9%-28%, p≤0.005; Garba & Gadanya, 2017). However, of the five noted above, an effect size was reported in just one study (Looijmans-vanden Akker et al., 2010), impeding interpretation and comparison.

Using a combination of two objective quality assessment tools, Garba and Gadanya (2017) rated 15 of the 22 studies as being of low methodological quality, observing that the majority did not report study design, data collection methods or statistical analysis; essential components of health behaviour change reports, noted earlier. Both barriers highlight a need for further development of
Step 6 of the IM framework, to include more explicit guidance for program users, and greater emphasis that intervention evaluation findings should be disseminated to the wider community irrespective of outcome, to contribute to IM knowledge base. More broadly, an additional issue which could not be ruled out by Garba and Gadanya (2017) was potential for publication bias, where manuscripts with null findings are less likely to be accepted for publication in preference to those with positive results (Jadad & Enkin, 2008) impacting the number of IM evaluations published.

Overall, IM provides an important and necessary bridge between intervention development theory and real-world practice, evidenced by the wide adoption of the framework in a multitude of contexts. Despite the evidence base being limited by lack of published evaluations and inconsistent quality of reporting, Garba and Gadanya (2017), conclude that IM-based studies are successful in identifying modifiable behavioural determinants and increasing uptake of disease prevention interventions, including screening behaviours, thus supporting the use of the IM framework in this program of PhD research.
2.5 Conclusion

In conclusion, DR is detectable via screening and effective treatments are available to slow its progression. Although lack of knowledge is a key retinal screening barrier, it does not fully explain low screening rates because most people living with diabetes know of a connection between diabetes and vision loss, and that eyes should be examined.

In the absence of DR symptoms, social cognitive factors such as attitudes, beliefs and self-efficacy, play an important role in motivating retinal screening and as such, a psychosocial approach is warranted. For example, the belief by young adults that eye examinations are only necessary for older people, or if symptoms are present (Shickle et al., 2014), and lack of age-appropriate diabetes education programs or resources identified in earlier studies (Browne et al., 2013a), are likely to be prominent factors.

To date however, paucity of research into the modifiable factors impacting retinal screening for young adults with T2D impedes the development of age-appropriate and evidence-based intervention materials which target determinants to screening behaviour. No qualitative studies have explored the nature of barriers or other factors contributing to low retinal screening rates among young adults with T2D, nor are there any retinal screening promotion interventions tailored to this priority population.

This literature review has drawn on existing evidence to demonstrate a theoretical understanding of the psychosocial determinants likely to impact retinal screening behaviour for young adults. A broad range of interventions are effective in promoting DR screening among adults with diabetes, including text-
based materials (such as leaflets and reminders), although their effectiveness has been limited. In contrast to current ‘best practice’, the content of earlier text-based intervention materials was generally didactic in nature, focussed primarily on mitigating lack of knowledge or awareness of DR. The absence of theoretically-derived, evidence-based persuasive messages, tailored to the contextual characteristics of the target group, may explain the limited effectiveness of earlier retinal screening interventions and lack of sustained impact.

Despite demonstrated low DR screening uptake, vulnerability to DR and disengagement with current diabetes services, and suboptimal health outcomes among young adults with T2D, there is a paucity of research exploring the factors impacting screening in this priority population, and no evidence-based interventions tailored specifically to their unmet needs. IM offers a suitable framework for development of a theoretically-grounded and evidence-based retinal screening intervention tailored to this priority population.

A vital first step in this process involves exploring and identifying individual-level barriers and facilitators, and modifiable behavioural determinants to screening behaviour for this priority population. The IMB model offers a suitable foundation upon which to base elicitation of DR screening determinants, enabling an evidence-based understanding of behaviour change, through which theory-based BCT can be matched to the identified mechanisms. Using the IM approach, intervention resources can be developed with the involvement of key stakeholders, including members of the priority population.
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2.6 References


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REducing risk of vision loss for young adults with type 2 diabetes


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medicine: What is it and how do we achieve it? *Annals of Behavioral Medicine, 26*(3), 161-171. doi: [http://dx.doi.org/10.1207/S15324796ABM2603_01](http://dx.doi.org/10.1207/S15324796ABM2603_01)


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Hussain, R., Rajesh, B., Giridhar, A., Gopalakrishnan, M., Sadasivan, S., James, J., . . . John, N. (2016). Knowledge and awareness about diabetes mellitus and diabetic retinopathy in suburban population of a South Indian state and its practice among the patients with diabetes mellitus: A population-
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the management of diabetes. *Journal of General Internal Medicine, 17*(7), 521-530.


diabetes at ophthalmic outpatient clinics. *Ophthalmic Epidemiology*, 14(6), 375-380. doi:10.1080/09286580701375195


health care workers in nursing homes: A cluster randomised controlled trial. *Vaccine, 28*(31), 5086-5092. doi:10.1016/j.vaccine.2010.05.003


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Silverstein, J., Cheng, P., Ruedy, K. J., Kollman, C., Beck, R. W., Klingensmith, G. J.,... Tamborlane, W. V. (2015). Depressive Symptoms in Youth With Type 1 or Type 2 Diabetes: Results of the Pediatric Diabetes Consortium Screening Assessment of Depression in Diabetes Study. *Diabetes Care, 38*(12), 2341-2343. doi:10.2337/dc15-0982


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and clinical audit improve the management of type 2 diabetic patients.

*Diabetes and metabolism, 25*(1), 55-63.


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2.7 Additional file 1: Literature Search Strategy and Summary of Findings

Population, Intervention, Control and Outcome (PICO)

- **Population:** all adults with diabetes who were eligible for screening but were either overdue (i.e. ‘lapsed’) or who had not initiated screening. Exclusion criteria: pediatric (<18 years)

- **Intervention:** all interventions designed to promote retinal screening. Studies were included if they were randomised controlled trials (RCTs), or non-randomised trials, of interventions. Cohort, observational, survey and qualitative studies were excluded.

- **Control or comparison groups:** classified as those who did not receive the intervention.

- **Outcome:** retinal screen for DR within a specified time frame.

**Search strategy**

1. Search terms were derived from Lawrenson et al. (2016) and Zhang et al. (2007), see Table 2 below.

2. Scoping of the PsychINFO database (via EBSCOHOST) found that 300 of the 309 papers were not relevant.

3. Search terms were refined, adding additional keyword limiters, and the search was repeated. As search terms were identifying RCTs of DR screening interventions, the search was repeated with key databases and double-checked results via Scopus and personal Endnote library (see Table 3 below).

4. Titles and abstracts (published in peer-reviewed journals in the English language from January 2005 to August 2017) were screened in relation to the
inclusion/exclusion criteria above, and full text retrieved for all potentially relevant studies.

5. Of the 28 abstracts screened, nine patient-level interventions were included in the review Table 1 (Section 2.3.1); reference lists were scanned for additional studies not identified in the search.

*Table 2: Literature search terms*

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Search terms</th>
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<tr>
<td>1: the condition</td>
<td>“diabetic retinopathy”</td>
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<td></td>
<td>“eye health”</td>
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<tr>
<td></td>
<td>vision</td>
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<td></td>
<td>ophthalmic</td>
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<td>2: the behaviour</td>
<td>screen*</td>
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<td></td>
<td>exam*</td>
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<tr>
<td></td>
<td>behaviour*</td>
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<tr>
<td></td>
<td>behavior*</td>
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<td>3: the method</td>
<td>intervention</td>
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<tr>
<td></td>
<td>tailor*</td>
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<td></td>
<td>target*</td>
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<td></td>
<td>program*</td>
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<td>4: the outcome</td>
<td>uptake</td>
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<td></td>
<td>compliance</td>
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<td></td>
<td>utili?at*</td>
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<td>adherence</td>
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**Summary of Findings**

*Table 3: Databases, literature search terms, and returned abstracts*

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<th>Database</th>
<th>Limiters</th>
<th>Abstracts^</th>
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<td>Psychinfo via</td>
<td>&quot;diabetic retinopathy&quot; OR &quot;diabetic retinopathy screening&quot; OR eye OR vision screen or screening or test OR exam* intervention or program* or strategy uptake OR attend* OR utili?at* OR promot*</td>
<td>9/309</td>
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<td>EBSCOHOST</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Medline complete</td>
<td>&quot;diabetic retinopathy&quot; OR &quot;eye health&quot; OR vision screen* or exam* or behavio?r* intervention or tailor* or target* or program* uptake or compliance or utili?at* or adherence</td>
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<tr>
<td>Embase</td>
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<td>Scopus*</td>
<td>(&quot;diabetic retinopathy&quot;) AND (screen* or exam*) and (intervention or program*) and (uptake or compliance or utili?at* or adherence) ABSTRACT ONLY</td>
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<td></td>
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<tr>
<td>Scopus</td>
<td>Added in ‘evaluation’</td>
<td>0/50</td>
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CHAPTER 3. What Factors Influence Uptake of Retinal Screening Among Young Adults with type 2 Diabetes? A Qualitative Study Informed By the Theoretical Domains Framework.\(^8\)

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\(^8\)This manuscript was published in *Journal of Diabetes and its Complications*, 31: 997-1006. The chapter has been formatted in APA style, to maintain consistency of structure and referencing throughout the thesis. Text content is identical to the published manuscript.
3.1  Authorship statement

1. Details of publication and executive author

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<tr>
<td>Amelia J. Lake</td>
<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td><a href="mailto:alake@acbrd.org.au">alake@acbrd.org.au</a></td>
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2. Inclusion of publication in a thesis

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<th>Is it intended to include this publication in a higher degree by research (HDR) thesis?</th>
<th>Yes</th>
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<td>If Yes, please complete Section 3. If No, go straight to Section 4.</td>
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3. HDR thesis author’s declaration

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
</tr>
</thead>
<tbody>
<tr>
<td>As above</td>
<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td>Reducing risk of vision loss for young adults with type 2 diabetes</td>
</tr>
</tbody>
</table>

If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

The thesis author managed the study, including contributing to the study methodology, design and development of the interview guide, planning and coordination of participant recruitment, ethics application, conduct of the interview guide validation activity and conduct of all participant interviews (data collection). The thesis author led the process of quality checking transcripts, data analysis and interpretation, including determination of coding themes and data coding (NVivo). The thesis author prepared the first and subsequent drafts of the manuscript.
4. Description of all author contributions

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Jessica L. Browne School of Psychology, Deakin University, Geelong, VIC Australia; The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, VIC Australia</td>
<td>Provided substantial input into the study methodology, design and development of interview guide. Substantial input into collaboratively reviewing coding decisions and determination of initial coding themes, data analysis and interpretation. Provided substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
<tr>
<td>Dr. Gwyneth Rees Centre for Eye Research Australia, Royal Victorian Eye and Ear Hospital, Melbourne, VIC Australia; Ophthalmology, Department of Surgery, University of Melbourne, Melbourne, VIC Australia</td>
<td>Provided substantial input into the study methodology, design and development of interview guide, including introduction to the theoretical domains framework.</td>
</tr>
<tr>
<td>Professor Jane Speight School of Psychology, Deakin University, Geelong, VIC Australia; The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, VIC Australia; AHP Research, Hornchurch, UK</td>
<td>Provided substantial input into the study methodology, design and development of interview guide. Substantial input into determination of coding themes, data analysis and interpretation. Provided substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
</tbody>
</table>
5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:

i. that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,
ii. that there are no other authors according to these criteria,
iii. that the description in Section 4 of my contribution(s) to this publication is accurate,
iv. that the data on which these findings are based are stored as set out in Section 7 below.

v. If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin University and, if the higher degree is awarded, the subsequent publication of the thesis by the university (subject to relevant Copyright provisions).

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Jessica L. Browne</td>
<td>[Signature]</td>
<td>23 October 2017</td>
</tr>
<tr>
<td>Dr. Gwyneth Rees</td>
<td>[Signature]</td>
<td>19 October 2017</td>
</tr>
<tr>
<td>Professor Jane Speight</td>
<td>[Signature]</td>
<td>19 October 2017</td>
</tr>
</tbody>
</table>

6. Other contributor declarations

I agree to be named as a non-author contributor to this work.

<table>
<thead>
<tr>
<th>Name and affiliation of contributor</th>
<th>Contribution</th>
<th>Signature* and date</th>
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</thead>
<tbody>
<tr>
<td>Not applicable</td>
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* If an author or contributor is unavailable or otherwise unable to sign the statement of authorship, the Head of Academic Unit may sign on their behalf, noting the reason for their unavailability, provided there is no evidence to suggest that the person would object to being named as author.

7. Data storage

The original data for this project are stored in the following locations. (The locations must be within an appropriate institutional setting. If the executive author is a Deakin staff member and data are stored outside Deakin University, permission for this must be given by the Head of Academic Unit within which the executive author is based.)
If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
3.2 Abstract

Aims: Young adults with type 2 diabetes (T2D, 18-39 years) face increased risk of vision loss from diabetic retinopathy (DR). Retinal screening is essential to detect DR, yet screening rates for this group are low and little is known about the underlying factors influencing this important behaviour. Using the Theoretical Domains Framework (TDF) to guide data collection and analysis, we explored screening barriers and facilitators, contrasting them with a comparator group of older adults with T2D (40+ years). Methods: Thirty semi-structured telephone interviews (10 younger, 20 older adults) were conducted. Data were coded into TDF domains with salience identified by “frequency” of reference. Screening facilitators and barriers were systematically compared between groups. Results: Although many screening facilitators and barriers were shared by younger and older adults, additional factors highly relevant to the former included: social comparison with others (‘social influences’); concern for the impact on the family unit, unrealistic optimism and perceived invulnerability (‘beliefs about consequences’); lack of time and financial resources (‘environmental context and resources’), and DR misconceptions (‘knowledge’). Conclusions: This study demonstrated that young adult retinal screening behaviour was influenced by additional social cognitive factors compared to older adults, providing a first-step evidence base for clinicians and other health professionals, and potential targets for future eye health and retinal screening interventions.

Keywords: type 2 diabetes, diabetic retinopathy, theoretical domains framework, qualitative research, young adults.
3.3 Introduction

Prevalence of young-onset type 2 diabetes (T2D), defined as a diagnosis before 40 years of age, is increasing worldwide, predisposing individuals to significant complication burden by the time they reach mid-life (Yeung et al., 2014). One such complication is diabetic retinopathy (DR), a leading cause of vision loss and blindness in working-age adults (Fong et al., 2004).

Retinal screening (henceforth ‘screening’) is key to the early detection of asymptomatic DR, with timely treatment significantly reducing risk of vision loss and blindness (Klein & Klein, 1997). Australian National guidelines recommend initiation of screening at diabetes diagnosis, and at least every two years thereafter, more often for those at higher risk (Mitchell & Foran, 2008).

Screening usually involves dilation of pupils with mydriasis drops, and slit lamp biomicroscopy or ophthalmoscope to detect presence and severity of DR. It is conducted by an optometrist or ophthalmologist in community settings, takes about 20 min and costs the individual about AUD$30.

Despite clear health benefits, some people with diabetes do not engage in screening. Common screening barriers for the general T2D population include lack of knowledge (e.g. DR, symptoms, confusion between screening and standard eye check), and practical obstacles (e.g. cost, time, access), (Al-Alawi, Al-Hassan, Chauhan, Al-Futais, & Khandekar, 2016; Ellish, Royak-Schaler, Passmore, & Higginbotham, 2007; Hartnett, Key, Loyacano, Horswell, & DeSalvo, 2005; Hipwell et al., 2014; John, Cooper, & Serrant-Green, 2014; Lewis, Patel, Yorston, & Charteris, 2007). Despite recognition of the crucial role that psychosocial factors play in diabetes self-management activities (Peyrot et al.,...
REduCING RISK OF VISION LOSS FOR youNG ADULTS WITH tyPe 2 DIABETES

2005), few studies have focussed specifically on exploring in-depth their impact on screening behaviour. Those that have, report that key barriers include lowered perception of risk, fear of outcome, and guilt with regard to suboptimal blood glucose management (Al-Alawi et al., 2016; Hipwell et al., 2014; Lewis et al., 2007).

Similarly, despite their value in promoting DR screening behaviour, few studies have specifically explored facilitating factors, beyond the assumption that they are the opposite of identified barriers. Those that have, report common screening facilitators as knowledge of DR, recommendation by GP, and social support (Ellish et al., 2007; Hartnett et al., 2005; John et al., 2014). Notably, the average age of participants with T2D in the above studies (where reported) was 60 years and most studies did not distinguish between diabetes types.

Although data are sparse, screening rates for young adults are low, despite high risk of early-onset and rapid progression of DR (Hanman et al., 2014; Li et al., 2015; Rajalakshmi et al., 2014; Song & Gray, 2011; Tryggestad & Willi, 2015). In Australia, a small survey of 16-35 year olds with T2D (average age 29 years) reported a 55% screening rate (Diabetes Australia, 2006), while a larger, population-based study conducted at a similar time reported that 77% of adults with T2D (average age 64 years) had engaged in retinal screening in the past two years (Tapp et al., 2004).

Young adults with T2D differ clinically, physiologically and psychosocially from older adults with T2D, and young adults with T1D (Browne, Nefs, Pouwer, & Speight, 2014; Gregg, Sattar, & Ali, 2016; Song, 2012). Previous research has established that young adults with T2D face unique barriers to diabetes self-
management, report dissatisfaction and disengagement with existing diabetes support programmes and services, and have specific unmet psychosocial and information needs (Browne, Scibilia, & Speight, 2013; Savage, Dabkowski, & Dunning, 2009). Despite increasing calls for concerted and targeted intervention to reduce the risk of long-term complications (Amutha & Mohan, 2016; Benhalima et al., 2011; Browne et al., 2014; Li et al., 2015; MacLennan, McGwin, Heckemeyer, & et al., 2014; Tryggestad & Willi, 2015; Wilmot & Idris, 2014), no studies, to our knowledge, have focussed specifically on the facilitators and barriers influencing screening behaviour in young adults with T2D.

Facilitators of, and barriers to, screening behaviour can be identified systematically using the Theoretical Domains Framework (TDF, Table 4). Focusing on individual-level determinants, the TDF comprises fourteen domains, derived from 33 behaviour change theories and 128 theoretical constructs (Cane, O'Connor, & Michie, 2012). Each domain comprises multiple, related but distinct component constructs. For example, the TDF domain ‘knowledge’ (defined as ‘an awareness of the existence of something’), comprises ‘knowledge of condition’, ‘scientific rationale’, and ‘procedural knowledge’. Participant information captured for this domain would include knowledge of DR risk factors, an understanding of the reasons for screening, and how to arrange the procedure. See Table 4 for definitions of each TDF domain and component constructs associated with the target behaviour.
Table 4: Definition of TDF domains and component constructs associated with retinal screening behaviour

<table>
<thead>
<tr>
<th>TDF domain and definition</th>
<th>Component constructs and additional behaviour specific beliefs used in coding framework</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge</strong>: Awareness of the existence of something</td>
<td><strong>Knowledge, procedural knowledge</strong>: Absence/presence of knowledge of: connection between diabetes and eye health, DR prevention activities and risk factors, DR symptoms, rationale for screening. Eye health misconceptions. When to initiation screening, and relevant intervals.</td>
</tr>
<tr>
<td><strong>Skills</strong>: Ability or proficiency acquired through practice</td>
<td><strong>Skills, competence</strong>: Ability to attend screening (including viewing screening as 'routine').</td>
</tr>
<tr>
<td><strong>Social professional role and identity</strong>: A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting</td>
<td><strong>Social and group identity</strong>: How the individual views screening behaviour relative to their identity (e.g. What kind of person has eye exams?).</td>
</tr>
<tr>
<td><strong>Beliefs about capabilities</strong>: Acceptance of the truth/reality about or validity of an ability, talent or facility that a person can put to constructive use</td>
<td><strong>Self-confidence, perceived competence, perceived behavioural control, self-efficacy</strong>: The extent to which the individual believes they are able to influence their eye health and attend screening.</td>
</tr>
<tr>
<td><strong>Optimism</strong>: Confidence that things will happen for the best or that desired goals will be attained</td>
<td><strong>Optimism, pessimism, unrealistic optimism</strong>: regarding susceptibility to DR or vision loss.</td>
</tr>
</tbody>
</table>
Table 4: Definition of TDF domains and component constructs associated with retinal screening behaviour (Cont.)

<table>
<thead>
<tr>
<th>TDF domain and definition</th>
<th>Component constructs and additional behaviour specific beliefs used in coding framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs about consequences: Acceptance of the truth/reality about or validity of outcomes of a behaviour in a given situation</td>
<td>Beliefs, outcome expectancies, consequents: Emotional expressions of regret or concern about the consequences of not attending screening or of vision loss. Beliefs regarding utility, effectiveness or value of screening. Anticipated outcomes of not participating in screening; anticipated or experienced outcomes of screening (positive or negative).</td>
</tr>
<tr>
<td>Reinforcement: Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus</td>
<td>Reinforcement, consequents: Screening to avoid or remove negative outcomes, screening to gain positive outcome.</td>
</tr>
<tr>
<td>Intentions: Conscious decisions to perform a behaviour or a resolve to act in a certain way</td>
<td>Stability of intentions, statement of intention: to engage in or maintain screening (or otherwise).</td>
</tr>
<tr>
<td>Goals: Mental representations of outcomes or end states that an individual wants to achieve</td>
<td>Goal priority, goals: for eye health and preservation of vision.</td>
</tr>
</tbody>
</table>
REducing risk of vision loss for young adults with type 2 diabetes

Table 4: Definition of TDF domains and component constructs associated with retinal screening behaviour (Cont.)

<table>
<thead>
<tr>
<th>TDF domain and definition</th>
<th>Component constructs and additional behaviour specific beliefs used in coding framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory attention decision processes: Ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives</td>
<td><strong>Memory, attention control, decision making, cognitive overload:</strong> The role of memory and act of remembering to ensure that screening is done (cognitive component only; behavioural component is linked to Action Planning). Feelings of being overwhelmed by diabetes diagnosis/management or life stresses (which may limit attention control with respect to screening behaviour).</td>
</tr>
<tr>
<td>Environmental context and resources: Any circumstance of a person’s situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour</td>
<td><strong>Environmental stressors, resources, salient events, and person x environment interaction:</strong> Environmental constructs include stressors such as cost, lack of time, illness and the experience of mydriasis. Facilitators may include ease and accessibility of screening.</td>
</tr>
<tr>
<td>Social influences: Interpersonal processes that can cause individuals to change their thoughts, feelings or behaviors</td>
<td><strong>Social pressure, social norms, social comparison, social support:</strong> Belief in authority of healthcare professionals; experience of professional and personal influence (including clinical inertia), experience of social support (positive or negative)</td>
</tr>
<tr>
<td>TDF domain and definition</td>
<td>Component constructs and additional behaviour specific beliefs used in coding framework</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Emotion: A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event</td>
<td><strong>Positive/negative affect, fear, anxiety, stress:</strong> Negative emotions may include expressions of fear, anxiety or sadness at the prospect of vision loss/DR diagnosis. Positive emotions may include relief/reassurance following screening.</td>
</tr>
<tr>
<td><strong>Behavioral regulation:</strong> Anything aimed at managing or changing objectively observed or measured actions</td>
<td><strong>Action planning:</strong> Steps taken to ensure that screening is remembered and conducted (includes absence of planning).</td>
</tr>
</tbody>
</table>

DR: diabetic retinopathy
Predominantly focussed on implementation challenges within healthcare systems and/or clinician behaviour, the TDF has been used increasingly to understand patient-level uptake of health behaviours (Burgess et al., 2015; Gray-Burrows et al., 2016) and, even in well-researched areas, has elicited previously unidentified psychosocial factors impacting the target behaviour (Dyson, Lawton, Jackson, & Cheater, 2011). A major benefit to using a framework such as the TDF is the systematic assessment of health behaviour implementation problems, allowing identification of key influencing domains and targets for intervention.

Thus, the aim of this study was to explore facilitators and barriers associated with retinal screening among young adults with T2D. In order to determine the relative influence of factors; we systematically compared young adults with a parallel group of older adults with T2D (for whom the majority of existing management guidelines, services and resources are developed). Following this method, we aimed to highlight key differences between the two groups, thereby contributing to clinician's knowledge of the burgeoning young adults with T2D population and identifying cohort-specific targets for intervention.
3.4 Subjects, Materials and Methods

3.4.1 Study design. Semi-structured telephone interviews were conducted using an interview guide developed and validated specifically for this study.

3.4.2 Participants. Younger adults (YA, aged 18-39 years) and older adults (OA, aged 40+ years) with T2D were eligible to participate. Exclusion criteria were: non-English speaking, other diabetes types (e.g. type 1, gestational) and evidence of cognitive impairment.

In anticipation of YA recruitment challenges (Savage et al., 2009; Turner et al., 2015), the study was advertised widely online (diabetes advocacy websites, social media, young adult support groups) and in community settings, as well as via postal invitations to members of a leading state-based diabetes consumer and advocacy organisation.

During the initial recruitment period, only two YA registered interest, necessitating a revision of the incentive (upgraded from a $20 department store voucher to a chance to win an iPad Mini) and timeline (extended by an additional three months).

3.4.3 Development and validation of interview guide. A 34-item, semi-structured interview guide was developed to explore screening facilitators and barriers, with items informed by published TDF-based interview guides (Burgess et al., 2015; Curran et al., 2013). To ensure that items accurately represented TDF domains, an online validation activity was conducted anonymously with 16
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volunteer clinicians/researchers from health/clinical psychology or health service backgrounds.

Each expert matched randomised items with clearly defined TDF domains. Concordance between nominated and intended domains was acceptable for 26 of the original 34 items (average 76%). The remaining eight items were revised, and five more added in response to reviewer feedback. The final interview guide (Appendix C) comprised 39 TDF-based questions, which were ordered to minimise the potential for introducing a knowledge bias to subsequent items. Sample questions for each of the 14 TDF domains are presented in Table 5.

Table 5: Example topic guide items by TDF domain

<table>
<thead>
<tr>
<th>Topic guide items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Knowledge:</strong> Are you aware of a connection between diabetes and eye health? Do you know of anything that a person can do to reduce their risk of getting retinopathy, or of slowing its progress?</td>
</tr>
<tr>
<td><strong>2. Skills</strong> Can you please describe how you would go about getting an eye examination?</td>
</tr>
<tr>
<td><strong>3. Social professional role and identity:</strong> What does having eye examinations mean to you? (Prompt: what kind of person are they?)</td>
</tr>
<tr>
<td><strong>4. Beliefs about capabilities:</strong> One a scale of 0 –10, where 0 is ‘not at all confident’ and 10 is ‘very confident’, how confident are you that you can talk to your GP or diabetes educator about eye examinations? What makes it easy/hard? What do you think would help you to overcome these problems?</td>
</tr>
<tr>
<td><strong>5. Optimism:</strong> Do you think that you are likely to experience vision problems due to diabetes?</td>
</tr>
<tr>
<td><strong>6. Beliefs about consequences:</strong> What are the positive benefits to having eye exams? Are there are any negatives or ‘down sides’ to having eye exams? What do you expect will happen if you don’t have regular eye examinations?</td>
</tr>
</tbody>
</table>
### Table 5: Example topic guide items by TDF domain (Cont.)

<table>
<thead>
<tr>
<th>Topic guide items (Cont.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7. Reinforcement:</strong> (If previous eye exam) Did the experience of having an eye examination make it more or less likely that you would have another one in the future?</td>
</tr>
<tr>
<td><strong>8. Intentions:</strong> Considering your other competing priorities...how likely is it for you to have eye examinations when they are next due? What are higher priorities and why?</td>
</tr>
<tr>
<td><strong>9. Goals:</strong> Considering your other priorities...how important is it for you to maintain your current vision? What are higher priorities and why?</td>
</tr>
<tr>
<td><strong>10. Memory attention decision processes:</strong> Have you ever forgotten, or delayed, an eye examination when it was due? Do you know why?</td>
</tr>
<tr>
<td><strong>11. Environmental context and resources:</strong> Sometimes our plans are hindered by things outside of our control. What things, outside of your control, could make it harder for you to have regular eye exams? What things could make it easier?</td>
</tr>
<tr>
<td><strong>12. Social influences:</strong> Have you been prompted by someone to have an eye examination? If Y, who? Has anyone you know had an eye examination for DR?</td>
</tr>
<tr>
<td><strong>13. Emotion:</strong> Can you please imagine/think back to when you are having an eye examination, what thoughts or feelings would you/did you, have?</td>
</tr>
<tr>
<td><strong>14. Behavioural regulation:</strong> Eye examinations don’t have to be done as often as other diabetes self-care tasks. If you want to have an eye examination, how do you think you will remember/remind yourself?)</td>
</tr>
</tbody>
</table>
3.4.4 **Procedure.** Semi-structured telephone interviews were conducted by an experienced interviewer with post-graduate training in health psychology (AL), (average length: 55 min, range: 31-106 min). All interviews were recorded, professionally transcribed, and de-identified. Demographic data were collected to describe the sample.

3.4.5 **Data handling and analysis**

3.4.5.1 **Development of coding framework.** As young adults with T2D are a sub-group of adults with T2D, we anticipated that differences between young adults and their older adult counterparts were likely to emerge at a component construct level, rather than a domain level. A coding framework was developed deductively by AL and JB, using the TDF domains and all component constructs as the foundation. Some of the component constructs were subsequently excluded because they were irrelevant, not evident in the data, or overlapped closely with similar constructs. For example, ‘knowledge of task environment’ and ‘procedural knowledge’ (both component constructs within the ‘knowledge’ domain) were indiscernible in the data and so the former was collapsed into the latter code. At this point, we found that the component constructs within some domains did not adequately provide the level of detail required to facilitate interpretation of our data, particularly when comparing young adults with T2D with their older adult counterparts. In these instances, we followed the example of other TDF-based studies and inductively generated additional sub-theme labels, which represented a belief statement specific to the target behaviour (Birken, Presseau, Ellis, Gerstel, & Mayer, 2014; Newlands et al., 2016). Using ‘Knowledge’ as an example, an additional sub-theme was ‘misconceptions about
eye health', which in turn, was a barrier to retinal screening (see Table 4 for description of component constructs and behaviour specific sub-themes used in coding framework). Once the framework and coding strategy was finalised, AL and JB independently coded 20% of transcripts. Inter-rater agreement was high (99.4%) with minor discrepancies resolved through discussion. The remaining transcripts were coded by AL.

3.4.5.2 Data coding and analysis. The primary coder (AL) conducted extensive data familiarisation of interview transcripts and kept notes in a reflective diary to ensure a clear overview of the material. All interview transcripts were checked for accuracy and imported into NVivo10 (QSR International Pty Ltd, Doncaster, VIC., Australia, 2012). Each participant utterance was coded for the relevant component construct or theme within a TDF domain(s), and again as either ‘facilitator’ or ‘barrier’ dependent upon the context in which the participant made the utterance. For example, responses to the question “do you know of anything that a person can do to reduce their risk of getting retinopathy, or of slowing its progress?” were coded as ‘knowledge of condition’ within the TDF ‘Knowledge’ domain. Correct responses, such as “keeping blood sugars under control and definitely having regular eye checks” (ID06_OA) were coded as a ‘facilitator’; incorrect description or utterances expressing lack of knowledge, such as “No, I don’t know how I can avoid it” (ID41_YA), were coded as ‘barrier’. Further, the same utterances would have been coded under a component construct or theme within the ‘Social influence’ TDF domain if they made direct reference to the presence (or absence) of recommendation from their GP.
Using a common approach (Birken et al., 2014; Bussieres et al., 2012), TDF domains were judged for relevance based on the relative frequency of coding for each TDF domain, which had been aggregated from all component constructs and behaviour-specific belief statements within that domain. TDF domains were then rank-ordered according to the relative frequency of coding (we interpreted higher frequency of utterance to indicate higher salience). Data analysis was conducted separately for facilitators and barriers and results were reported for each group. As a final step, the facilitators/barriers and those TDF domains most frequently coded for each group were systematically compared between YA and OA, to identify and contrast those of greatest salience to each group.
3.5 Results

3.5.1 Participant characteristics. Forty-nine people (14 YA, 35 OA) expressed interest in the study and were screened for eligibility by telephone. All YA were eligible and were mailed study information; 10 YA returned signed consent forms, the remaining four could not be contacted. Of the 10 YA, five reported no previous screen, and a sixth was overdue. Of the 35 OA, two were ineligible (one did not have T2D, one showed evidence of cognitive impairment). We purposively selected 20 OA to ensure representation in a range of demographic factors. Each was mailed study information and all returned signed consent forms. All of the 20 OA had previously engaged in retinal screening and none were overdue. Participant characteristics are presented in Table 6.
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

Table 6: Participants’ demographic and self-reported clinical characteristics by age group

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Young adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>32.6 (32.0-34.8)</td>
<td>62.5 (55.9-72.8)</td>
</tr>
<tr>
<td>Women</td>
<td>5 (50)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Geographic location&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major metropolitan</td>
<td>8 (80)</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Inner regional</td>
<td>2 (20)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Outer regional</td>
<td>0 (0)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>6 (60)</td>
<td>14 (70)</td>
</tr>
<tr>
<td>UK</td>
<td>0 (0)</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Asia (incl India, Sri Lanka)</td>
<td>3 (30)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Africa</td>
<td>1 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Age at diabetes diagnosis, years</td>
<td>30.5 (28.2-32.0)</td>
<td>51.5 (47.5-60.5)</td>
</tr>
<tr>
<td>Duration of diabetes, years</td>
<td>1.45 (0.3-4.5)</td>
<td>13.0 (2.8-15.3)</td>
</tr>
<tr>
<td>Previous retinal screen&lt;sup&gt;b&lt;/sup&gt;</td>
<td>5 (50)</td>
<td>20 (100)</td>
</tr>
<tr>
<td>Diagnosis of diabetic retinopathy&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0 (0)</td>
<td>5 (25)</td>
</tr>
</tbody>
</table>

Data are median (interquartile range) or number (%),
<sup>a</sup> Australian Standard Geographical Classification (ASGC) remoteness index
<sup>b</sup> Self-report data

Median age was 33 years for YA and 63 years for OA and median diabetes duration was 1.5 and 13 years, respectively. Gender was distributed equally in both groups, although geographic location was not, with 20% OA residing in outer regional areas compared to no YA. The majority of YA and OA participants were Australian-born.

3.5.2 Facilitators of and barriers to screening. More than 80% of all facilitator references for both YA and OA were captured by the same six TDF domains: ‘social influences’, ‘beliefs about consequences’, ‘reinforcement’, ‘intentions’, ‘emotion’, and ‘knowledge’. Similarly, more than 80% of all barrier
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

references for YA and OA were accounted for by five domains, the first four of which were shared: ‘environmental context and resources’, ‘knowledge’, ‘social influences’, and ‘beliefs about consequences’. The fifth barrier domain was cohort-specific: ‘emotion’ for YA, and ‘behavioural regulation’ for OA participants. All further description of study results focuses on the above TDF domains.

Overall, each YA and OA participant made a similar number of references to screening facilitators (averaging 26 and 29, respectively). In contrast, YA made more references to screening barriers than their OA counterparts (averaging 19 and 6, respectively). A summary of facilitator and barrier TDF domains, including relative rank and frequency of reference are presented in Table 7.
### Table 7: Summary of facilitator and barrier TDF domains for younger and older adults

<table>
<thead>
<tr>
<th>TDF domain</th>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rank order</td>
<td>Freq. of utterance</td>
</tr>
<tr>
<td><strong>Facilitators to retinal screening</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social influences</td>
<td>1</td>
<td>58</td>
</tr>
<tr>
<td>Belief about conseq.</td>
<td>2</td>
<td>46</td>
</tr>
<tr>
<td>Reinforcement</td>
<td>3</td>
<td>34</td>
</tr>
<tr>
<td>Intentions</td>
<td>4</td>
<td>28</td>
</tr>
<tr>
<td>Emotion</td>
<td>5</td>
<td>27</td>
</tr>
<tr>
<td>Knowledge</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>Env. context/resources</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Goals</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Belief about capability</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Social professional role and identity</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Behaviour regulation</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Skills</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Memory, attention &amp; decision making</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Optimism</td>
<td>N/A</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>261</strong></td>
<td><strong>100</strong></td>
</tr>
<tr>
<td><strong>Av. utterance per participant</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* The TDF domains accounting for the top 80% of all utterances in either the facilitator or barrier categories are presented above the double line
Table 7: Summary of facilitator and barrier TDF domains for younger and older adults (Cont.)

<table>
<thead>
<tr>
<th>TDF domain</th>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rank order</td>
<td>Freq. of utterance</td>
<td>% of total utterance</td>
<td>Rank order</td>
</tr>
<tr>
<td>Barriers to retinal screening*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Env. context/resources</td>
<td>1</td>
<td>63</td>
<td>34</td>
<td>1</td>
</tr>
<tr>
<td>Social Influences</td>
<td>2</td>
<td>28</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Knowledge</td>
<td>3</td>
<td>26</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Belief about conseq.</td>
<td>4</td>
<td>18</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Emotion</td>
<td>5</td>
<td>17</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Behaviour regulation</td>
<td>8</td>
<td>7</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Belief about capability</td>
<td>6</td>
<td>14</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Optimism</td>
<td>7</td>
<td>8</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Memory, attention &amp; decision making</td>
<td>8</td>
<td>7</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Social professional role and identity</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Reinforcement</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Intention</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Goals</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Skills</td>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>Total</td>
<td>188</td>
<td>100</td>
<td></td>
<td>126</td>
</tr>
<tr>
<td>Av. utterance per participant</td>
<td>19</td>
<td>6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* The TDF domains accounting for the top 80% of all utterances in either the facilitator or barrier categories are presented above the double line.
Although YA and OA participants shared the majority of facilitator and barrier domains (with slight differences in relative rank), considerable differences were observed with respect to component constructs and key beliefs once the data were analysed qualitatively; illustrative quotes are presented in Table 8 and Table 9 below.

3.5.2.1 Facilitators

3.5.2.1.1 Social influences. The influence of others, particularly health professionals, was noted as a screening facilitator for both YA and OA. Participants indicated that they placed high value on advice from their GP, with a common view being “if a GP says get a test, I get a test” (ID38_YA), while others screened to “keep my doctor and endocrinologist happy” (ID39_YA). Individuals who were advised by their GP to have an eye examination, or were referred to an eye specialist for screening at diagnosis, reported initiating screening in a timely manner. Participants also indicated that when it came to screening, they were reminded by family members and friends, who were “the ones that care about me the most, and want me to be around for as long as possible” (ID36_YA).

Among YA only, social comparison was a strong facilitator of screening. When asked who would influence their uptake of screening, a common response was “another diabetic patient who had the same control as myself but had some eye problems” (ID33_YA).
3.5.2.1.2 Beliefs about consequences The overwhelming belief expressed by YA and OA participants was that the benefits of screening, such as early detection of DR and feeling reassured, outweighed the negatives. Description of common barriers or disadvantages, such as cost or discomfort due to mydriasis, were commonly followed by counteracting views, such as screening is a “wise spend” (ID32_YA) and “the stinging is not for long” (ID20_OA).

Although most participants understood that screening was undertaken for the early detection of DR, YA and OA participants expressed optimism that there “shouldn’t be any problems with [my] eyesight” (ID33_YA).

Shared too, were the beliefs regarding consequences if screening was missed. Both YA and OA anticipated feelings of regret and expectations of a poor outcome, such as vision loss. However, YA regularly focussed on the impact this would have on their family, summed up by one single mother who explained “ultimately if I lose my vision, it’s going to affect everybody, so I had to make it [screening] a high priority” (ID32_YA).
3.5.2.1.3 Reinforcement. Participants cited rewards associated with screening (i.e. positive reinforcement) when receiving an all-clear screening result as an important facilitator. A positive screening outcome was often subsequently interpreted by the participant as an indicator that they were “managing my diabetes well” (ID12_OA). Having an eye examination in order to avoid negative outcomes (i.e. negative reinforcement), where “the eyes might deteriorate without being detected” (ID04_OA) was also a strong shared facilitator. This was particularly true of OA who commonly stated that they engaged in screening to preserve their independence, including their “driving licence, which is very precious” (ID07_OA).

3.5.2.1.4 Intentions. The majority of YA and OA participants indicated high screening intention, including YA who had not screened: “I need to get my eyes checked soon, just to know” (ID38_YA). Older adults rarely had their good intentions thwarted by barriers, with one stating “it couldn’t be any easier” (ID20_OA). In contrast, YA intention statements were often followed by a list of barriers. For example, one YA who was overdue for screening, stated: “I’ve...a building project happening, I had to go overseas, I had to go home for about three months... [we’re] expecting another child...life is hectic” (ID34_YA).
3.5.2.1.5 Emotion. Young adult and OA participants who engaged in screening reported feeling “comfortable and positive” (ID33_YA) about the behaviour, indicating feelings of “assurance [and] peace of mind” (ID08_OA). Many described positive emotions such as “relief when [the optometrist] says that everything is fine” (ID14_OA), leaving the examination “feeling in a good mood” (ID40_YA) with “absolute evidence that things are great” (ID15_OA). An additional emotion facilitating ongoing screening was enjoyment of the experience itself: “the really exciting thing is you can actually see your eyes and your vessels” (ID15_OA).

3.5.2.1.6 Knowledge. Young adults and OA demonstrated basic knowledge about the connection between diabetes and eye health, and the steps required to undergo screening, but detailed knowledge was lacking. When asked to list anything that a person could do to reduce their risk of getting DR, or of slowing its progress, most participants were unable to specify more detail beyond “trying to keep your blood sugars at ... normal level” (ID04_OA). Similarly, although most participants understood that regular screening was necessary, they were unable to articulate clearly when to initiate and how often to attend, with no differences between YA and OA.
Table 8: Illustrative quotes for main facilitators of screening (TDF domains and constructs) for younger and older adults

<table>
<thead>
<tr>
<th>Social Influences</th>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Professional influence.</td>
<td>“I had got a few reading materials from NDSS when I was signed up, and I found it was advised in that that I should get an annual eye checkups, so I thought I should go ahead with it.” ID37</td>
<td>“When I first got diagnosed...they sent me to the optometrist. I said ’Why am I going to an optometrist?’ and he [GP] explained that this is what could happen and I said ‘Ok, I’ll go’.” ID05</td>
</tr>
<tr>
<td>b. Personal influence from family/friends</td>
<td>“My wife...she’s always encouraging me, she always reminds me. She’s always asking ‘Are you due for an eye check. Have you done your eye check’?” ID34</td>
<td>“My daughter would nag me. She is very bossy and intelligent and has my best interest at heart. My husband would tell me to have an eye exam because he worries that I won’t be able to look after him.” ID06</td>
</tr>
<tr>
<td>c. Social norms</td>
<td>“Someone that’s informed and responsible would have an eye exam...I think you would have to be pretty negligent to leave it.” ID32</td>
<td>“They’re taking responsibility for their actions and for their medical state...if you didn’t have an eye examination you’d be an absolute idiot.” ID02</td>
</tr>
</tbody>
</table>
### Table 8: Illustrative quotes for main facilitators of screening (TDF domains and constructs) for younger and older adults* (Cont.)

<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Influences (Cont.)</strong></td>
<td></td>
</tr>
</tbody>
</table>
| d. **Comparison with others**. “I was talking to a friend before my exam yesterday and she’s now got it [DR] in both eyes...I have empathy for [her], but then I think ‘Gee, I’m glad it’s not me’...this is why I go and get my eyes tested every year”.

ID40 |
| **Beliefs about Consequences** |                      |
| a. **Beliefs about the value of screening** |                      |
| “I think at least having [screening] every two years is...vital to ensure good eye health.” ID39 | “[Eye examinations] are an important part of regular health monitoring, so they are a good thing.” ID11 |
| b. **Expectations of a positive outcome** |                      |
| “I have confidence when I go there, my sugar is under control, so I generally expect good results.” ID33 | “I just expect to get an all clear. That’s my expectation. I go in there expecting everything to be looking pretty good and I expect something from the optometrist to say ‘Look, it’s all great, it’s on track, nothing is happening’...It’s just that well-being feeling that you’re okay.” ID15 |
### Table 8: Illustrative quotes for main facilitators of screening (TDF domains and constructs) for younger and older adults (Cont.)

<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Beliefs about Consequences (Cont.)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>c. Anticipated regret</strong></td>
<td></td>
</tr>
<tr>
<td>“[If I don’t have screening] I’ll be under mental torture. I’ll be thinking about it, ‘Oh my gosh, is something wrong with my eyes?’ So, I’d rather go and get it done then, go ahead, even with the discomfort [otherwise] the rest of the days I’d be thinking something is wrong with my eyes.” ID37</td>
<td></td>
</tr>
<tr>
<td>“I need to go so I can get it checked out. There’s no other way I can really put it...if you have a problem and it builds up, you might not know until it’s too late. And then you end up blind, don’t you?” ID17</td>
<td></td>
</tr>
<tr>
<td><strong>d. Impact of vision loss on family.</strong> “I drive, going to work, coming back home and on the weekend I’m driving family around...I need my eyes to do all these things.” ID34</td>
<td></td>
</tr>
<tr>
<td><strong>Reinforcement</strong></td>
<td></td>
</tr>
<tr>
<td><strong>a. Positive reinforcement (screening to gain a positive outcome)</strong></td>
<td></td>
</tr>
<tr>
<td>“I think if I can keep my doctor and endocrinologist happy its good.” ID39</td>
<td></td>
</tr>
<tr>
<td>“I’ll always have [screening]...just to make sure my eyes remain healthy.” ID07</td>
<td></td>
</tr>
<tr>
<td><strong>b. Negative reinforcement (screening to avoid a negative outcome)</strong></td>
<td></td>
</tr>
<tr>
<td>“I always think if I don’t go, I won’t know; but then I really want to know because then it would be worse next time.” ID40</td>
<td></td>
</tr>
<tr>
<td>“Just to make sure that my eyes are being looked after, and if there was a problem starting, then hopefully it can be rectified before it gets too bad.” ID20</td>
<td></td>
</tr>
</tbody>
</table>
### Table 8: Illustrative quotes for main facilitators of screening (TDF domains and constructs) for younger and older adults (Cont.)

<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reinforcement (Cont.)</strong></td>
<td></td>
</tr>
<tr>
<td>c. Avoiding vision loss – preservation of independence</td>
<td>“You need your sight to be able to get around. It would mean a loss of independence, having to rely on people to do things for you, take you places. I would find that difficult because I’m an independent person.” ID14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Intentions</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Intention to commence or maintain screening</td>
</tr>
<tr>
<td>“I’ve been in Australia probably six years now and I always did it [screening].” ID33</td>
</tr>
<tr>
<td>“I’d come back from holidays to have one. How’s that!” ID08</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Emotion</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive emotions related to screening</td>
</tr>
<tr>
<td>“I was having a ball...’the chair is going up, the chair is going down.’ I’ve had orange dye put in my eyes, which I just loved...it was actually nice to relax and not have to worry about the kids.” ID32</td>
</tr>
<tr>
<td>“Well, straight after the last time, the optometrist said ‘You’re eyes are fine, no problems whatsoever’ and I’m like ‘What, so there’s no damage?’ and he goes ‘No, you’re doing really good’ and it’s just a sigh of relief.” ID05</td>
</tr>
</tbody>
</table>
**Table 8: Illustrative quotes for main facilitators of screening (TDF domains and constructs) for younger and older adults*** (Cont.)

<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge</strong></td>
<td></td>
</tr>
<tr>
<td>a. <strong>Knowledge of the connection between diabetes and eye health</strong></td>
<td></td>
</tr>
<tr>
<td>“[The] moment you don’t keep your blood pressure in target then you are going to have those blood vessels leaking...and if you don’t go for regular examinations you don’t know if there is damage happening to you.” ID34</td>
<td>“I got onto the internet and learnt about [diabetes]. I knew that I had to watch my eyes and the circulation around my feet.” ID01</td>
</tr>
<tr>
<td>b. <strong>Knowledge of the purpose of screening</strong></td>
<td></td>
</tr>
<tr>
<td>“Going once a year to get your eyes checked, to make sure that there’s no issues with the eyes. You can’t just look at someone’s eye and go ‘yep, you’re okay’, you need to take that... photo of the back of the retina of the eye.” ID39</td>
<td>“I always understand that eyes and feet are so important in diabetes and that’s why I think it’s important that you have the eye test annually.” ID08</td>
</tr>
</tbody>
</table>

*Blank cells indicate that the facilitator or component construct was not frequently discussed by that group*

NDSS: National Diabetes Service Scheme, GP: General Practitioner
3.5.2.2 Barrier.

3.5.2.2.1 Environmental context and resources. Older adults mentioned the cost of screening, but commonly indicated: “I can afford that” (ID06_OA). In contrast, cost was a prominent barrier for YA, some of whom reported experiencing “financial stress” (ID38_YA). Furthermore, application of mydriasis drops resulted in a period of time where participants “can’t see properly for a bit” (ID38_YA), or in some cases “hours and hours” (ID20_OA). Time-related barriers were more salient for YA than their OA counterparts, with YA commenting that specialist appointments were often conducted only “within work hours” (ID36_YA). The main barriers anticipated to impede screening for OA participants were “health issues” (ID04_OA) or being “on holiday” (ID15_OA).

3.5.2.2.2 Social influences. Many participants who had not been advised to have screening by their GP indicated that they “didn’t immediately go to the optician” (ID01_OA) once they became aware that screening was required. Comments from some YA suggested that their GPs were reluctant to acknowledge the seriousness of young-onset T2D, reflected in a comment by one YA who felt her GP “played down” (ID41_YA) her T2D diagnosis. The GP neglected to recommend screening, instead advising the YA to “go and book the appointment with the educator and ask all of your questions then” (ID41_YA).
3.5.2.2.3 Knowledge. Both YA and OA participants lacked knowledge of screening guidelines and relied on “what the eye doctor says” (ID01_OA) regarding screening. Although broader knowledge deficits, such as lack of knowledge of DR symptoms and risk factors, did not seem to impede screening uptake for OA, they appeared to perpetuate health misconceptions for YA participants; including the view that DR was only a concern for older people. When asked if they were likely to experience vision problems, a common response was “No ... [I have] never had any complications, no sight problems or anything” (ID33_YA). Lack of symptoms, combined with perceptions of invulnerability and unrealistic optimism also contributed to lack of engagement with DR screening among YA participants: “I put [screening] off because ... my vision is quite good and just my age ... [32 years]” (ID36_YA).

3.5.2.2.4 Beliefs about consequences. Much of the participant commentary around negative consequences of screening focussed on the discomfort of mydriasis, such as “oh, not that dye again” (ID08_OA). The time taken to recover and the need to “hang around for a while” (ID32_YA) impacted participants, although none of the YA or OA participants indicated that this would prevent them from screening.
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3.5.2.2.5 *Emotion (YA only).* Younger adults expressed negative emotions and fear about their diabetes diagnosis, noting that “when I read about diabetes, I get really stressed out” (ID38_YA). Others reported being afraid of screening due to concerns about losing their freedoms (e.g. driving license), vision, or being told they have DR. Further, the knowledge that they had developed diabetes at “quite an early age, so I know it’s going to go on for some time...it’s going to build up” (ID37_YA) generated distress. Rather than acting to reduce their DR risk, some YA response to the potential threat of vision loss was “just total denial” (ID32_YA), “blocking it all out and not dealing with it” (ID38_YA).

3.5.2.2.6 *Behaviour regulation (OA only).* Older adults reported primarily relying on receiving screening reminders from eye health specialists. Such reliance resulted in an absence of behaviour regulation strategies, and in appointments that were missed or forgotten. However, once the omission was discovered, participants reported that they “got in as quick as I could” (ID09_OA).
<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Environmental Context and Resources</strong></td>
<td></td>
</tr>
<tr>
<td>a. <strong>Cost of procedure</strong></td>
<td></td>
</tr>
<tr>
<td>“I thought it should be covered by Medicare but he said this particular picture it’s not going to be covered so I had to pay out of my pocket there.” ID38</td>
<td></td>
</tr>
<tr>
<td>b. <strong>Lack of time</strong></td>
<td></td>
</tr>
<tr>
<td>“I put off [screening] for a while because I kept thinking ‘I need to make sure that my kids are taken care of. I won’t be right for the afternoon. I’ll have to have a lift to get in there and a lift to get out or I’ll have to get a taxi.’” ID32</td>
<td></td>
</tr>
<tr>
<td>c. <strong>Deteriorating health</strong></td>
<td></td>
</tr>
<tr>
<td>I can look after [screening] OK at the moment, but I’ve got a lot of things wrong with me, and if I get any worse I may not be able to.” ID13</td>
<td></td>
</tr>
<tr>
<td><strong>Social Influences</strong></td>
<td></td>
</tr>
<tr>
<td>a. <strong>Lack of clinician recommendation</strong></td>
<td></td>
</tr>
<tr>
<td>“If he [GP] had told me that sometimes even before the diagnosis there could be retinopathy that would definitely have an influence.” ID31</td>
<td></td>
</tr>
<tr>
<td>Interviewer: Were you advised to have your eyes checked at diabetes diagnosis? “Um, no…it wasn’t until…the endocrinologist that I saw [6 years later], said ‘you should go and see this eye doctor’.” ID21</td>
<td></td>
</tr>
</tbody>
</table>
Table 9: Illustrative quotes for main barriers to screening (TDF domains and constructs) for younger and older adults° (Cont.)

<table>
<thead>
<tr>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Influences (Cont.)</strong></td>
<td><strong>Beliefs about Consequences</strong></td>
</tr>
<tr>
<td><strong>b.Clinical inertia</strong></td>
<td><strong>Consequences of mydriasis</strong></td>
</tr>
<tr>
<td>“[My GP] said ‘Look, for the moment, if you’re not feeling any pressure, you’ve got excellent eyesight at the moment anyway’ [and that], in the next six months, I would have to go and see an optometrist or an eye specialist.” ID32</td>
<td>“The only that’s annoying for me is that…they dilate the pupils…and then you can’t see that clearly and that well for the next two to three hours until it wears off.” ID39</td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td><strong>Eye health misconceptions</strong></td>
</tr>
<tr>
<td><strong>a.Lack of knowledge about screening</strong></td>
<td>“[DR] is something that happens to elderly people; it’s not a concern for me.” ID32</td>
</tr>
<tr>
<td>“As wonderful as [my GP] is, I wish that I had have known from word go just how important [screening] was.” ID32</td>
<td>“The guideline is when I get the annual letter from the optometrist.” ID11</td>
</tr>
<tr>
<td><strong>b.Eye health misconceptions</strong></td>
<td><strong>Beliefs about Consequences</strong></td>
</tr>
<tr>
<td>“I think it’s [mydriasis] a necessary evil, but I don’t think you’d neglect it [screening] for it.” ID07</td>
<td><strong>Consequences of mydriasis</strong></td>
</tr>
<tr>
<td>“The only that’s annoying for me is that…they dilate the pupils…and then you can’t see that clearly and that well for the next two to three hours until it wears off.” ID39</td>
<td></td>
</tr>
</tbody>
</table>
Table 9: Illustrative quotes for main barriers to screening (TDF domains and constructs) for younger and older adults (Cont.)

<table>
<thead>
<tr>
<th>Emotion</th>
<th>Younger adults (N=10)</th>
<th>Older adults (N=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of DR diagnosis</td>
<td>“I was afraid. Everything was coming in at the same time. I was diagnosed with diabetes...and I thought ‘now, this [DR] is going to be the last thing, it’s going to be the topping of the cake’. There was going to be something wrong with my eyesight.” ID37</td>
<td></td>
</tr>
</tbody>
</table>

**Behaviour Regulation**

| Absence of planning          | “I am a calendar person. But two years, no, I don’t keep that calendar. I suppose really I do rely on the [reminder] letter coming.” ID18 |

*a* Blank cells indicate that the barrier or component construct was not frequently discussed by that group

GP: General Practitioner, DR: diabetic retinopathy
3.6 Discussion

3.6.1 Summary of findings. This is the first in-depth exploration of the factors which influence screening behaviour among young adults with T2D who are at high risk of complication burden from diabetes, including vision loss from DR (Yeung et al., 2014). The study was conducted in response to an urgent need for behavioural and ophthalmic research focussed on the needs of this group (Forward, Hewitt, & Mackey, 2012; Shickle et al., 2014).

We identified seven behaviour change domains associated with screening among both younger and older adults with T2D: ‘social influences’, ‘beliefs about consequences’, ‘reinforcement’, ‘intentions’, ‘emotion’, ‘knowledge’, and ‘environmental context and resources’. Within those domains, we identified component constructs that were of greater salience to the young adult cohort, and which are consistent with constructs identified in the broader qualitative literature on healthcare engagement for youth and young adults. For example, social normative factors (which include social influence, an important screening facilitator in the current study), have been demonstrated to be more strongly correlated with health promoting behaviours than knowledge-based factors for young people (Bengel, Belz-merk, & Farin, 1996; DiClemente, 1991). Similarly, screening barriers identified to be of greater salience to young adults with T2D in this study, such as stage of life constraints, low perceived personal risk and unrealistic optimism have previously been reported to impact perception of T2D risk and utilisation of eye care services (MacLennan et al., 2014; Reyes-Velazquez & Sealey-Potts, 2015; Turner et al., 2015). Our study also suggests that the distress associated with having a chronic condition usually associated with older
adults, and fear of the possibility of serious complications, which was previously reported by Browne et al. (2013), negatively impacts screening behaviour, with some participants avoiding screening altogether.

By utilising a known comparator group, we were able to demonstrate that the young adult participants made a high number of barrier references compared to the older adult participants. High frequency of barriers was made irrespective of screening behaviour, suggesting that even those young adults who had engaged in DR screening had overcome more barriers to do so than their older counterparts. These findings support the assertion by earlier studies that accumulation of barriers, rather than any specific one, may explain lower screening rates (Lindenmeyer et al., 2014; Waqar et al., 2012).

3.6.2 Implications for policy and practice. Retinal screening initiatives that focus on high-risk sub-groups, such as young adults with T2D, benefit from using educational materials tailored to the target group (Noar, Benac, & Harris, 2007; Zhang et al., 2007). We have identified individual-level contextual and motivational factors which impact screening behaviour for young adults with T2D, many of which may be amenable to change. In order to assist clinicians and those involved with supporting young adults with T2D, we recommend the development of tailored message content which targets the potentially modifiable factors. Considering the challenges associated with reaching and engaging young adults with T2D in their diabetes care (Browne et al., 2013; COAG Reform Council, 2014), we recommend that tailored messages be
incorporated into individual-level eye health resources, such as a leaflet, and embedded within both provider and system-level initiatives.

At a provider level, research demonstrates that GPs are the primary information source for the majority of younger adults living with T2D (Browne et al., 2013; Diabetes Australia, 2006), and important facilitators of screening, as identified in this and other qualitative studies (Lindenmeyer et al., 2014; van Eijk, Blom, Gussekloo, Polak, & Groeneveld, 2012). The current study confirmed that some GPs may not be actively promoting retinal screening at diabetes diagnosis for young adults, or reinforcing it thereafter. This is a form of clinical inertia, a phenomenon demonstrated to have a much larger impact on young adults with T2D than on their older counterparts in clinical settings (Al-Saeed et al., 2016; Rosenberg, Friedman, & Gurland, 2011). The introduction of quality improvement strategies (e.g. GPs providing evidence-based, targeted resources to emphasise the importance of screening alongside reminders to prompt screening behaviour) may ensure that young adults’ interactions with the health system facilitate uptake and maintenance of this crucial vision-loss prevention activity.

Recently, it has been shown that young adults with T2D are the least likely to initiate screening promptly after diabetes diagnosis, exposing them to high risk of severe DR at their first screen (Scanlon et al., 2016). Thus, at an Australian health system level, we recommend targeting young adults with T2D via the National Diabetes Services Scheme (NDSS). The NDSS is an initiative of the Australian Government, which provides subsidised supplies (e.g. needles, blood glucose testing strips) and programs and services (e.g. information,
education and advice), to registrants. With approximately 86% of people with T2D registered on the NDSS, it is considered to be the “best available source to monitor type 2 diabetes in children and young people in Australia” (p.36, Australian Institute of Health and Welfare, 2014). Each new registrant receives a diabetes management information booklet, which could include eye health resources tailored to this group. The use of the NDSS as a vehicle for targeted mail-outs of eye health messages appears to have been successful in an earlier community-based screening program, with anecdotal reports of an increase in enquiries after each mail campaign (Lee et al., 2000).

3.6.3 **Strengths and limitations.** This study has a number of strengths. It is the first in-depth exploration of factors impacting screening for young adults with T2D, an under-researched group at high risk for vision loss and blindness from DR. Although small, the sample of young adults with T2D included a diverse group of participants, with respect to key demographic factors (e.g. gender, country of birth), and screening behaviour. The systematic comparison of facilitators and barriers with a known comparator group (older adults with T2D, aged 40+ years) permitted identification of salient factors likely to influence young adult screening behaviour which can now be targeted by health care professionals and those developing tailored resources for this group. Finally, this is the first study to use the TDF, a theoretically-driven behaviour change framework, to systematically identify facilitators and barriers to screening behaviour. The key benefit of this novel approach is that the behavioural determinants and key differences, which were systematically identified in this study, can be matched to evidence-based behaviour change techniques in a
future eye health intervention (Cane, Richardson, Johnston, Ladha, & Michie, 2014), providing clear justification for intervention content.

This study also has some important limitations. We experienced recruitment challenges specific to each group, which limit the interpretability and generalisability of the findings. Firstly, despite doubling the recruitment period to six months, and introducing a technology-based incentive, we were unable to recruit young adults with T2D in sufficient numbers to confirm data saturation. Although diverse in gender and screening behaviour, there was a recruitment bias toward the upper age range (average age 33 years). This can be understood in the context of the skewed nature of the demographic (Australian Institute of Health and Welfare, 2014), but nevertheless means that the views and experiences of the youngest members of the young adult group are not well represented in our data.

While we were able to recruit sufficient numbers of older adults, the challenge focussed on engaging those who had not attended retinal screening. In contrast to the young adults with T2D, all the older adults who volunteered to participate had previously engaged in screening. Although this may be a reflection of a genuine disparity in screening behaviour, the 100% screening rate of our older adults sample is higher than recently reported general population rates (78%, Foreman et al., 2016), raising the strong possibility of self-selection bias (Chou et al., 2013). Absence of older adults who had not attended screening compromises the interpretability of the barrier findings because we do not know if the barriers cited by the young adults with T2D also apply to older adults who had not screened, or indeed, whether they face different barriers altogether.
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However, as a first step towards understanding the barriers and facilitators of retinal screening amongst young adults with T2D, our study still makes a meaningful contribution to the existing literature.

Finally, despite our comprehensive validation exercise, we faced coding challenges due to conceptually overlapping constructs from different TDF domains (e.g. ‘reinforcement’/’beliefs about consequences’, ‘behaviour regulation’/’memory, attention and decision processes’). Although we addressed this challenge by always exploring the context of the utterance to inform coding decisions, the issue of discriminant validity of questionnaire items has been raised by other TDF-studies (Birken et al., 2014; Bussieres et al., 2012) and remains a work in progress for the TDF framework.

3.6.4 Future research. The findings of this study suggest that there are facilitators and barriers to retinal screening that are of greater salience to young adults with T2D than older adults, indicating that tailored resources are warranted in order to promote screening uptake in this group. As this study was descriptive and exploratory in nature, a logical next step is to confirm them in a larger, quantitative survey. Subsequently, identified deficits can be targeted in a future eye health intervention, using content mapped to specific behaviour change techniques. Additional efforts to boost recruitment and minimise self-selection bias will be important for any future studies with this target group on this topic.

3.6.5 Conclusion. Our study has identified a number of attitudinal and motivational factors associated with retinal screening behaviour among young
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adults with T2D. Some of these factors appear to differ from those reported by older adults who, given their majority, are the target group for most diabetes self-management resources and services. As many of the identified factors, such as social influence and knowledge, are modifiable, this study is an important first step in establishing an evidence base for tailored resources and greater understanding among clinicians and other health professionals of the issues associated with retinal screening uptake among young adults with T2D.
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3.7 References


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REDDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


Hipwell, A. E., Sturt, J., Lindenmeyer, A., Stratton, I., Gadsby, R., O'Hare, P. O., & Scanlon, P. H. (2014). Attitudes, access and anguish: a qualitative
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interview study of staff and patients’ experiences of diabetic retinopathy screening. *BMJ Open, 4*(12), e005498. doi:10.1136/bmjopen-2014-005498


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REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REducing risk of vision loss for young adults with type 2 diabetes

Screening attendance, age group and diabetic retinopathy level at first screen. *Diabetic Medicine, 33*(7), 904-911. doi:10.1111/dme.12957


3.8 Declarations

3.8.1 Ethics approval and consent to participate. This study was approved by the Deakin University Human Research Ethics Committee (2013-157). All participants were given a detailed Plain Language Statement and provided informed consent prior to commencement of the study.

3.8.2 Conflict of interest. None

3.8.3 Funding. This study was a designated Vision Initiative project, funded by Vision 2020 Australia [http://www.visioninitiative.org.au/]. AL was supported directly from this funding. JB and JS are supported by the core funding to The Australian Centre for Behavioural Research in Diabetes, provided by the collaboration between Diabetes Victoria and Deakin University. GR is funded by National Health and Medical Research Council Career Development Award 1061801. Centre for Eye Research Australia receives Operational Infrastructure Support from the Victorian Government.

3.8.4 Acknowledgements. We thank the study participants for their time, insights and experiences. For their professional input, we thank: Carolyn Hines (Diabetes Education Manager, Diabetes Victoria) and Dee Tumino (Vision Initiative Manager, Vision 2020 Australia). We thank the 16 experts who participated in the interview guide validation activity. We thank Dr Adriana Ventura for her assistance with practice interviewing, and Dr Nimarta Dharni and Dr Alison Wright for sharing their patient-focused TDF interview schedules to inform our research. Finally, we thank the membership team at Diabetes Victoria for their help with participant recruitment.
CHAPTER 4. A Tailored Intervention to Promote Uptake of Retinal Screening among Young Adults with Type 2 Diabetes - an Intervention Mapping Approach

This manuscript is under review in *BMC Health Services Research*. The chapter has been formatted in APA style, to maintain consistency of structure and referencing throughout the thesis. Text content is identical to the submitted manuscript.
4.1 Authorship statement

1. Details of publication and executive author

<table>
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<th>Publication details</th>
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</table>

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<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
</tr>
</thead>
<tbody>
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<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td><a href="mailto:alake@acbrd.org.au">alake@acbrd.org.au</a></td>
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2. Inclusion of publication in a thesis

<table>
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<tr>
<th>Is it intended to include this publication in a higher degree by research (HDR) thesis?</th>
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<tr>
<td>If Yes, please complete Section 3. If No, go straight to Section 4.</td>
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3. HDR thesis author’s declaration

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
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<tbody>
<tr>
<td>As above</td>
<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td>Reducing risk of vision loss for young adults with type 2 diabetes</td>
</tr>
</tbody>
</table>

If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

The thesis author led and managed all aspects of the study.

Needs assessment activities included:

- Literature review: Development and execution of search strategy and protocol
- In-depth qualitative interviews: Development of TDF-based interview guide, planning and coordination of participant recruitment, ethics application, conduct of interview guide validation activity, conduct of all participant interviews (data collection), quality checking and coding of all
transcripts (NVivo), data analysis and interpretation, including
determination of coding themes and conduct of validity checks.

- Nationwide online survey: Development of study protocol, development
  and validation of interview schedule, development of study website
  [www.yoursay.org.au], development and conduct of online survey
  (Qualtrics), conducted data cleaning, analysis and interpretation

Leaflet development activities conducted by the thesis author included:

- Development of the persuasive messages
- Liaison with priority population and other stakeholder groups and graphic
  designers
- Leaflet piloting activities.

As a member of the planning team, AJL provided substantial input throughout
the project and reviewed and approved materials at all stages.

The thesis author prepared the first and subsequent drafts of the manuscript

I declare that the above is an accurate
description of my contribution to this paper, and the contributions of other
authors are as described below.

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Jessica L. Browne</td>
<td>Conceived the study in collaboration with JS and DT. As a member of the planning team, JLB provided substantial input throughout the project and reviewed and approved materials at all stages. JLB provided substantial input into study design analysis and interpretation of online survey data. Provided substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
<tr>
<td>Professor Charles Abraham</td>
<td>Substantial contribution to study design and intervention development. Provided expert advice on Intervention Mapping, theoretical basis, the quantitative study; closely involved with content validation of the leaflet. Provided substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
<tr>
<td>Ms. Dee Tumino</td>
<td>Conceived the study in collaboration with JS and JLB. As a member of the planning team, DT provided substantial input throughout the project and reviewed and approved materials at all stages. All authors made substantial contributions to study</td>
</tr>
<tr>
<td>Ms. Carolyn Hines</td>
<td>Substantial contribution to study design and intervention development. As a member of the planning team, CH provided substantial input throughout the project and reviewed and approved materials at all stages.</td>
</tr>
<tr>
<td>Diabetes Victoria, Melbourne, VIC Australia</td>
<td></td>
</tr>
<tr>
<td>Dr. Gwyneth Rees</td>
<td>Substantial contribution to study design and intervention development. As a member of the planning team, GR provided substantial input throughout the project and reviewed and approved materials at all stages. GR provided substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
<tr>
<td>Centre for Eye Research Australia, Royal Victorian Eye and Ear Hospital, Melbourne, VIC Australia; Ophthalmology, Department of Surgery, University of Melbourne, Melbourne, VIC Australia</td>
<td></td>
</tr>
<tr>
<td>Professor Jane Speight</td>
<td>Conceived the study in collaboration with JLB and DT. As a member of the planning team, JS provided substantial input throughout the project and reviewed and approved materials at all stages. Substantial input into study design, analysis and interpretation of online survey data. Substantial intellectual input through reviewing the first and subsequent drafts of the manuscript.</td>
</tr>
<tr>
<td>School of Psychology, Deakin University, Geelong, VIC Australia; The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, VIC Australia; AHP Research, Hornchurch, United Kingdom</td>
<td></td>
</tr>
</tbody>
</table>

5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:

i. that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,

ii. that there are no other authors according to these criteria,

iii. that the description in Section 4 of my contribution(s) to this publication is accurate,

iv. that the data on which these findings are based are stored as set out in Section 7 below.

If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further

v. consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin University and, if the higher degree is awarded, the subsequent publication of the thesis by the university (subject to relevant Copyright provisions).
6. Other contributor declarations

I agree to be named as a non-author contributor to this work.

<table>
<thead>
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<th>Name and affiliation of contributor</th>
<th>Contribution</th>
<th>Signature* and date</th>
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</tbody>
</table>

* If an author or contributor is unavailable or otherwise unable to sign the statement of authorship, the Head of Academic Unit may sign on their behalf, noting the reason for their unavailability, provided there is no evidence to suggest that the person would object to being named as author.

7. Data storage

The original data for this project are stored in the following locations. (The locations must be within an appropriate institutional setting. If the executive author is a Deakin staff member and data are stored outside Deakin University, permission for this must be given by the Head of Academic Unit within which the executive author is based.)
If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
4.2 Abstract

**Background:** Young adults (18-39 years) with type 2 diabetes are at risk of early development and rapid progression of diabetic retinopathy, a leading cause of vision loss and blindness in working-age adults. Retinal screening is key to the early detection of diabetic retinopathy, with risk of vision loss significantly reduced by timely treatment thereafter. Despite this, retinal screening rates are low among this at-risk group. The objective of this study was to develop a theoretically-grounded, evidence-based retinal screening promotion leaflet, tailored to young adults with type 2 diabetes. **Methods:** Utilising the six steps of Intervention Mapping, our multidisciplinary planning team conducted a mixed-methods needs assessment (Step 1); identified modifiable behavioural determinants of screening behaviour and constructed a matrix of change objectives (Step 2); designed, reviewed and debriefed leaflet content with stakeholders (Steps 3 and 4); and developed program implementation and evaluation plans (Steps 5 and 6). **Results:** Step 1 included in-depth qualitative interviews (N=10) and an online survey that recruited a nationally-representative sample (N=227), both informed by literature review. The needs assessment highlighted the crucial roles of knowledge (about diabetic retinopathy and screening), perception of personal risk, awareness of the approval of significant others and engagement with healthcare team, on retinal screening intentions and uptake. In Step 2, we selected five modifiable behavioural determinants to be targeted: knowledge, attitudes, normative beliefs, intention, and behavioural skills. In Steps 3 and 4, the "Who is looking after your eyes?" leaflet was developed,
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containing persuasive messages targeting each determinant and utilising engaging, cohort-appropriate imagery. In Steps 5 and 6, we planned Statewide implementation and designed a randomised controlled trial to evaluate the leaflet. **Conclusions:** This research provides an example of a systematic, evidence-based approach to the development of a simple health intervention designed to promote uptake of screening in accordance with national guidelines. The methods and findings illustrate how Intervention Mapping can be employed to develop tailored retinal screening promotion materials for specific priority populations. This paper has implications for future program planners and is intended to assist those wishing to use Intervention Mapping to create similar theoretically-driven, tailored resources.
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4.3 Background

Worldwide increase in the prevalence of type 2 diabetes (T2D) in young adults (<40 years), with its associated considerable morbidity and mortality, is a burgeoning public health concern (Chan et al., 2014; Constantino et al., 2013; Harding, Shaw, Peeters, Davidson, & Magliano, 2016; Tancredi et al., 2015; Zimmet, Magliano, Herman, & Shaw, 2014). Adverse phenotype (Song & Hardisty, 2009), sub-optimal glycemic (blood glucose) control and long diabetes duration expose young adults with T2D to a high lifetime risk of diabetes-related complications (Al-Saeed et al., 2016; Dart et al., 2014). One of the most common is diabetic retinopathy (DR), which is a leading cause of vision loss and blindness in working age adults (Leasher et al., 2016; Wong, Molyneaux, Constantino, Twigg, & Yue, 2008).

Early detection of DR via retinal screening (‘screening’), followed by timely treatment, are crucial factors in preventing vision loss (Ferris, 1993). Australian national Guidelines for the Management of Diabetic Retinopathy recommend screening uptake at diabetes diagnosis, repeated at least every two years thereafter (Mitchell & Foran, 2008), an interval less frequent than that prescribed for adults with T2D in the United States (US) and United Kingdom (UK) (American Diabetes Association, 2017; National Institute for health and Care Excellence, 2015). Unfortunately however, young adults (aged 18-39 years) are the least likely to initiate retinal screening in accordance with national guidelines and have lower overall screening rates than older adults (aged ≥40 years) or young adults with type 1 diabetes (Scanlon et al., 2016; Villarroel, Vahratian, & Ward, 2015; Wang et al.,
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2017). In addition to their low engagement with existing diabetes services (Savage, Dabkowski, & Dunning, 2009), additional communication challenges exist due to the lack of dedicated programs, hubs or services for young adults with T2D. Thus, there is need for the development of tailored, evidence-based health promotion resources, using an application appropriate to the culture and context, in order to encourage screening uptake among this priority population (Browne, Scibilia, & Speight, 2013; Forward, Hewitt, & Mackey, 2012; MacLennan, McGwin, Heckemeyer, & et al., 2014; Song, 2015; Wilmot & Idris, 2014).

Best-practice development of health promotion resources targets modifiable behavioural determinants for a clearly specified health behaviour. The UK Medical Research Council (MRC) framework for the design and evaluation of complex interventions recommends use of good quality evidence from a range of sources, strong theoretical underpinnings, causal modelling and a well-designed evaluation (Craig et al., 2008). Intervention mapping (IM) is a six-step protocol encompassing MRC elements, which provides an effective and useful framework for this purpose (Bartholomew Eldredge et al., 2016). Key activities are: 1) detailed needs assessment, developing causal logic model of the problem, 2) stating program outcomes and performance objectives, developing logic model of change, 3) utilising theory and evidence-based change methods, designing program to target identified behavioural determinants, 4) producing, pre-testing and refining program with broad stakeholder input, 5) planning for program implementation, and 6) planning for evaluation ("Intervention mapping,"). Intervention mapping has been widely
used by intervention planners to guide the development of effective health promotion materials in a variety of contexts and populations (Ball, Mushquash, Keaschuk, Ambler, & Newton, 2017; Gray-Burrows et al., 2016; Hurley et al., 2016; Newby et al., 2017; Song, Choi, Kim, Seo, & Lee, 2015) and has been shown to be effective both in identifying determinants and increasing uptake for a range of disease prevention interventions (Garba & Gadanya, 2017). Utilising IM, the aim of the current study was to identify determinants of screening behaviour for young adults with T2D, and develop an engaging psycho-educational resource to target these factors, designed to promote screening uptake.
4.4 Method and Results

In this section, IM steps 1-4 are presented in detail, followed by summaries of Steps 5 and 6. Method and results are reported separately for each step, including illustrative examples of key IM activities (with full detail provided in Additional files).

Table 10 provides an overview of each IM step as it was applied to this project.

Table 10: Overview of IM steps and activities applied to the current leaflet development program

<table>
<thead>
<tr>
<th>IM steps</th>
<th>IM activities</th>
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<tbody>
<tr>
<td>Step 1: Logic model of the problem</td>
<td>• Establish and work with a planning group</td>
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<td></td>
<td>• Conduct mixed-methods needs assessment</td>
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<td></td>
<td>• Create logic model of the problem</td>
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<td></td>
<td>• Describe context of the intervention and state program goals</td>
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<tr>
<td>Step 2: Program outcomes and objectives; logic model of change</td>
<td>• State expected behavioural outcomes and Performance Objectives (PO)</td>
</tr>
<tr>
<td></td>
<td>• Create logic model of change</td>
</tr>
<tr>
<td></td>
<td>• Create matrix of Change Objectives</td>
</tr>
<tr>
<td>Step 3: Program design</td>
<td>• Generate program themes, components, scope and sequence</td>
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<tr>
<td></td>
<td>• Choose theory and evidence-based change methods</td>
</tr>
<tr>
<td>Step 4: Program production</td>
<td>• Draft persuasive message content and leaflet</td>
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<td></td>
<td>• Pre-test, refine and produce leaflet</td>
</tr>
<tr>
<td>Step 5: Program implementation</td>
<td>• Identify program implementers, adopters and maintainers</td>
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<tr>
<td></td>
<td>• Design implementation and liaise with program implementers</td>
</tr>
<tr>
<td>Step 6: Program evaluation</td>
<td>• Write effect and process evaluation questions</td>
</tr>
<tr>
<td></td>
<td>• Develop measures for assessment</td>
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<td></td>
<td>• Specify and complete evaluation plan</td>
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</tbody>
</table>
4.4.1 Logic model of the problem.

4.4.1.1 Establish and work with a planning group. A six-person multidisciplinary planning team was convened comprising representatives from The Australian Centre for Behavioural Research in Diabetes (AJL, JLB, JS); Centre for Eye Research Australia (GR); Diabetes Victoria (CH); and Vision 2020 Australia (DT). Combined, the planning team provided expertise in psychosocial and clinical aspects of diabetes and vision loss, health promotion, behaviour change research methodologies and intervention development. Monthly meetings (chaired by JS) were held throughout the project, with additional meetings held as-needed and quarterly progress reports provided to the funding body. Throughout the study, the planning team consulted a practicing health psychologist (CA) with expertise in IM and a track record of developing and analysing evidence-based health promotion leaflets (Abraham, Southby, Quandte, Krahé, & van der Sluijs, 2007; Elliott, White, Taylor, & Abraham, 2016; Hill & Abraham, 2008; Krahé, Abraham, & Scheinberger-Olwig, 2005). Additional expert input was provided by representatives from key stakeholder organisations, such as the National Diabetes Services Scheme (NDSS, an initiative of the Australian Government, which provides free or subsidised self-management supplies and services to registrants), Optometry Australia and key units within Diabetes Victoria.

Patient and public involvement (PPI) is essential for the development of high-quality health behaviour change interventions (Stewart, Wilson, Selby, & Darbyshire, 2011) and is recommended specifically as a strategy for engaging groups at high risk
of underutilisation of eye healthcare services (Elam & Lee, 2013). In this study, five young adults with T2D were involved, providing feedback on all study documentation, piloting the quantitative survey and providing detailed review of the eye health leaflet.

4.4.1.2 Conduct mixed methods needs assessment. Our study of the literature (summarised in Additional file 1) revealed that, while there was a paucity of research in this specific area, sub-optimal diabetes self-management (in general) among young people is likely driven by low socioeconomic status (Koelmeyer, Dharmage, & English, 2016), low general and health literacy (Koelmeyer et al., 2016), low engagement with diabetes self-management education (Browne, Nefs, Pouwer, & Speight, 2014; Browne et al., 2013; Hessler, Fisher, Mullan, Glasgow, & Masharani, 2011; Koelmeyer et al., 2016), cultural diversity of the priority population (Tuomi et al., 2014), optimistic bias and low risk perception (Reyes-Velazquez & Sealey-Potts, 2015), life-stage demands (Lake, Browne, Rees, & Speight, 2017), high rates of diabetes-related distress (Browne et al., 2014) and complex healthcare needs (Owen, 2016).

In our empirical needs assessment studies, we sought to determine the relevance of these factors to DR screening specifically, and to identify any additional factors that may facilitate or impede this target behaviour. As other researchers have found it challenging to recruit young adults with T2D to research studies (Nguyen et al., 2014; Zeitler, Chou, Copeland, & Geffner, 2015), several steps were taken to boost recruitment in the mixed-methods needs assessment. These included: giving
priority to ease of participant access; distribution of engaging, cohort-appropriate recruitment invitations with an NDSS and Diabetes Australia branded cover letter introducing the study; reminder invitation after four weeks; age-appropriate incentives (e.g. entry to a technology-based prize draw), and extension of recruitment periods until participant registration visibly flagged.

4.4.1.2.1 In-depth qualitative interviews.

Qualitative interview procedure: Detailed description of the study methods and findings, including the participants, procedure, interview guide and analysis, are published elsewhere (Lake et al., 2017), see Appendix C for interview guide. In brief, we conducted in-depth semi-structured interviews to explore factors affecting screening behaviour for young adults with T2D, with an emphasis on those that were individual-level and modifiable. The study was advertised widely online and in community settings, and recruitment invitations were mailed to eligible members of a leading state diabetes consumer advocacy organisation. All interviews were conducted via telephone by an experienced interviewer (AJL), audio-recorded and transcribed verbatim. All transcripts were checked for accuracy and imported into NVivo10 (QSR International Pty Ltd, Doncaster, VIC., Australia, 2012). Transcripts were subjected to content analysis (by AJL), with each participant utterance coded for behavioural determinants (using an *a priori* coding framework informed by the literature (Cane, O'Connor, & Michie, 2012)), and again as either ‘facilitator’ or ‘barrier’ dependent upon the context. Twenty percent of transcripts were double-coded (by JLB), with high inter-rater reliability of 99%. Screening determinants were
rank-ordered by frequency of coding (higher frequency of utterances interpreted to indicate higher salience).

**Qualitative interview findings:** In brief, ten young adults with T2D (50% women, aged 29-37 years) were interviewed (average length: 55 min, range: 31-106 min). Fifty percent had not attended retinal screening previously. Although young adults with T2D knew of a link between diabetes and vision loss, they did not have a comprehensive understanding of DR or screening (e.g. symptoms, risk factors, screening guidelines, distinction between screening and standard vision checks). Participants reported distress related to having a condition stereotypically associated with older people, and many did not know others of similar age with T2D. Participants indicated that absence of social influence (e.g. prompting from significant others, social comparison with others), and low DR risk perception, combined with life-stage barriers (e.g. lack of time and finances), negatively impacted screening uptake. Concerned about negative judgment by others, and fearing a DR diagnosis, participants reported that they did not always disclose their diabetes diagnosis or proactively seek healthcare or social support, thus losing crucial pathways to timely screening uptake. Irrespective of their screening history, young adults with T2D identified a range of screening barriers, suggesting that a cumulation of factors may impact uptake, thus highlighting the need to acknowledge and address a broad range of barriers in a tailored intervention.

Screening facilitators were often conceptualised by participants as the opposite of the barriers (e.g. improved, as opposed to inadequate, knowledge or
access to social support). However, the study also highlighted other screening facilitators: participants compared themselves with others experiencing diabetes-related vision loss, and were thus influenced to engage in screening due to concerns about the impact that vision loss would have on their lives, including anticipated regret at the potential impact on their spouses and/or children. For those who previously attended screening, feelings of relief and reassurance facilitated repeat screening behaviour, with participants expressing intent to sustain the behaviour and expectation of a positive outcome (i.e. no DR diagnosis).

4.4.1.2.2 National online survey.

Online survey procedure

Survey development. Using the Information-Motivation-Behavioural skills (IMB) model (Fisher, Fisher, & Harman, 2003) as a foundation, the planning team developed a survey designed to identify modifiable behavioural determinants for screening. The IMB model posits that although information is a key element in changing behaviour, increasing knowledge and awareness of a behaviour is not sufficient in itself, and requires the integration of motivational and skills elements to ensure behaviour change. Use of the IMB model in behaviour change research requires identification of deficits in each of the three key areas, to be addressed in a subsequent intervention. The IMB model has been effective both as a framework for intervention design (Fisher, Fisher, Bryan, & Misovich, 2002) and as a predictive model for health-related screening behaviours, such as breast self-examination (Misovich, Martinez, Fisher, Bryan, & Catapano, 2003).
Increasingly used with chronic conditions, the IMB model has been validated recently in a model of diabetes self-care behaviours (Osborn & Egede, 2010) and medication adherence (Mayberry & Osborn, 2014). Survey items were based on IMB-based questionnaires previously validated for diabetes self-management (Mayberry & Osborn, 2014; Osborn & Egede, 2010), the widely-used Theory of Planned Behaviour (Fishbein & Ajzen, 2010), and cognitive constructs shown to be relevant to young adults with T2D (e.g. optimism/fatalism, social support, risk perception, anticipated regret, self-efficacy) (Reyes-Velazquez & Sealey-Potts, 2015; Turner et al., 2015).

In brief, the survey comprised 54 items assessing information/knowledge, motivation and behavioural skills (see Additional file 2 for individual items). **Information:** 16 items assessed knowledge of the link between diabetes and vision loss, diabetic retinopathy and retinal screening. Responses scored dichotomously (incorrect / correct). **Motivation:** 21 items collectively assessed three attitudinal constructs (attitudes toward screening for DR, perception of personal risk, and anticipated regret); three items assessed normative beliefs and three items assessed intention. **Behavioural skills:** 11 items collectively assessed two behavioural skills constructs (perceived control over screening and overcoming barriers).

Unless otherwise noted, each item was rated on a 7-point Likert scale (“strongly disagree” to “strongly agree”). Individual items were aggregated to provide a composite score for each construct, with good internal consistency (see Additional file 3). For each, higher scores indicated greater endorsement of the
construct measured (e.g. stronger intentions, more positive attitudes). In addition, we collected socio-demographic data to describe the sample at baseline. The survey was piloted with young adult PPI members and representatives from selected stakeholder organisations, who also commented on readability, format, accessibility and content; no substantive changes were required.

**Data collection and participants.** The survey was conducted nationwide and hosted via a secure online survey platform, Qualtrics™ (Provo, UT, 2014-2015). In Australia, the majority of people with a confirmed diagnosis of diabetes are registered by their health professional with the NDSS (Australian Institute of Health and Welfare, 2014). All young adults with T2D who had been registered on the NDSS in the previous three years (registration date was used as a proxy for diagnosis date), and who had consented to be contacted for research (N=5,354) were invited to participate. Exclusion criteria included non-English speaking; those aged 40+ years, and diagnosis of another type of diabetes. Study invitations were managed by the NDSS in order to preserve registrant confidentiality, but purposive sampling of those who had not previously screened for DR was not possible, due to lack of available data on retinal screening status of NDSS registrants. Recruitment to the online survey continued for seven weeks.

**Statistical analyses.** Statistical analyses were conducted using SPSS version 22 (SPSS Inc., Chicago IL, USA). Univariate analyses (chi-square and independent measures t-tests, two-sided) were conducted to explore between-group (previous retinal screen: yes/no) differences on demographic variables and modifiable
behavioural determinants at the item level (to inform specific intervention message content). Given the large number of analyses, a conservative $p<0.01$ was considered statistically significant.

**Online survey findings:** Overall, 129 participants (2% of eligible population) completed the full survey, and their sociodemographic characteristics are presented in Table 11. Sixty percent were women, average age 34±5 years (range: 19-39 years), and 74% had previously screened for DR. No significant differences in sociodemographic characteristics were found between screening groups.
Table 11: Sociodemographic characteristics by screening behaviour (N=129)

<table>
<thead>
<tr>
<th>Sociodemographic characteristics</th>
<th>Retinal screen</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (n=33)</td>
<td>Yes (n=96)</td>
</tr>
<tr>
<td>Age, years</td>
<td>34.39 (33, 37)</td>
<td>34.04 (32, 37)</td>
</tr>
<tr>
<td>Duration, years</td>
<td>1.00 (1.84)</td>
<td>1.69 (1.97)</td>
</tr>
<tr>
<td>Gender: women</td>
<td>15 (45)</td>
<td>62 (65)</td>
</tr>
<tr>
<td>Primary diabetes management:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle only</td>
<td>5 (15)</td>
<td>21 (22)</td>
</tr>
<tr>
<td>Medication (not insulin)</td>
<td>23 (70)</td>
<td>64 (67)</td>
</tr>
<tr>
<td>Insulin</td>
<td>5 (15)</td>
<td>11 (11)</td>
</tr>
<tr>
<td>Country of birth: Australian born</td>
<td>18 (55)</td>
<td>66 (69)</td>
</tr>
<tr>
<td>Main language spoken at home:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>27 (82)</td>
<td>81 (84)</td>
</tr>
<tr>
<td>Employment status: employed</td>
<td>20 (61)</td>
<td>57 (59)</td>
</tr>
<tr>
<td>Socioeconomic status$^a$</td>
<td>984.55 (83.52)</td>
<td>991.48 (57.11)</td>
</tr>
<tr>
<td>Family history of T2D$^b$</td>
<td>22 (67)</td>
<td>72 (75)</td>
</tr>
<tr>
<td>≥1 comorbid health condition$^b$</td>
<td>25 (76)</td>
<td>75 (79)</td>
</tr>
<tr>
<td>Depression (PHQ-2)$^c$</td>
<td>2.94 (2.48)</td>
<td>2.12 (2.07)</td>
</tr>
</tbody>
</table>

Data are number (%), mean (SD), or median (IQR); $p$-value is Pearson’s chi-square or independent t-tests (two-sided); statistical significance $p<0.05$.

$^a$Index of Relative Socio-economic Advantage and Disadvantage: lower score indicates relatively greater disadvantage, range 300-1250.

$^b$Missing data (average 6%, range 2-11%)

$^c$PHQ-2 range 0-6: ≥3 indicating likely depression

**Behavioural determinants of screening.** Selected findings for information (knowledge), motivation and behavioural skills items are detailed in Table 12 (full detail and construct-level findings provided in Additional file 3).
Table 12: Selected behavioural determinant items by retinal screen (N=129)

<table>
<thead>
<tr>
<th>Modifiable behavioural determinants</th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No (n=33)</td>
<td>Yes (n=96)</td>
</tr>
<tr>
<td><strong>INFORMATION (KNOWLEDGE) ITEMS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes can lead to vision loss</td>
<td>30 (91)</td>
<td>93 (97)</td>
<td>.174</td>
</tr>
<tr>
<td>All people with diabetes are at risk of DR</td>
<td>26 (79)</td>
<td>89 (93)</td>
<td>.004</td>
</tr>
<tr>
<td>Recommended target HbA1c&lt;sup&gt;a&lt;/sup&gt;</td>
<td>17 (53)</td>
<td>81 (87)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Initiate eye examinations ‘at diabetes diagnosis’</td>
<td>5 (15)</td>
<td>42 (45)</td>
<td>.004</td>
</tr>
<tr>
<td>Screen ‘at least every 2 years’ if no DR present</td>
<td>0 (0)</td>
<td>18 (19)</td>
<td>.003</td>
</tr>
<tr>
<td><strong>MOTIVATION ITEMS</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td>An eye health check for DR would be...&lt;sup&gt;c&lt;/sup&gt;</td>
<td>3.71 (0.94)</td>
<td>3.86 (1.07)</td>
</tr>
<tr>
<td>...(not) ‘unpleasant’</td>
<td>3.71 (0.94)</td>
<td>3.86 (1.07)</td>
<td>.500</td>
</tr>
<tr>
<td>...reassuring</td>
<td>3.94 (0.96)</td>
<td>4.63 (0.61)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>...important</td>
<td>4.06 (1.06)</td>
<td>4.89 (0.35)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>...empowering</td>
<td>3.10 (1.19)</td>
<td>3.73 (0.97)</td>
<td>.004</td>
</tr>
<tr>
<td>...comfortable</td>
<td>3.26 (1.15)</td>
<td>3.68 (1.10)</td>
<td>.073</td>
</tr>
<tr>
<td>I believe I will develop DR due to my diabetes&lt;sup&gt;d&lt;/sup&gt;</td>
<td>4.03 (1.45)</td>
<td>4.14 (1.62)</td>
<td>.734</td>
</tr>
<tr>
<td>Expect to be diagnosed with DR at next eye check&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.97 (1.47)</td>
<td>2.43 (1.66)</td>
<td>.114</td>
</tr>
<tr>
<td>Can reduce risk of vision problems...&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.32 (1.44)</td>
<td>1.43 (0.79)</td>
<td>.002</td>
</tr>
<tr>
<td>If I did NOT have an eye health check for DR, I would feel...&lt;sup&gt;d&lt;/sup&gt;</td>
<td>5.03 (1.70)</td>
<td>5.88 (1.40)</td>
<td>.007</td>
</tr>
<tr>
<td>...concerned</td>
<td>5.03 (1.70)</td>
<td>5.88 (1.40)</td>
<td>.007</td>
</tr>
<tr>
<td>...fearful</td>
<td>4.48 (1.79)</td>
<td>5.13 (1.70)</td>
<td>.073</td>
</tr>
<tr>
<td>...worried</td>
<td>4.65 (1.80)</td>
<td>5.53 (1.47)</td>
<td>.007</td>
</tr>
<tr>
<td>My family/close friends would approve...&lt;sup&gt;d&lt;/sup&gt;</td>
<td>5.94 (1.69)</td>
<td>6.82 (0.80)</td>
<td>.008</td>
</tr>
<tr>
<td>I plan to attend an eye health check...&lt;sup&gt;d&lt;/sup&gt;</td>
<td>4.26 (2.32)</td>
<td>6.76 (0.77)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>I intend to have an eye health check...&lt;sup&gt;d&lt;/sup&gt;</td>
<td>4.42 (2.32)</td>
<td>6.74 (0.77)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>BEHAVIOURAL SKILLS ITEMS</strong>&lt;sup&gt;b,e&lt;/sup&gt;</td>
<td>How confident are you that you...</td>
<td>2.39 (1.17)</td>
<td>3.06 (1.29)</td>
</tr>
<tr>
<td>...know steps to reduce the risk of developing DR</td>
<td>2.39 (1.17)</td>
<td>3.06 (1.29)</td>
<td>.012</td>
</tr>
<tr>
<td>...will remember to have an eye health check...</td>
<td>2.68 (1.35)</td>
<td>4.36 (0.90)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>...can talk to your doctor about your eye health...</td>
<td>3.39 (1.28)</td>
<td>4.17 (1.03)</td>
<td>.001</td>
</tr>
<tr>
<td>...can find the time to attend an eye health check...</td>
<td>2.74 (1.37)</td>
<td>4.55 (0.75)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>...can afford to pay for the eye health check...</td>
<td>2.68 (1.49)</td>
<td>3.52 (1.48)</td>
<td>.008</td>
</tr>
</tbody>
</table>
Almost all participants (irrespective of previous screening behaviour) knew of a link between diabetes and vision loss. However, compared to their non-screening counterparts, those who had previously screened knew that all people with diabetes were at risk of DR, the clinically-recommended HbA1c (average blood glucose) target for DR prevention, when to initiate screening and recommended screening intervals.

Overall, participants who had screened indicated more positive attitudes towards the behaviour (e.g. empowering, reassuring and important) than those who had not screened. No differences were observed between groups on how pleasant or comfortable the eye check was perceived to be, although scores were lower for all participants compared to other attitude items. Perception of personal risk of vision problems and DR were moderate for all participants with low expectations of a DR diagnosis in the short term. Although all participants believed they could not reduce their risk of vision problems, those who had screened held this belief more strongly. All participants reported negative emotions when thinking about not screening, including fear, which was high for both groups. Compared to their non-
screening counterparts, those who had previously screened reported greater concern and worry at the prospect of not screening. Participants who had previously screened were significantly more likely to agree that significant others (i.e. family/friends, healthcare team) would approve of screening. Intention to screen was high among all participants but significantly higher for those who had previously screened compared to those who had not.

Those who had screened previously reported significantly greater confidence on all aspects of behavioural control over screening (e.g. how to make an appointment for screening, ability to screen regularly, remember and attend an appointment). No differences were observed between groups on confidence in knowing the steps that can be taken to reduce the risk of DR, although scores were lower for all participants compared to other behavioural control items. Those who had screened also reported significantly higher confidence in overcoming common screening barriers (including time and cost, and discussing diabetes and DR with healthcare professionals).

4.4.1.2.3 Summary of key learnings from needs assessment. Key learnings from the literature review, qualitative interviews and quantitative survey are summarised in Table 13 below.
Table 13: Key lessons learned from needs assessment

1. Compared to their older adult counterparts, young adults with T2D have different psychosocial and information needs.

2. There is a lack of behavioural interventions focused on encouraging screening uptake among young adults with T2D, indicating that development of a tailored intervention is warranted.

3. Perceived barriers to and facilitators of screening (which are modifiable and within the scope of the current intervention) include:

   - **Knowledge**: diabetic retinopathy (awareness of asymptomatic nature of DR, high personal DR risk, modifiable risk factors), screening (consequences of not screening, role of screening in early detection of DR and subsequent benefit of timely treatment, distinction between standard eye check and retinal screen)

   - **Attitudes**: low perception of personal risk, recognition of the benefit of screening

   - **Normative beliefs**: awareness of screening approval by significant others, and screening approval and behaviour of similar others

   - **Intention**: low prioritisation of target behaviour

   - **Behavioural skills**: self-efficacy in overcoming common screening barriers to ensure screening attendance (e.g. lack of time or resources), engagement with healthcare (sharing diabetes diagnosis, participation in diabetes self-management behaviours)

The survey identified that compared to their non-screening counterparts, those who had previously attended screening reported: significantly higher knowledge of both DR and retinal screening; more positive attitudes towards screening; stronger agreement that significant others would approve of the behaviour; higher intention to screen; greater perceived behavioural control (i.e.
confidence that they could arrange and attend screening when due), and greater confidence in addressing common screening barriers.

The findings suggest that messages highlighting the prevalence of DR and link between DR and diabetes duration are warranted to prompt reassessment of personal risk. Information on modifiable DR risk factors (blood glucose, blood pressure and cholesterol), asymptomatic nature of the condition and screening guidelines are needed to encourage individuals to both reduce DR risk and initiate screening.

Messages designed to highlight the health and material consequences of screening, including likely positive emotional consequences, are warranted in order to promote positive screening attitudes. Findings suggesting that all participants perceived screening as potentially ‘unpleasant’, ‘uncomfortable’ and disruptive to normal activities are realistic considering that many people experienced discomfort and delay from pupil dilation (mydriasis) drops. Consequently, positive messages should be balanced by acknowledgement of the potential for negative consequences related to mydriasis in order to maintain credibility.

Although moderately high levels of distress in the priority population mean that it is important to avoid direct ‘fear appeal’ messages, low anticipated regret scores for those who had not screened reinforce the need for messages which emphasise personal susceptibility and describe the likely consequences of not screening. Similarly, responses to risk perception items point to a possible unrealistic level of optimism, highlighting the need to emphasise personal susceptibility while
providing information-based content on steps that can be taken to reduce DR risk. As with many other preventive behaviours, awareness of the potential effectiveness of screening followed by subsequent protective action did not necessarily result in intention formation or prioritisation of preventive intentions. Cognitive dissonance induction techniques have been found to have generally positive effects on changing attitudes, motivations and health-related behaviour patterns (Freijy & Kothe, 2013). Consequently, we selected dissonance reduction as a technique that could promote screening motivation.

Responses to normative behaviour items suggest that messages that provide information about significant others’ approval are warranted. The findings suggest that inclusion of procedural information and messages to promote confidence in knowing steps that can be taken to reduce DR risk including how to book and remember a retinal screen, as well as overcoming common barriers are warranted. Emphasis is required to minimise misconceptions about some barriers (e.g. inclusion of messages which accurately describe the cost and time taken for the procedure).

4.4.1.3 Logic model of the problem. Giving consideration to both the qualitative and quantitative needs assessments, we synthesised our findings into a logic model for DR screening. The aim of the logic model was to identify the pathways of problem causation moving from determinants, to low screening rates and consequent impact on health and quality of life (Figure 5).
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

Figure 5: Logic model of the problem


*Identified in the needs assessment but cannot be modified by the current intervention.
4.4.1.4 **Context of the intervention and program goals.** The intervention was to be evaluated and implemented in a real-world setting where intervention format and delivery medium were dictated by broader policy-level initiatives and a fixed delivery timeline. The intervention was funded by Vision 2020 Australia and grounded within a suite of Vision Initiative projects collectively designed to achieve the aims of the Commonwealth government ‘National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss’ (Commonwealth of Australia, 2005). Vision Initiative policy required that the resource be targeted at the individual-level and delivered directly to eligible young adults with T2D (NDSS registrants). As such, it was determined by the planning team members who were involved in conception of the study, that the most efficient, cost-effective way to meet these criteria was for the intervention to take the form of a leaflet, to be posted to eligible NDSS registrants. Furthermore, this enabled the leaflet to be included in future ‘NDSS starter packs’ for new registrants, and to be made available online. This decision was supported by previous research, which showed that printed materials are acceptable to young adults with T2D, who give preference to consistent, centralised information over format, and who specifically state that the NDSS ‘starter pack’ is a useful resource.

With 86% of Australians with T2D registered, the NDSS is considered the “best available source to monitor type 2 diabetes in children and young people in Australia” (p.36, 2014). However, the NDSS database primarily records registrant
postal addresses, which necessitated the use of a print-based intervention tool that could be posted to registrants.

Overall, the purpose of the intervention was to promote uptake of screening among young adults with T2D. Accounting for real-world logistical considerations, the program goal was to develop a leaflet intervention that: could be delivered by post, was tailored to young adults with T2D, and included persuasive messaging targeting behavioural determinants of the target behaviour.

4.4.2 Program outcomes and objectives; logic model of change.

4.4.2.1 Expected behavioural outcomes and Performance Objectives. The multidisciplinary planning team defined a single, measurable primary outcome when planning for the subsequent evaluation (uptake of screening for those young adults with T2D who had not previously screened for DR), and multiple secondary outcomes (i.e. change in nominated modifiable behavioural screening determinants).

Working from the designated program outcomes, and informed by the findings of the needs assessment, the planning team established the foundation for the intervention by defining four Performance Objectives (PO, Table 14). We increased the specificity of each Performance Objective by defining sub-objectives, each identifying a behaviour or cognitive process that would promote screening uptake.
### Table 14: Performance Objectives (e.g. PO.1) & sub-objectives (e.g. PO.1.1, PO.1.2..)

<table>
<thead>
<tr>
<th>Performance Objective</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO.1.</td>
<td>... demonstrate a clear understanding of diabetic retinopathy (DR)</td>
</tr>
<tr>
<td>PO.1.1.</td>
<td>Modifiable and non-modifiable DR risk factors</td>
</tr>
<tr>
<td>PO.1.2.</td>
<td>Clinical targets for reducing risk of DR</td>
</tr>
<tr>
<td>PO.1.3.</td>
<td>Symptoms of DR</td>
</tr>
<tr>
<td>PO.1.4.</td>
<td>Role of DR in vision loss</td>
</tr>
<tr>
<td>PO.1.5.</td>
<td>Prevalence of DR</td>
</tr>
<tr>
<td>PO.2.</td>
<td>...demonstrate clear understanding of retinal screening</td>
</tr>
<tr>
<td>PO.2.1.</td>
<td>Role in detecting DR and reducing vision loss</td>
</tr>
<tr>
<td>PO.2.2.</td>
<td>Screening procedure and experience</td>
</tr>
<tr>
<td>PO.2.3.</td>
<td>Booking and examination procedure</td>
</tr>
<tr>
<td>PO.3.</td>
<td>...be motivated to engage in retinal screening</td>
</tr>
<tr>
<td>PO.3.1.</td>
<td>Prioritise retinal screening</td>
</tr>
<tr>
<td>PO.3.2.</td>
<td>Understand personal risk of DR</td>
</tr>
<tr>
<td>PO.3.3.</td>
<td>Identify personal barriers to retinal screening</td>
</tr>
<tr>
<td>PO.3.4.</td>
<td>Perceive personal responsibility to engage in screening</td>
</tr>
<tr>
<td>PO.4.</td>
<td>...proactively engage with the healthcare system and their healthcare team</td>
</tr>
<tr>
<td>PO.4.1.</td>
<td>Discuss diabetes and eye health with healthcare professionals</td>
</tr>
<tr>
<td>PO.4.2.</td>
<td>Understand treatment benefits and options</td>
</tr>
<tr>
<td>PO.4.3.</td>
<td>Seek more information about diabetes and eye health</td>
</tr>
</tbody>
</table>
4.4.2.2 Create logic model of change. We developed a logic model of change (Figure 6) to depict the hypothetical causal pathway from the intervention to program outcomes, and anticipated health and quality of life improvements. Commencing with the intervention, we outlined the five modifiable behavioural determinants (from Figure 5) and four Performance Objectives (Table 14), which were expected to change the measurable behavioural outcome. The planning team also acknowledged external factors that may affect screening behaviour (i.e. factors that cannot be changed through an individual-level intervention) in the logic model, even though these were beyond the scope of our intervention.
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

Leaflet intervention tailored to young adults with T2D

Behavioural Determinants
- Knowledge
- Attitudes
- Normative beliefs
- Intention
- Behavioural skills

Performance Objectives
- Understand DR
- Understand retinal screening
- Motivated to screen
- Engage with healthcare

Intervention Outcome
Uptake of screening for young adults with T2D who had not screened for DR since diabetes diagnosis

Long term impact
Health problem
- Reduce risk of DR by managing modifiable risk factors
- Prevent vision loss from DR by early detection and timely treatment

Quality of life
- Maintain independence, workforce participation, family functioning

Other factors (e.g. economic, access, language and cultural)
Identified in the needs assessment but cannot be modified by the current intervention

T2D: type 2 diabetes, DR: diabetic retinopathy, GP: general practitioner

Figure 6: Logic model of change
4.4.2.3 *Create matrix of Change Objectives.* Once the health behaviours, Performance Objectives and determinants were defined, Change Objectives were developed. Change Objectives are integral to intervention content because they represent the behaviour or cognition being targeted. A sub-group of the planning team generated Change Objectives by creating a matrix, with modifiable behavioural determinants (in columns) and sub-objectives (in rows).

Table 15 presents a matrix of Change Objectives for Performance Objective 3 (Young adults with type 2 diabetes will be motivated to engage in retinal screening). To illustrate, two Change Objectives were generated for sub-objective 3.2 (Understand personal risk of DR), at the intersection with two determinants (knowledge and attitudes). The first (K.3.2) sought to improve knowledge that risk of DR increases over time, and the second (A.3.2) sought to change attitudes regarding personal risk and susceptibility to DR. See Table 20 (Additional files) for a complete matrix of Change Objectives.
Table 15: Illustrative matrix of Change Objectives for Performance Objective 3 (PO.3) - Young adults with type 2 diabetes will be motivated to engage in retinal screening*

<table>
<thead>
<tr>
<th>Sub-objectives</th>
<th>Knowledge</th>
<th>Attitudes</th>
<th>Normative beliefs</th>
<th>Intention</th>
<th>Behavioural skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO.3.1 Prioritise retinal screening</td>
<td></td>
<td></td>
<td>NB.3.1 Recognise that similar others have overcome screening barriers</td>
<td>I.3.1 Form an intention to prioritise retinal screening</td>
<td></td>
</tr>
<tr>
<td>PO.3.2 Understand personal risk of DR</td>
<td>K.3.2 Know that DR risk increases over time</td>
<td>A.3.2 Perceive high personal risk and susceptibility to DR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PO.3.3 Identify personal barriers to retinal screening</td>
<td>A.3.3 Believe that attending screening will relieve fear and guilt and be a positive experience</td>
<td>NB.3.3 See that similar others face screening barriers (e.g. cost, fear of adverse effects)</td>
<td></td>
<td>BS.3.3 Be confident in one’s ability to identify and overcome common screening barriers</td>
<td></td>
</tr>
</tbody>
</table>
Table 15: Illustrative matrix of Change Objectives for Performance Objective 3 (PO.3) - Young adults with type 2 diabetes will be motivated to engage in retinal screening* (Cont.)

<table>
<thead>
<tr>
<th>Sub-objectives^</th>
<th>Knowledge</th>
<th>Attitudes</th>
<th>Normative beliefs</th>
<th>Intention</th>
<th>Behavioural skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO.3.4 Perceive</td>
<td>K.3.4 Know that</td>
<td>A.3.4 Adopt</td>
<td>NB.3.4 Believe that</td>
<td>BS.3.4 Be confident</td>
<td></td>
</tr>
<tr>
<td>personal</td>
<td>they can take steps</td>
<td>personal</td>
<td>similar others take</td>
<td>they have the tools</td>
<td></td>
</tr>
<tr>
<td>responsibility</td>
<td>to protect eye</td>
<td>responsibility for</td>
<td>responsibility for</td>
<td>to act on personal</td>
<td></td>
</tr>
<tr>
<td>to engage in</td>
<td>health</td>
<td>retinal screening</td>
<td>their own eye health</td>
<td>responsibility</td>
<td></td>
</tr>
<tr>
<td>screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

^See Table 14 for full list of Performance Objectives and sub-objectives

*Full matrix of Change Objectives for every Performance Objective is provided in Additional file 3

PO=performance objective, DR=diabetic retinopathy, GP=general practitioner.

Determinants: K=Knowledge, A=Attitudes, NB=Normative Beliefs, I=Intention, BS=Behavioural Skills
4.4.3 Intervention design.

4.4.3.1 Intervention themes, components, scope and sequence. Ensuring that all components of the intervention reflected the needs and preferences of young adults with T2D was a crucial consideration for the planning team. The health behaviour change and health communication literature provided ample foundation on best practice presentation of message content (Abraham & Kools, 2012; Bailey et al., 2014; Bartholomew Eldredge et al., 2016; Beard, Clark, Hurel, & Cooke, 2010; Browne et al., 2014; Browne et al., 2013; Cialdini & Goldstein, 2004; Muller et al., 2014; Werrij, Ruiter, van’t Riet, & de Vries, 2012). Informed by this evidence and the findings of the needs assessment, we developed seven guiding principles for leaflet intervention design (Table 16). Consultation with young adult PPI members and experts from key stakeholder groups confirmed that these were appropriate guiding principles from their perspective.
### Table 16: Guiding principles for retinal screening leaflet intervention design

<table>
<thead>
<tr>
<th><strong>Readability and comprehension:</strong></th>
<th>content to be written to acceptable (health) literacy standards, with minimal technical or medical terminology (Bailey et al., 2014; Beard et al., 2010).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scope:</strong></td>
<td>the scope of intervention messages to be restricted to targeting individual-level, modifiable behavioural determinants.</td>
</tr>
<tr>
<td><strong>Framing:</strong></td>
<td>despite long term benefit, retinal screening can be considered a high-risk behaviour due to the potential for immediate DR diagnosis (Werrij et al., 2012). Loss-framed messages are effective in promoting engagement with high-risk behaviours and will be used in this leaflet (Bartholomew Eldredge et al., 2016). The majority of headings to be framed as questions to engage the reader while minimising any potentially defensive reaction (Muller et al., 2014).</td>
</tr>
<tr>
<td><strong>Sequence:</strong></td>
<td>content to follow the logical order of reading. In order to balance loss-framed messages against the high levels of diabetes-related distress and anxiety experienced by young adults with T2D (Browne et al., 2014; Browne et al., 2013), potentially threatening content to be immediately followed by an empowering or reassuring statement.</td>
</tr>
<tr>
<td><strong>Use of quotes:</strong></td>
<td>in recognition of the subtle aspects of social influence, where an individual’s’ beliefs are influenced by those accepted and encouraged by the majority (Cialdini &amp; Goldstein, 2004), quotes from similar others to be used to reinforce key persuasive messages. All quotes to be sourced verbatim from interview study with descriptors (age and diabetes duration) included to reinforce group membership.</td>
</tr>
<tr>
<td><strong>Credibility:</strong></td>
<td>quote descriptors within the leaflet to reflect demographic characteristics of the priority population to prompt identification with a credible source. Similarly, logos of leading diabetes and eye health organisations that had contributed to the content to be included to enhance credibility of information. Important yet necessary negative information</td>
</tr>
</tbody>
</table>
(e.g. discomfort associated with mydriasis, time required to recover clear vision) to be included to provide balance.

**Graphics and imagery:** to reflect the demographic characteristics of the priority population (e.g. young adults from a range of ethnicities, with and without children). National interpreter symbol to indicate availability of language assistance services to those with limited English proficiency (Abraham & Kools, 2012).

4.4.3.2 *Choose theory and evidence-based behaviour change methods.*

Having established guiding principles, the planning team selected types of theory-based psychological change techniques (or change strategies) (Abraham, 2012; Abraham & Michie, 2008) grouped into six broad change mechanisms designed to ‘boost motivation and prompt action’ (Abraham, 2012, p.104). The constituent techniques (or practical methods) included in the leaflet focused on: i) changing beliefs about the benefits of screening (e.g. providing general information on behaviour-health links, describing likely consequences of behaviour); ii) changing risk perception (e.g. emphasising personal susceptibility to negative consequences, prompting recipients to assess own risk); iii) changing attitudes associated with screening uptake (e.g. describing likely emotional or affective consequences, potentially inducing cognitive dissonance among those not intending to act in the face of negative consequences); iv) changing (normative) beliefs about others’ behaviour (e.g. emphasising significant others’ approval of screening behaviour, providing information about others’ screening behaviour); v) fostering a positive screening identity (e.g. providing a positive group identity for those engaging in
screening); and vi) enhancing self-efficacy (e.g. using persuasive argument to bolster self-efficacy, providing instruction, prompting barrier identification and planning in relation to anticipated barriers, prompting goal setting).

4.4.4 Intervention development.

4.4.4.1 Draft persuasive message content and leaflet.

Develop message content: Working from the matrix of Change Objectives, the guiding principles, and theory and evidence-based intervention strategies noted above, a pool of more than 60 persuasive messages was developed. From this pool, specific change techniques or practical methods were selected to encourage screening. For example, to achieve Change Objective A.3.4 (View retinal screening as a personal responsibility), four potential leaflet heading messages were developed: ‘Eyes: they’re important any way you look at it’, ‘The only way to know is to go...’ (verbatim quote), ‘Who is looking after your eyes?’, and ‘Looking at the facts’. All messages were reviewed by the planning team, and a sub-set selected based on the perceived capacity of the message to achieve program goals, target individual Change Objectives, and satisfy the leaflet guiding principles. Thus, in the above example, the third option (‘Who is looking after your eyes?’) was selected because it was phrased as an engaging question, promoting personal responsibility with potential to reduce defensive reaction while motivating screening.

A selected example, linking leaflet content to Performance Objective 3, is presented in Table 17. Full intervention map detail for all Performance and Change Objectives is provided in Table 21 (Additional files).
Table 17: Illustrative intervention map linking leaflet content directly back to Performance Objective 3 (PO.3: Young adults with T2D will be motivated to engage in retinal screening)

<table>
<thead>
<tr>
<th>Sub-objective (i.e. 3.1) and related Change Objectives</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
<th>Panel number*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PO.3.1 Prioritise retinal screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NB.3.1 Recognise that similar others have overcome screening barriers</strong></td>
<td>“I was scared. I was scared of what damage was done...of confronting the fact that my eyesight could be damaged, and of going through the exam and being confronted with what’s there.”</td>
<td>7</td>
</tr>
<tr>
<td><strong>I.3.1 Form an intention to prioritise retinal screening</strong></td>
<td>(What can I do to protect myself from DR and prevention vision loss?) 1. Have a diabetes eye health check. (Note: eye health check listed as Step 1, highest priority)</td>
<td>5</td>
</tr>
<tr>
<td><strong>PO.3.2 Understand personal risk of DR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>K.3.2 Know that DR risk increases over time</strong></td>
<td>The longer you have diabetes the more at risk you are of DR.</td>
<td>1</td>
</tr>
<tr>
<td><strong>A.3.2 Perceive high personal risk and susceptibility to DR</strong></td>
<td>Image: mother and daughter smiling. Child holding hands over mother’s eyes But I’m still young. Am I at risk of DR? Yes you are. Anyone with diabetes can develop DR, which is the leading cause of vision loss for people under 60 years. There are over 34,000 Australians with type 2 diabetes who are under 40 years of age. More than 8,500 will already have DR. The longer you have diabetes the more at risk you are of DR. (Lucas, aged 34, diagnosed with type 2 diabetes 2 years ago)</td>
<td>1 1 1 1 1</td>
</tr>
</tbody>
</table>
### Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

<table>
<thead>
<tr>
<th>Sub-objective (i.e. 3.1) and related Change Objectives</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
<th>Panel number*</th>
</tr>
</thead>
</table>
| **PO.3.3 Identify personal barriers to retinal screening** | "I didn't know that I was at risk."
(Jane 25 years, diagnosed with type 2 diabetes 3 years ago) | 1 |
| | "You might have good vision, you might think that your eyes are absolutely brilliant and there’s no issue. But in the back of your eye, there could be a problem with those little tiny veins that you don’t realise." | 4 |
| **A.3.3 Believe that attending screening will relieve fear and guilt and be a positive experience** | (Jenny’s story: before and after the eye health check) | 7 |
| | “It was actually quite fun; I don’t know why I put it off. I was really scared going in there, but definitely not now – I’m not fazed by it at all.” | |
| **NB.3.3 See that similar others face screening barriers (e.g. cost, fear of adverse effects)** | (Jenny’s story: before and after the eye health check) | 7 |
| | “The eye drops were a bit uncomfortable and there was a small cost – but I think it’s a wise spend considering what you’re preventing.” | |
| **BS.3.3 Be confident in one’s ability to identify and overcome common screening barriers** | (What else do I need to know?) A diabetes eye health check takes about 30 minutes. (What else do I need to know?) It may be free (bulk-billed) or there may be a small fee. (What else do I need to know?) Your optometrist may use eye drops which helps them to see the back of your eye. If you do have eye drops, they may be a little uncomfortable. The drops will also leave you sensitive to light, so bring your sunglasses and be prepared to wait a while for your vision to return to normal. | 6 |
### Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

#### Panel number*

<table>
<thead>
<tr>
<th>Sub-objective (i.e. 3.1) and related Change Objectives^</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
<th>Panel number*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PO.3.4 Perceive personal responsibility to engage in screening</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>K.3.4</strong> Know that they can take steps to protect eye health</td>
<td>What can I do to protect myself from DR and prevent vision loss?</td>
<td>5</td>
</tr>
<tr>
<td><strong>A.3.4</strong> Adopt personal responsibility for retinal screening</td>
<td>&quot;I’m a busy person and my family depend on me.&quot;</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Leaflet heading: Who is looking after your eyes?</td>
<td>3</td>
</tr>
<tr>
<td><strong>NB.3.4</strong> Believe that similar others take responsibility for their own eye health</td>
<td>Images: mother and daughter, smiling couple selfie, young man of indeterminate cultural origin, Asian female (a.k.a. ‘Jenny’)</td>
<td>1,3,5,8</td>
</tr>
<tr>
<td><strong>BS.3.4</strong> Be confident they have the tools to act on personal responsibility</td>
<td>Leaflet sub-heading: Your guide to preventing vision loss from diabetes eye disease</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Protect your sight for life</td>
<td>2</td>
</tr>
</tbody>
</table>

Complete intervention map for all Performance and Change Objectives is provided in Additional file 5.

PO=Performance Objective (in bold), DR=diabetic retinopathy. ^See Table 15 for illustrative matrix of Change Objectives and Additional file 3 for complete matrix.

*See Figure 7 for leaflet panels.

Determinants: K=knowledge, A=attitudes, NB=normative behaviour, I=intention, BS=behavioural skills.
Assessing readability and suitability: The leaflet was assessed using a combination of an online readability consensus calculator and the Suitability Assessment of Materials (SAM) test, consistent with best practice (Ryan et al., 2014). The consensus calculator reports synthesised results from seven assessment tools (e.g. Flesch Reading Ease formula, Flesch-Kincaid Grade), to provide two composite scores by grade (range: 4-9) and reading level (range: 0-29 ‘very confusing’ to 90-100 ‘very easy’) (Scott, 2016). The SAM test uses six evaluation criteria (content, literacy demand, graphics, layout and type, learning stimulation and motivation, cultural appropriateness) to determine overall suitability (Doak, Doak, & Root, 1996), with scores summed and converted to a percentage score and classified as ‘not suitable’ (0-39%), ‘adequate’ (40-69%), or ‘superior’ (70-100%).

We excluded the front and back panels of the ‘Who is looking after your eyes?’ leaflet from assessment, as they included minimal text. For the remaining panels, the median readability consensus grade was 6; median reading ease level was 75.6 (fairly easy), and SAM test outcome was 75% (superior).

Draft intervention materials: The planning team selected an 8-panel leaflet design, with panels opening outward from the centre, which could fit into a standard DL-size envelope. A range of leaflet design options were created in close consultation with a graphic designer who had expertise in producing health promotion materials for people with diabetes. The designs varied in structure, imagery and organisation, but all adhered to the guiding principles and included consistent messaging.
4.4.4.2 Pre-test, refine and produce leaflet.

Validation and pilot testing: The draft leaflet was reviewed by the planning team and representatives from key stakeholder organisations to confirm that all content was factually accurate and clinically appropriate, and that the resource was likely to meet the project objective. Young adult PPI members participated in a thorough piloting process to determine whether: the images and quotes were culturally relevant and resonated with the reader; participants perceived the leaflet would have met their information needs at the time of their T2D diagnosis; and there were any unintended adverse effects in the messaging, imagery or format. Each young adult PPI member received the draft leaflet by post and, after reviewing it, participated in a telephone interview during which they commented on the leaflet’s suitability, responding to questions based on the SAM criteria (Doak et al., 1996).

Feedback from stakeholder reviewers was positive, with minimal critique offered. Young adult PPI members gave more considered commentary on what they found useful and what could be improved (Table 18). Where appropriate, the leaflet was revised to improve content, imagery, readability and cultural acceptability. Once finalised, leaflet printing was managed by Diabetes Victoria (the state agent of the NDSS).
**Table 18: Suitability Assessment Materials (SAM) evaluation criteria, young adults’ feedback and changes made to leaflet**

<table>
<thead>
<tr>
<th>Sample pilot questions</th>
<th>Young adults’ feedback</th>
<th>Changes to leaflet</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content:</strong> Do you think that this leaflet achieves the purpose of the project?</td>
<td>“Key information came through really clearly. I didn’t know that early DR doesn’t have any symptoms...the doctors tend to focus on blood glucose, so I knew the 7% (HbA1c) but I didn’t know what the cholesterol target and normal blood pressures were.” ID32</td>
<td>Make ‘Protect your sight for life’ a stand-alone statement and place at top of panel 2, which signposts location of more information</td>
</tr>
<tr>
<td>• Did you learn anything new?</td>
<td>“This leaflet improved my intentions. (DR) is not something you would think could happen to young people.” ID32</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“‘Protect your sight for life’ is a powerful statement.” ID36</td>
<td></td>
</tr>
<tr>
<td><strong>Literacy demand:</strong> Was the length of the leaflet acceptable to you?</td>
<td>“It only took about 5 minutes to read.” ID33</td>
<td>Discuss whether to include ‘DR’ in leaflet. By consensus, a decision was made to include it, but to bold initial definition of diabetic retinopathy and DR acronym at top of panel 4.</td>
</tr>
<tr>
<td>• How about the number of words?</td>
<td>“Language is pretty relaxed which is good for young people.” ID40</td>
<td></td>
</tr>
<tr>
<td>• How easy was it to read and understand the information in the leaflet?</td>
<td>“The only thing that caught me was ‘DR’. Did you mean ‘doctor’ or ‘diabetic retinopathy’? I think you should bold it when it is first defined.” ID32</td>
<td></td>
</tr>
<tr>
<td>• Are the words used simple, clear and informal?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Were medical terms defined adequately?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Graphics:</strong> What do you think of the front panel image?</td>
<td>“Very professional. Looks like it's targeted at my demographic.” ID36</td>
<td>Bold text ‘When diabetes is first’</td>
</tr>
<tr>
<td>Sample pilot questions</td>
<td>Young adults’ feedback</td>
<td>Changes to leaflet</td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------</td>
<td>-------------------</td>
</tr>
</tbody>
</table>
| Are the other images and graphics ‘friendly’ and relevant? | “Maybe bold ‘When diabetes is first diagnosed’ so that you hammer home that it’s never too early to have an eye check.” ID32  
“I’ve never really looked at a graph in a pamphlet. It might appeal to some people, but I don’t know...” ID40 | diagnosed’ in panel 5. Remove graph, which depicted rate of DR progression over time. |

**Layout and typography:** What do you think of the sequence of information?  
- Is the text type size and font easy to read, or could it be easier?  
- Is the information in the leaflet well-spaced, or does it appear cluttered or confusing?  

“Main headings need to be in a larger sized font and bold, and sub-headings in smaller font. Keep the blue colouring.” ID39  
“Is there a way that you can make more white space? The different colours are more attractive.” ID33

**Learning stimulation, motivation:**  
Thinking back to when you first were told that you had diabetes or when you learnt that diabetes could affect the eyes – would the leaflet have met your information needs at that time?  
- Do you feel that the leaflet is friendly or formal?  
- Do you feel like you want to read it now or later? Why?  

“Jenny’s story is a good thing to have in there. Including name, age and diabetes duration makes the quotes more meaningful.” ID39  
“Wow, that looks awesome...I didn’t expect to see two smiling faces on the front because most diabetes things are all doom and gloom, they’re so terrifying and then you don’t want to read them. Whereas, I read this and thought, this was a reminder for me to book in for my eye check.”ID40  
“I loved the ‘What happens if I had DR’ section. I kept putting off an eye check because I was scared of what would happen. Revisit Performance Objectives to include understanding the treatment options (PO.4.2), populating this through the matrix of Change Objectives and into the leaflet content. Add more treatment detail to
**Sample pilot questions**

**Cultural appropriateness:** Do the quotes represent key emotions or experiences that you have felt about eye examinations? Was the language used throughout the leaflet familiar and culturally appropriate to you?

- Were there any sections that you found confusing or were unsure about?

<table>
<thead>
<tr>
<th>Sample pilot questions</th>
<th>Young adults’ feedback</th>
<th>Changes to leaflet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you add more about what the treatment is?” ID32</td>
<td>“I love the pictures; they speak to different cultural backgrounds.” ID32</td>
<td>Retain multicultural imagery.</td>
</tr>
<tr>
<td></td>
<td>“English is not my first language, but I didn’t have any problem reading the leaflet.” ID33</td>
<td></td>
</tr>
</tbody>
</table>
4.4.5 **Intervention implementation.** Planning for program adoption and implementation started at study commencement and was heavily influenced by contractual obligations with the funder. These included a one-off statewide distribution of the leaflet to all eligible NDSS registrants, timed to coincide with Vision 2020 Australia public awareness campaign.

To protect registrants’ privacy, the NDSS distributed the final leaflet (presented in Figure 7) directly to members of the priority population, on behalf of the planning team. Plans are underway for a revision of the NDSS ‘starter pack’ to include the eye health leaflet for young adults with T2D, ensuring long-term sustainability of the intervention. Further, to enhance reach, an electronic copy of the leaflet was made freely available via Diabetes Victoria and Vision 2020 Australia (Diabetes Victoria; Vision 2020 Australia, 2017) and promoted to healthcare professionals and members of the priority population.
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

Figure 7: ‘Who is looking after your eyes?’ tailored leaflet © Vision 2020 Australia, 2017. All rights reserved.
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

Panel 5

Getting a diabetes eye health check is easy.

- You don't need a referral from your GP.
- You can book an appointment directly with an optometrist. When you do, be sure to tell them you have diabetes.

What is a diabetes eye health check?

- It is different to a standard eye check because it specifically looks to see whether diabetes is affecting your eyes.
- It is usually done by an optometrist who will take a photo of the back of your eye.
- Your optometrist will look at the photo to check the blood vessels at the back of your eye for signs of diabetes-related eye damage.

What else do I need to know?

- A diabetes eye health check takes about 30 minutes.
- It may be free (bulk-billed) or there may be a small fee.
- Your optometrist may use eye drops which helps them to see the back of your eye. If you do have eye drops, they may be a little uncomfortable. The drops will also leave you sensitive to light, so bring your sunglasses and be prepared to wait a while for your vision to return to normal.

What happens next?

- If they see any signs of damage to the back of your eye, your optometrist will either arrange treatment with an ophthalmologist (medical eye specialists).
- Either way, discuss your results with your GP or diabetes specialist.

Panel 6

Jenny’s story

Jenny, aged 36, diagnosed with type 2 diabetes 6 years ago

Before the diabetes eye health check

“I was scared. I was scared of what damage was done... of confronting the fact that my sight could be damaged, and of going through the exam and being confronted with what there was.

But I want to take care of my kids. I want to be able to see their children one day. I want to be able to grow older and have my vision.”

After the eye health check

“It was actually quite fun; I don’t know why I put it off. I was really scared going in there, but definitely not now — I’m not fazed by it at all.

The eye drops were a bit uncomfortable and there was a small cost — but I think it’s a wise spend considering what you’re preventing.

Overall, it was worth it and the thought that I can control this gives me real peace of mind.”

Panel 7

Jenny’s advice to you

“I suppose if I was telling someone that’s just been diagnosed, I would be saying, to them: Don’t wait to be told and don’t wait until you notice changes — book an eye health check now.

Discuss with the optometrist what to expect, what you should be aware of and so on. I had a lovely optometrist, she really put me at ease.”

What happens if I have DR?

- Your eye health professional will advise you of your treatment options.
- In the early stages, treatment may not be needed, but you may be asked to have eye health checks more frequently to monitor the DR.
- You can slow progression of DR by keeping your blood glucose, blood pressure and cholesterol as close to target as possible.
- If DR progresses, you may need to take tablets or have specialist treatment (usually laser therapy).

Figure 7: ‘Who is looking after your eyes?’ tailored leaflet © Vision 2020 Australia, 2017. All rights reserved.
4.4.6 Planning for intervention evaluation. Similarly, evaluation planning started at study commencement. The planning group determined that the best method of evaluation of the leaflet intervention was a two-arm, wait-list randomised controlled trial with screening uptake as the primary outcome and change in modifiable behavioural determinant constructs as secondary outcomes. The trial, registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12614001110673), is now complete, and a manuscript is in preparation.
4.5 Discussion

Uptake of retinal screening from diabetes diagnosis is crucial for the early identification of DR. In this study, we undertook the systematic development of an evidence-based health behaviour change intervention tailored to the needs of a priority population, young adults with T2D, who are at risk of low retinal screening uptake and vision loss from DR.

To date, lack of information on the determinants of retinal screening behaviour among young adults with T2D, and on the elements of individual-level DR screening interventions (Lawrenson et al., 2016), has hampered development of effective, targeted intervention strategies for this priority population. Further, previous print-based retinal screening interventions have been limited in focus, aiming primarily to increase knowledge and awareness of DR, and of retinal screening, and neglecting to target other behavioural determinants, such as social norms and intentions (Lawrenson et al., 2016; Zhang et al., 2007), despite the acknowledged role of psychosocial factors in health behaviour (Michie & Abraham, 2004).

The needs assessment described here is the first large-scale, mixed-method exploration of modifiable behavioural factors impacting retinal screening behaviour among young adults with T2D. The findings highlighted that many of clinical and psychosocial barriers to diabetes self-management faced by young adults with T2D more broadly (Auslander, Sterzing, Zayas, & White, 2010; Brouwer et al., 2012; Browne et al., 2014; Browne et al., 2013; Hessler et al., 2011; Savage et al., 2009;
Sillars, Davis, Kamber, & Davis, 2010; Waitzfelder et al., 2011), also apply to retinal screening. Importantly, when compared to older adults with T2D, young adults with T2D face both an accumulation of barriers to retinal screening, and a number of uniquely salient barriers and facilitators (Lake et al., 2017), warranting tailored intervention.

Combined with consensus-driven selection of Performance Objectives, theoretically-grounded change methods and comprehensive pilot and review, IM provided the means by which to develop a retinal screening promotion intervention that was both evidence-based and sensitive to the needs and characteristics of young adults with T2D. However, despite this being a relatively simple, single-focus intervention, we shared the experience of other programmes, which reported the IM process to be both resource and time-intensive (Gray-Burrows et al., 2016; Greaves et al., 2016; Hurley et al., 2016). In particular, we found the high degree of process documentation time-consuming, although we acknowledge that this activity was crucial for transparency of reporting, and conforms to key items in the Template for Intervention Description and Replication (TIDieR) checklist and guidance (Hoffmann et al., 2014).

4.5.1 **Strengths and limitations.** The key strengths of this work relate to the use of the IM, which combines both innovative and traditional intervention development activities into an organised, systematic process, and which is consistent with the UK MRC framework for the design and evaluation of complex interventions (Craig et al., 2008). In the face of limited existing evidence, the
empirical needs assessment, complemented by contribution from the multidisciplinary planning team, key stakeholders and the young adults with T2D PPI group, enabled comprehensive exploration of the problem, providing a robust foundation to the intervention. Further, the use of sound theoretical underpinnings, causal modelling, and detailed pilot and review, provided assurance as to the validity of the outcome. As such, the ‘Who is looking after your eyes?’ leaflet was both evidence-based and sensitive to the needs and characteristics of young adults with T2D.

Nonetheless, this study was subject to several limitations. First, the vast majority of studies targeting youth and young adults with T2D face recruitment challenges (Browne et al., 2013; Nguyen et al., 2014; Speight, Browne, Holmes-Truscott, Hendrieckx, & Pouwer, 2012), and our empirical studies were no different in this respect. Despite numerous steps taken to improve recruitment, only 10 young adults with T2D participated in the qualitative study and only 2% of the eligible population completed the quantitative online study.

It is likely that recruitment was impacted by a range of challenges typically specific to young adults with T2D, such as social disadvantage, disengagement with existing services, and complex psychosocial and health needs (Lake et al., 2017; Nadeau et al., 2016; Nguyen et al., 2014; Zeitler et al., 2015). Furthermore, the needs assessment studies were conducted concurrent with a number of other research projects managed by the NDSS, which may have contributed to study ‘fatigue’ for this already small population (personal communication, D. Rae, National
Inventory Manager, NDSS). Although low sample size potentially impacted the generalisability of the needs assessment findings, the response rate for the national survey was larger than any other conducted to date with this priority population.

Second, this study was limited to one priority population where in fact, several populations have been identified as at-risk for low retinal screening and vision loss from DR. These include young adults with T1D, those living in socio-economically deprived areas or from minority ethnic and Indigenous populations (Foreman et al., 2017; Moreton, Stratton, Chave, Lipinski, & Scanlon, 2017; Paksin-Hall, Dent, Dong, & Ablah, 2013; Shi, Zhao, Fonseca, Krousel-Wood, & Shi, 2014), each of which warrant targeted evidence-based intervention, informed by population-specific needs assessments.

Finally, many key contextual elements (e.g. intervention level, delivery medium and format) were externally prescribed within a broader sphere of real-world logistic and contractual limitations. Although unavoidable, this limitation meant that our intervention was unable to address external factors known to impact screening behaviour, such as the cultural diversity of young adults with T2D, low socioeconomic status and lack of English language proficiency, potentially limiting effectiveness. Given that NDSS database strictures limited the intervention to a format suited to postal delivery, the leaflet design was suited to the stated purpose for state-wide implementation. Diabetes Victoria has ensured sustainability and reach of the intervention by regularly updating their resources and making an electronic version of the leaflet freely available on its website (Diabetes Victoria).
4.5.2 **Future directions.** Recent research suggests that an individual’s beliefs about diabetes and self-management, are most likely to be influenced early in their diabetes trajectory (Skinner et al., 2014). Certainly, this appears to be the case for retinal screening where, once initiated, the behaviour is generally sustained (Zhang et al., 2007). Thus, we recommend targeting individuals recently diagnosed with T2D via the NDSS, with registration date considered a proxy for date of diabetes diagnosis. The leaflet could be used to promote national retinal screening programmes in this age group and would be of greatest benefit if translated into additional languages. Further, this process could be utilised to produce tailored resources designed to increase awareness and screening for other populations at high-risk of DR (such as young adults with T1D), or for other diabetes-related complications which impact young adults with T2D (such as nephropathy and cardiovascular disease (Tryggestad & Willi, 2015)).

Our experience of the time and resource-intensive nature of IM reinforces that expressed by others and we suggest that undertaking the full IM methodology may not be suitable for all situations. As such, we recommend that future programme planners explore alternative options where possible, such as adapting an existing, effective intervention to their target population. This can be enabled by use of a simplified process (IM Adapt), which guides decisions regarding selection of appropriate intervention, and components, to adapt (Highfield et al., 2015).

4.5.3 **Conclusions.** In conclusion, our mixed method needs assessment has highlighted salient challenges faced by young adults with T2D and we have
demonstrated that IM is a feasible and worthwhile approach to use for the development of an evidence-based, engaging resource to promote retinal screening to young adults with T2D. This detailed illustration will enable researchers and health promotion specialists to adopt IM methods when developing interventions tailored to high-risk groups. Meanwhile, preliminary evaluation of the ‘Who is looking after your eyes?’ leaflet shows it meets the needs of young adults with T2D and its effectiveness in promoting uptake of retinal screening can now be evaluated in a fully-powered RCT.
4.6 References


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REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REduciNg risk of vision loss for young adults with type 2 diabetes


Date accessed 22 August 2017.


RECORDING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

program. Research and Theory for Nursing Practice, 29(2), 94-112. doi:10.1891/1541-6577.29.2.94


4.7 Declarations

4.7.1 Ethics approval and consent to participate. The studies received ethics approval from the Deakin University Human Research Ethics Committee (in-depth interview component: 2013-157, quantitative survey and planned randomised controlled trial evaluation: 2014-156). Participants provided written informed consent and permission for publication of de-identified quotations at study registration.

4.7.2 Availability of data and material. The datasets used in the current study are available from the corresponding author.

4.7.3 Competing interests. The authors declare that they have no competing interests.

4.7.4 Funding. The study was a designated Vision Initiative activity. The Vision Initiative is an integrated health promotion program funded by the Victorian Government and managed by Vision 2020 Australia. The funding body had no role in design of the study, data collection, analysis or interpretation, or preparation of the manuscript.

4.7.5 Acknowledgements. We thank the people with diabetes who participated in the needs assessments and piloting of the leaflet. We thank Virginia Hagger (previously of Diabetes Victoria) for her involvement in study scoping, prior to CH joining the planning team. We thank Nino Soerendata (Diabetes Victoria) for his skilled graphic design work on the leaflet.
4.8 Additional files

4.8.1 Literature study

**Literature study procedure.** We conducted a preliminary literature search (see box), which focused on screening facilitators and barriers, effective elements of existing individual-level screening interventions, and health information-seeking preferences and behaviours of the priority population. The literature study was maintained throughout the project via regular updates from search alerts; search terms were reviewed annually.

<table>
<thead>
<tr>
<th>Search engines and key databases:</th>
<th>Cochrane Reviews, EBSCOhost, ProQuest, Scopus, Psychlit, Medline, PubMed and CINAHL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Publication period:</strong></td>
<td>10 years prior to February 2013.</td>
</tr>
</tbody>
</table>

**Literature study findings.**

**Screening facilitators and barriers:** Although barriers and facilitators to screening varied across countries, healthcare systems and population groups, shared themes were identified. For example, screening uptake depended on population awareness of health risk (Strutton, Du Chemin, Stratton, & Forster, 2016), health consequences (MacLennan, McGwin, Heckemeyer, & et al., 2014) and treatment benefits following identification through screening (Hua, Cao, Cui, Maberley, &
Common awareness-related barriers included lack of awareness of DR, asymptomatic nature of early-stage DR, confusion between screening for DR and a standard vision-related eye check, absence of clinician recommendation and lack of diabetes self-management education (Al-Alawi, Al-Hassan, Chauhan, Al-Futais, & Khandekar, 2016; Ellish, Royak-Schaler, Passmore, & Higginbotham, 2007; Hartnett, Key, Loyacano, Horswell, & DeSalvo, 2005; Hipwell et al., 2014; John, Cooper, & Serrant-Green, 2014; Klein & Klein, 2006; Lewis, Patel, Yorston, & Charteris, 2007; Livingston et al., 1998; Müller, Lamoureux, Bullen, & Keeffe, 2006; Peng, 2010). Conversely, improvements in the above were common facilitators of screening (John et al., 2014; van Eijk, Blom, Gussekloo, Polak, & Groeneveld, 2012; Walker et al., 1997). In addition to lack of awareness, common screening barriers included low perceived personal risk; fear of screening or of a DR diagnosis if screening was undertaken, and denial of diabetes. Common screening facilitators included anticipated regret at not screening (e.g. undetected eye damage), clinician referral, social support from family, and social comparison (Ellish et al., 2007; Hipwell et al., 2014; Lewis et al., 2007; Strutton et al., 2016).

The evidence base specific to young adults with T2D was scant, with the majority of information either from pediatric-focused population-based studies or clinical trials (Hanman et al., 2014; TODAY study group, 2013), or from retrospective medical record data (Al-Saeed et al., 2016; Wong, Molyneaux, Constantino, Twigg, & Yue, 2008). Younger age (under 40 years) was often controlled or excluded in adult-focused T2D and ophthalmic studies (Forward, Hewitt, & Mackey, 2012; Hessler,
Fisher, Mullan, Glasgow, & Masharani, 2011), and the few available studies targeted specific ethnic or cultural groups, limiting generalisability (Al-Alawi et al., 2016; Hall, Hall, Kok, Mallya, & Courtright, 2016). More broadly, the review identified modifiable factors impacting young adults’ health behaviours, including elevated rates of psychological distress (Anderson et al., 2011; Berge, Bauer, Eisenberg, Denny, & Neumark-Sztainer, 2013; Chittleborough, Winefield, Gill, Koster, & Taylor, 2011; Hessler et al., 2011), perceptions of invulnerability leading to lowered perceived risk (Lapsley & Hill, 2010; Nguyen et al., 2014), and disengagement with healthcare (including diabetes-specific) services (Müller et al., 2006; Nguyen et al., 2014; Savage, Dabkowski, & Dunning, 2009). Such factors are likely to have relevance for screening uptake among young adults with T2D. The need to target a range of behavioural determinants was reinforced by studies focusing specifically on populations at high risk of vision loss (e.g. low socio-economic status, suboptimal glycemic control), which singled out perception of personal risk (MacLennan et al., 2014), cultural appropriateness, and literacy levels of patient education materials (Elam & Lee, 2013), as important screening barriers and consequently, considerations for intervention.

**Effective elements of existing individual-level screening interventions.** A systematic review by Zhang of the effectiveness of interventions to promote retinal screening (Zhang et al., 2007), reported that most interventions significantly increased screening rates, suggesting that a range of methodologies were effective. However, the lack of specificity of the effective elements of screening interventions
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

(Lawrenson et al., 2016), combined with lack of interventions specifically targeting young adults with T2D, highlight considerable gaps in the evidence base. Research suggests that screening interventions with the highest degree of effectiveness involve raising knowledge and awareness of DR, and/or involved ‘registration, reminder and recall’ (i.e. where a patient registered on a database received regular screening prompts) (Halbert, Kwan-Moon, Nichol, & Legorreta, 1999; Zhang et al., 2007). The former (increasing knowledge and awareness) is an achievable intervention target in an Australian context. However, the reminder/recall is not because, currently, Australia does not have a nationally coordinated DR screening programme, such as that offered in the United Kingdom where people with diabetes are registered and automatically receive a screening invitation (Scanlon, 2008).

**Health information-seeking preferences and behaviours.** The information needs of people living with diabetes change over time dependent upon life stage and progress of the condition (Beeney, Bakry, & Dunn, 1996). Young adults with T2D nominated their primary sources of diabetes-related information as: parents/family, healthcare practitioners, the national diabetes advocacy organisation, and the internet (Diabetes Australia, 2006; Dunning & Savage, 2013; Greene, Choudhry, Kilabuk, & Shrank, 2011), with credibility of information given priority over delivery medium (Kumah-Crystal et al., 2015; Savage et al., 2009).

Literature focusing more broadly on young adult health behaviours demonstrated that knowledge is a weaker correlate of preventative health behaviour compared to other modifiable factors, such as subjective norms, self-efficacy and risk perception
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

(Abraham, Krahe, Dominic, & Fritsche, 2002; Bengel, Belz-merk, & Farin, 1996; DiClemente, 1991). This highlights the importance of including motivation and skills, as well as knowledge, as behaviour change targets for this group.
**Literature study references**


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES


Peng, P.-H. (2010). *Assessment of the factors associated with the acceptance of retinal screening among patients with diabetes in Taiwan.* (PhD Doctor of Philosophy (Health Services Policy and Management)), University of South Carolina.

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TODAY study group. (2013). Retinopathy in Youth With Type 2 Diabetes Participating in the TODAY Clinical Trial. *Diabetes Care, 36*, 3.


Table 19: Additional file 2 – Modifiable behavioural determinants by baseline retinal screen

<table>
<thead>
<tr>
<th>Modifiable behavioural determinants</th>
<th>Retinal screen</th>
<th></th>
<th></th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (n=33)</td>
<td>Yes (n=96)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>INFORMATION (KNOWLEDGE) ITEMS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes can lead to vision loss</td>
<td>30 (91)</td>
<td>93 (97)</td>
<td>.174</td>
<td></td>
</tr>
<tr>
<td>All people with diabetes are at risk of DR</td>
<td>26 (79)</td>
<td>89 (93)</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td>Approximately 1 in 4 people with T2D have DR</td>
<td>8 (24)</td>
<td>38 (40)</td>
<td>.164</td>
<td></td>
</tr>
<tr>
<td>DR can cause vision loss or blindness</td>
<td>29 (91)</td>
<td>92 (99)</td>
<td>.051</td>
<td></td>
</tr>
<tr>
<td>DR can develop without symptoms</td>
<td>15 (47)</td>
<td>56 (61)</td>
<td>.268</td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high blood pressure</td>
<td>10 (31)</td>
<td>44 (47)</td>
<td>.167</td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high cholesterol</td>
<td>7 (22)</td>
<td>29 (31)</td>
<td>.437</td>
<td></td>
</tr>
<tr>
<td>DR is treatable if detected early via an eye health check</td>
<td>21 (66)</td>
<td>65 (70)</td>
<td>.819</td>
<td></td>
</tr>
<tr>
<td>DR is more likely to develop the longer you have diabetes</td>
<td>21 (66)</td>
<td>68 (73)</td>
<td>.561</td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high blood glucose</td>
<td>23 (72)</td>
<td>83 (89)</td>
<td>.025</td>
<td></td>
</tr>
<tr>
<td>Early DR is asymptomatic</td>
<td>4 (12)</td>
<td>9 (9)</td>
<td>.738</td>
<td></td>
</tr>
<tr>
<td>Recommended target HbA1c(^a)</td>
<td>17 (53)</td>
<td>81 (87)</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Recommended target blood pressure</td>
<td>21 (66)</td>
<td>67 (72)</td>
<td>.644</td>
<td></td>
</tr>
<tr>
<td>Optometrist most likely to conduct DR examination</td>
<td>31 (94)</td>
<td>89 (96)</td>
<td>.652</td>
<td></td>
</tr>
<tr>
<td>Initiate eye examinations ‘at diabetes diagnosis’</td>
<td>5 (15)</td>
<td>42 (45)</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td>Screen ‘at least every 2 years’ if no DR present</td>
<td>0 (0)</td>
<td>18 (19)</td>
<td>.003</td>
<td></td>
</tr>
<tr>
<td><strong>MOTIVATION ITEMS(^b)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attitudes to retinal screening(^c):</strong></td>
<td>An eye health check for DR would be...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...a good idea</td>
<td>4.19 (1.14)</td>
<td>4.94 (0.23)</td>
<td>.001</td>
<td></td>
</tr>
<tr>
<td>...(not) ‘unpleasant’</td>
<td>3.71 (0.94)</td>
<td>3.86 (1.07)</td>
<td>.500</td>
<td></td>
</tr>
<tr>
<td>...wise</td>
<td>4.29 (0.97)</td>
<td>4.86 (0.44)</td>
<td>.004</td>
<td></td>
</tr>
<tr>
<td>...(not) ‘difficult’</td>
<td>3.10 (1.17)</td>
<td>4.02 (0.96)</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>...(not) ‘frightening’</td>
<td>3.52 (1.06)</td>
<td>4.07 (1.13)</td>
<td>.019</td>
<td></td>
</tr>
<tr>
<td>...(not) ‘unnecessary’</td>
<td>3.52 (1.18)</td>
<td>4.50 (0.62)</td>
<td>&lt;.001</td>
<td></td>
</tr>
</tbody>
</table>
### Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

**Modifiable Behavioural Determinants**

<table>
<thead>
<tr>
<th></th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (n=33)</td>
<td>Yes (n=96)</td>
<td><em>P</em></td>
</tr>
<tr>
<td>...reassuring</td>
<td>3.94 (0.96)</td>
<td>4.63 (0.61)</td>
<td>.001</td>
</tr>
<tr>
<td>...important</td>
<td>4.06 (1.06)</td>
<td>4.89 (0.35)</td>
<td>.001</td>
</tr>
<tr>
<td>...beneficial</td>
<td>4.03 (0.95)</td>
<td>4.86 (0.38)</td>
<td>.001</td>
</tr>
<tr>
<td>...comfortable</td>
<td>3.26 (1.15)</td>
<td>3.68 (1.10)</td>
<td>.073</td>
</tr>
<tr>
<td>...empowering</td>
<td>3.10 (1.19)</td>
<td>3.73 (0.97)</td>
<td>.004</td>
</tr>
<tr>
<td>11 items (range: 11-55, α=.86)</td>
<td>40.71 (8.42)</td>
<td>48.03 (4.26)</td>
<td>.001</td>
</tr>
</tbody>
</table>

**Attitudes: Risk Perception**

<table>
<thead>
<tr>
<th></th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe I will develop DR due to my diabetes</td>
<td>4.03 (1.45)</td>
<td>4.14 (1.62)</td>
<td>.734</td>
</tr>
<tr>
<td>I expect to be diagnosed with DR at my next eye health check</td>
<td>2.97 (1.47)</td>
<td>2.43 (1.66)</td>
<td>.114</td>
</tr>
<tr>
<td>I believe I can reduce my risk of vision problems if I manage my diabetes well</td>
<td>2.32 (1.44)</td>
<td>1.43 (0.79)</td>
<td>.002</td>
</tr>
<tr>
<td>I believe I will develop vision problems due to diabetes</td>
<td>4.26 (1.69)</td>
<td>4.49 (1.68)</td>
<td>.511</td>
</tr>
<tr>
<td>4 items (range: 4-28, α=.70)</td>
<td>13.58 (4.46)</td>
<td>12.50 (4.34)</td>
<td>.238</td>
</tr>
</tbody>
</table>

**Attitudes: Anticipated Regret**

<table>
<thead>
<tr>
<th></th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>...indifferent</td>
<td>3.65 (1.64)</td>
<td>3.24 (1.89)</td>
<td>.295</td>
</tr>
<tr>
<td>...concerned</td>
<td>5.03 (1.70)</td>
<td>5.88 (1.40)</td>
<td>.007</td>
</tr>
<tr>
<td>...fearful</td>
<td>4.48 (1.79)</td>
<td>5.13 (1.70)</td>
<td>.073</td>
</tr>
<tr>
<td>...worried</td>
<td>4.65 (1.80)</td>
<td>5.53 (1.47)</td>
<td>.007</td>
</tr>
<tr>
<td>...regretful</td>
<td>4.81 (1.68)</td>
<td>5.54 (1.49)</td>
<td>.023</td>
</tr>
<tr>
<td>...guilty</td>
<td>4.58 (1.75)</td>
<td>5.47 (1.57)</td>
<td>.010</td>
</tr>
<tr>
<td>6 items (range: 6-42, α=.87)</td>
<td>22.61 (7.02)</td>
<td>25.33 (6.04)</td>
<td>.040</td>
</tr>
</tbody>
</table>

**Normative Beliefs**

<table>
<thead>
<tr>
<th></th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>My family/close friends would approve of me attending an eye health check</td>
<td>5.94 (1.69)</td>
<td>6.82 (0.80)</td>
<td>.008</td>
</tr>
<tr>
<td>My health professionals would approve of me attending an eye health check</td>
<td>5.84 (1.75)</td>
<td>6.94 (0.28)</td>
<td>.001</td>
</tr>
<tr>
<td>2 items (range: 2-14; α=.93, r=.87)</td>
<td>11.77 (3.43)</td>
<td>13.77 (1.02)</td>
<td>.003</td>
</tr>
</tbody>
</table>

**Intention**

<table>
<thead>
<tr>
<th></th>
<th>Retinal screen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Most people I know with diabetes have regular eye health checks</td>
<td>4.55 (1.57)</td>
<td>5.07 (1.42)</td>
<td>.091</td>
</tr>
</tbody>
</table>
## Reducing Risk of Vision Loss for Young Adults with Type 2 Diabetes

<table>
<thead>
<tr>
<th>Modifiable Behavioural Determinants</th>
<th>Retinal Screen</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No (n=33)</td>
<td>Yes (n=96)</td>
</tr>
<tr>
<td>I plan to attend an eye health check...</td>
<td>4.26 (2.32)</td>
<td>6.76 (0.77)</td>
</tr>
<tr>
<td>I will make an effort to have an eye health check...</td>
<td>4.55 (2.42)</td>
<td>6.74 (0.87)</td>
</tr>
<tr>
<td>I intend to have an eye health check...</td>
<td>4.42 (2.32)</td>
<td>6.74 (0.77)</td>
</tr>
<tr>
<td>3 items (range: 3-21, ( \alpha=.98 ))</td>
<td>13.22 (6.97)</td>
<td>20.24 (2.16)</td>
</tr>
</tbody>
</table>

### behavioural Skills Items\(^{b,e}\)

<table>
<thead>
<tr>
<th>Perceived Control</th>
<th>How confident are you that you...</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>...know what steps you can take to reduce the risk of developing DR?</td>
<td>2.39 (1.17)</td>
</tr>
<tr>
<td></td>
<td>...will have regular eye health checks?</td>
<td>3.16 (1.16)</td>
</tr>
<tr>
<td></td>
<td>...know how to make the appointment for an eye health check?</td>
<td>3.35 (1.36)</td>
</tr>
<tr>
<td></td>
<td>...will remember to have an eye health check in the next 4 weeks OR next due?</td>
<td>2.68 (1.35)</td>
</tr>
<tr>
<td></td>
<td>...will attend the eye health check that you have booked?</td>
<td>3.84 (1.16)</td>
</tr>
<tr>
<td></td>
<td>...can reschedule the eye health check to a different time or day if needed? (n=119)</td>
<td>3.45 (1.15)</td>
</tr>
<tr>
<td>6 items (range: 6-30, ( \alpha=.87 ))</td>
<td>18.87 (5.44)</td>
<td>25.63 (3.75)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overcoming Barriers</th>
<th>How confident are you that you...</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>...can talk to your doctor about your eye health?</td>
<td>3.39 (1.28)</td>
</tr>
<tr>
<td></td>
<td>...can find the time to attend an eye health check in the next 4 weeks or when next due?</td>
<td>2.74 (1.37)</td>
</tr>
<tr>
<td></td>
<td>...will mention you have diabetes when you make the eye check appointment?</td>
<td>3.68 (1.25)</td>
</tr>
<tr>
<td></td>
<td>...can resume your normal activities immediately after the eye health check?</td>
<td>3.55 (1.26)</td>
</tr>
<tr>
<td></td>
<td>...can afford to pay for the eye health check, if there is a charge?</td>
<td>2.68 (1.49)</td>
</tr>
<tr>
<td>5 items (range: 5-25, ( \alpha=.76 ))</td>
<td>16.03 (4.88)</td>
<td>20.80 (3.49)</td>
</tr>
</tbody>
</table>

DR: diabetic retinopathy. Data are number (%) of participants who answered each item correctly (Knowledge items); mean (SD) Motivation and Behavioural skills items. \( p \)-value is Pearson’s Chi-Square (or Fisher’s exact test if expected cell count<5), or Independent-samples t-test (two-sided); statistical significance \( p<0.01 \). \(^a\)Glycated haemoglobin (measure of average blood glucose over the past 8-12 weeks, and indicator of DR risk). \(^b\)Minimal missing data (average 6%, range 2-11%). Valid n: 121 (motivation items), 120 (behavioural skills items, unless noted otherwise). Cronbach’s alpha noted (plus Pearson’s r for 2-item constructs). Some items responses reverse coded where required.

Item response range: \(^c\)1 (Strongly disagree) to 5 (Strongly agree), \(^d\)1 (Strongly disagree) to 7 (Strongly agree), \(^e\)1 (Not at all confident) to 5 (Extremely confident).
Table 20: Additional file 3 - Matrix of Change Objectives

<table>
<thead>
<tr>
<th>Performance Objectives and sub-objectives^</th>
<th>Knowledge</th>
<th>Attitudes</th>
<th>Modifiable behavioural determinants</th>
<th>Intention</th>
<th>Behavioural skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO.1 Young adults with type 2 diabetes will demonstrate a clear understanding of diabetic retinopathy (DR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PO.1.1 Modifiable and non-modifiable DR risk factors</td>
<td>K.1.1 Understand DR and know key modifiable risk factors</td>
<td></td>
<td>I.1.1 Form a positive intention to actively manage modifiable DR risk factors</td>
<td></td>
<td>BS.1.1 Identify and initiate the actions required to reduce risk of developing DR</td>
</tr>
<tr>
<td>PO.1.2 Clinical targets for reducing risk of DR</td>
<td>K.1.2 Know clinical targets for modifiable DR risk factors to prevent DR or slow progression</td>
<td></td>
<td></td>
<td></td>
<td>BS.1.2 Believe that they can avoid negative consequences</td>
</tr>
<tr>
<td>PO.1.3 Symptoms of DR</td>
<td>K.1.3 Understand asymptomatic nature of early DR and explain symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PO.1.4 Role of DR in vision loss</td>
<td>K.1.4 Understand how DR affects the eye</td>
<td>A.1.4 Perceive consequences for family unit/future family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performance Objectives and sub-objectives^</td>
<td>Knowledge</td>
<td>Attitudes</td>
<td>Modifiable behavioural determinants</td>
<td>Behavioural skills</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>-------------------------------------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td><strong>PO.1.5 Prevalence of DR</strong></td>
<td>K.1.5 Know that DR is a common complication of diabetes</td>
<td>NB.1.5 Believe that similar others are at risk of DR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PO.2 Young adults with type 2 diabetes will demonstrate a clear understanding of retinal screening</strong></td>
<td>K.2.1 Know the role of retinal screening in reducing vision loss</td>
<td>A.2.1 Explain the clinical benefit of retinal screening</td>
<td>NB.2.2 Believe that similar others approve of, and would recommend screening</td>
<td>BS.2.2 Express confidence in retinal screening procedure (prepare reader for the experience)</td>
<td></td>
</tr>
<tr>
<td><strong>PO.2.1 Role in detecting DR and reducing vision loss</strong></td>
<td>K.2.2 Know when to have first and subsequent retinal screen</td>
<td>A.2.2 Believe that screening promotes positive feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PO.2.2 Screening procedure and experience</strong></td>
<td>K.2.3 Know that retinal screening can be self-referred</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PO.2.3 Booking and examination procedure</strong></td>
<td></td>
<td></td>
<td></td>
<td>BS.2.3 Be confident that they can get an eye health check</td>
<td></td>
</tr>
<tr>
<td><strong>PO.3 Young adults with type 2 diabetes will be motivated to engage in retinal screening</strong></td>
<td>NB.3.1 Recognise that similar others have</td>
<td>I.3.1 Form an intention to prioritise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PO.3.1 Prioritise retinal</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performance Objectives and sub-objectives</td>
<td>Knowledge</td>
<td>Attitudes</td>
<td>Modifiable behavioural determinants</td>
<td>Behavioural skills</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>-------------------------------------</td>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>screening</td>
<td>K.3.2</td>
<td>A.3.2</td>
<td>overcome screening barriers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Know that DR risk increases over time</td>
<td>Perceive high personal risk and susceptibility to DR</td>
<td>retinal screening barriers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PO.3.2 Understand personal risk of DR</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>PO.3.3 Identify personal barriers to retinal screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>A.3.3</td>
<td>NB.3.3 See that similar others face screening barriers (e.g. cost, fear of adverse effects)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Believe that attending screening will relieve fear and guilt and be a positive experience</td>
<td></td>
<td>BS.3.3 Be confident in one’s ability to identify and overcome common screening barriers</td>
<td></td>
</tr>
<tr>
<td>PO.3.3 Identify personal barriers to retinal screening</td>
<td>K.3.4</td>
<td>A.3.4</td>
<td>NB.3.4 Believe that similar others take responsibility for their own eye health</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Know that they can take steps to protect eye health</td>
<td>Adopt personal responsibility for retinal screening</td>
<td></td>
<td>BS.3.4 Be confident they have the tools to act on personal responsibility</td>
<td></td>
</tr>
<tr>
<td>PO.3.4 Perceive personal responsibility to engage in screening</td>
<td>K.4.1a</td>
<td>A.4.1</td>
<td>NB.4.1 Believe that similar others approve of, and recommend, sharing their diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Know that GP should be involved in monitoring diabetes-related</td>
<td>Anticipate a positive social and emotional experience</td>
<td></td>
<td>BS.4.1a Prompt GP contact</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>BS.4.1b Be confident in sharing diabetes diagnosis with</td>
<td></td>
</tr>
<tr>
<td>PO.4 Young adults with type 2 diabetes will proactively engage with the healthcare system and their healthcare team</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Performance Objectives and sub-objectives^ | Knowledge | Attitudes | Modifiable behavioural determinants | Behavioural skills
--- | --- | --- | --- | ---

### For young adults with Type 2 diabetes

**K.4.1b** Know that an eye examination for DR is different to a standard eye check

**K.4.2** Know treatment trajectory

**A.4.2** Understand benefits of early treatment

**PO.4.2** Understand treatment benefits and options

**K.4.3a** Know how to find more information (e.g. optometrist, diabetes or DR)

**K.4.3b** Know that information is available in other languages

**PO.4.3** Seek more information about diabetes and eye health

**I.4.3** Form intention to access credible information about DR and screening

**BS.4.2** Know that they will receive expert advice

PO=Performance Objective, DR=diabetic retinopathy, GP=general practitioner.
Determinants: K=Knowledge, A=Attitudes, NB=Normative Beliefs, I=Intention, BS=Behavioural Skills
^See Table 5 for full list of Performance Objectives and sub-objectives
**Table 21: Additional file 4 - Intervention map linking leaflet content directly back to Performance Objectives and Change Objectives**

<table>
<thead>
<tr>
<th>Performance Objectives (PO) and Change Objectives(^a)</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
<th>Panel No.*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PO.1</strong> YOUNG ADULTS WITH T2D WILL DEMONSTRATE A CLEAR UNDERSTANDING OF DIABETIC RETINOPATHY (DR)</td>
<td><strong>Panel 4</strong></td>
<td><strong>Panel 5</strong></td>
</tr>
<tr>
<td><strong>PO.1.1</strong> Modifiable and non-modifiable DR risk factors</td>
<td><strong>Panel 4</strong></td>
<td><strong>Panel 5</strong></td>
</tr>
<tr>
<td>K.1.1 Understand DR and know key modifiable risk factors</td>
<td>What is diabetes eye disease? Diabetes eye disease is also called Diabetic Retinopathy (DR). It is caused by having high blood glucose levels over a long time. Other things that increase your risk of DR are high blood pressure and high cholesterol.</td>
<td>4</td>
</tr>
<tr>
<td>I.1.1 Form a positive intention to actively manage modifiable DR risk factors</td>
<td>(What can I do to protect myself from DR and prevent vision loss?)</td>
<td>3. Follow your diabetes treatment plan which includes the diabetes ABCs</td>
</tr>
<tr>
<td><strong>BS.1.1</strong> Identify and initiate the actions required to reduce risk of developing DR</td>
<td>(What happens if I have DR?)</td>
<td>You can slow progression of DR by keeping your blood glucose, blood pressure and cholesterol as close to target as possible.</td>
</tr>
<tr>
<td><strong>PO.1.2</strong> Clinical targets for reducing risk of DR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>K.1.2 Know clinical targets for modifiable DR risk factors to prevent DR or slow progression</td>
<td>A Average blood glucose (HbA1c) below 7% (53mmol/mol)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Every 1% (11mmol/mol) decrease in HbA1c lowers your risk of developing DR by 30–40%.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>B Blood pressure below 130/80 mm Hg</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keeping your blood pressure at target slows progression of DR</td>
<td></td>
</tr>
<tr>
<td></td>
<td>C Cholesterol at target</td>
<td></td>
</tr>
<tr>
<td></td>
<td>LDL cholesterol less than 2.0 mmol/L, triglycerides less than 2.0 mmol/L</td>
<td></td>
</tr>
</tbody>
</table>
**Performance Objectives (PO) and Change Objectives**

<table>
<thead>
<tr>
<th>Panel No.*</th>
<th>Performance Objectives (PO) and Change Objectives^</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BS.1.2</td>
<td>Believe that they can avoid negative consequences</td>
<td>(The good news is) there are things you can do to reduce your risk</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(The good news is) this leaflet provides the information you need to help prevent vision loss from DR.</td>
</tr>
<tr>
<td>PO.1.3</td>
<td>Symptoms of DR</td>
<td>Will I know if I have DR?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>You may not know. In the early stages, DR has no symptoms at all. In the later stages, you may notice blurred, hazy or double vision or you may have sudden loss of vision.</td>
</tr>
<tr>
<td>PO.1.4</td>
<td>Role of DR in vision loss</td>
<td>(What is diabetes eye disease?) DR damages the tiny blood vessels in the back of your eye. If left untreated, your vision can be affected.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Jane 25 years, diagnosed with type 2 diabetes 3 years ago) &quot;You might have good vision, you might think that your eyes are absolutely brilliant and there's no issue. But in the back of your eye, there could be a problem with those little tiny veins that you don't realise.&quot;</td>
</tr>
</tbody>
</table>
### Performance Objectives (PO) and Change Objectives

<table>
<thead>
<tr>
<th>Panel No.*</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A.1.4 Perceive consequences for family unit / future family</strong></td>
<td>Image: mother and daughter smiling. Child holding hands over mother’s eyes</td>
</tr>
<tr>
<td></td>
<td>(Lucas, aged 34, diagnosed with type 2 diabetes 2 years ago) &quot;I’m a busy person and my family depend on me. “I know I can’t do all the things I do without my sight.&quot;</td>
</tr>
<tr>
<td></td>
<td>(Jenny’s story: before and after the eye health check: “I was scared. I was scared of what damage was done...of confronting the fact that my eyesight could be damaged, and of going through the exam and being confronted with what’s there.”)</td>
</tr>
<tr>
<td></td>
<td>“But I want to take care of my kids; I want to be able to see their children one day. I do want to be able to grow older and have my vision.”</td>
</tr>
<tr>
<td><strong>K.1.5 Know that DR is a common complication of diabetes</strong></td>
<td>There are over 34,000 Australians with type 2 diabetes who are under 40 years of age.</td>
</tr>
<tr>
<td></td>
<td>More than 8,500 will already have DR.</td>
</tr>
<tr>
<td><strong>NB.1.5 Believe that similar others are at risk of DR</strong></td>
<td>But I’m still young. Am I at risk of DR?</td>
</tr>
<tr>
<td></td>
<td>Yes you are. Anyone with diabetes can develop DR, which is the leading cause of vision loss for people under 60 years</td>
</tr>
<tr>
<td></td>
<td>(Jane, 25 years, diagnosed with type 2 diabetes 3 years ago) &quot;You might have good vision, you might think that your eyes are absolutely brilliant and there’s no issue. But in the back of your eye, there could be a problem with those little tiny veins that you don't realise.&quot;</td>
</tr>
<tr>
<td>Performance Objectives (PO) and Change Objectives*</td>
<td>Leaflet content (antecedent leaflet text in brackets illustrates context)</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>PO.2 YOUNG ADULTS WITH T2D WILL DEMONSTRATE A CLEAR UNDERSTANDING OF RETINAL SCREENING</td>
<td></td>
</tr>
<tr>
<td>PO.2.1 Role in detecting DR and reducing vision loss</td>
<td></td>
</tr>
<tr>
<td>K.2.1 Know the role of retinal screening in reducing vision loss</td>
<td>Having a diabetes eye health check and treating DR early can prevent severe vision loss.</td>
</tr>
<tr>
<td>A.2.1 Explain the clinical benefit of retinal screening</td>
<td>The only way to know if you have DR is to have a diabetes eye health check</td>
</tr>
<tr>
<td>PO.2.2 Screening procedure and experience</td>
<td></td>
</tr>
<tr>
<td>K.2.2 Know when to have first and subsequent retinal screen</td>
<td>Have a diabetes eye health check when diabetes is first diagnosed and then at least every 2 years (more often if recommended by your optometrist)</td>
</tr>
<tr>
<td>A.2.2 Believe that (Jenny’s story: before and after the eye health check)</td>
<td>“Overall, it was worth it and the screening promotes thought that I can control this gives me real peace of mind.” positive feelings</td>
</tr>
<tr>
<td>NB.2.2 Believe that (Jenny’s advice to you)</td>
<td>&quot;I suppose if I was telling someone that’s just been diagnosed, I would be saying to them 'Don't wait to be told and don't wait until you notice changes - book an eye health check now’.&quot;</td>
</tr>
<tr>
<td>BS.2.2 Express confidence in retinal screening procedure</td>
<td>It is usually done by an optometrist who will take a photo of the back of your eye. Your optometrist will look at the photo to check the blood vessels at the back of your eye for signs of diabetes-related eye damage</td>
</tr>
</tbody>
</table>
## Performance Objectives (PO) and Change Objectives

<table>
<thead>
<tr>
<th>Panel No.*</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PO.2.3</strong></td>
<td><strong>Booking and examination procedure</strong></td>
</tr>
<tr>
<td>K.2.3</td>
<td>Know that retinal screening can be self-referred</td>
</tr>
<tr>
<td>I.2.3</td>
<td>Form an intention to book first screen soon</td>
</tr>
<tr>
<td>BS.2.3</td>
<td>Be confident that they can get an eye health check</td>
</tr>
<tr>
<td><strong>PO.3</strong></td>
<td><strong>YOUNG ADULTS WITH T2D WILL BE MOTIVATED TO ENGAGE IN RETINAL SCREENING</strong></td>
</tr>
<tr>
<td>PO.3.1</td>
<td>Prioritise retinal screening</td>
</tr>
<tr>
<td>NB.3.1</td>
<td>Recognise that similar others have overcome screening barriers</td>
</tr>
<tr>
<td>I.3.1</td>
<td>Form an intention to prioritise retinal screening</td>
</tr>
<tr>
<td><strong>PO.3.2</strong></td>
<td>Understand personal risk of DR</td>
</tr>
<tr>
<td>K.3.2</td>
<td>Know that DR risk increases over time</td>
</tr>
<tr>
<td>Panel No.</td>
<td>Performance Objectives (PO) and Change Objectives</td>
</tr>
<tr>
<td>----------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>A.3.2  Perceive high personal risk and susceptibility to DR</td>
</tr>
</tbody>
</table>

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### Performance Objectives (PO) and Change Objectives^<sup>a</sup>

<table>
<thead>
<tr>
<th>Panel No.</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td><strong>PO.3.3 Identify personal barriers to retinal screening</strong></td>
</tr>
<tr>
<td></td>
<td><strong>A.3.3</strong> Believe that attending screening will relieve fear and guilt and be a positive experience (Jenny’s story: before and after the eye health check) “It was actually quite fun; I don’t know why I put it off. I was really scared going in there, but definitely not now – I’m not fazed by it at all.”</td>
</tr>
<tr>
<td></td>
<td><strong>NB.3.3</strong> See that similar others face screening barriers (e.g. cost, fear of adverse effects) (Jenny’s story: before and after the eye health check) “The eye drops were a bit uncomfortable and there was a small cost – but I think it’s a wise spend considering what you’re preventing.”</td>
</tr>
<tr>
<td></td>
<td><strong>BS.3.3</strong> Be confident in one’s ability to identify and overcome common screening barriers (What else do I need to know?) A diabetes eye health check takes about 30 minutes. It may be free (bulk-billed) or there may be a small fee. (What else do I need to know?) Your optometrist may use eye drops which helps them to see the back of your eye. If you do have eye drops, they may be a little uncomfortable. The drops will also leave you sensitive to light, so bring your sunglasses and be prepared to wait a while for your vision to return to normal</td>
</tr>
<tr>
<td>6</td>
<td><strong>PO.3.4 Perceive personal responsibility to engage in screening</strong></td>
</tr>
<tr>
<td></td>
<td><strong>K.3.4</strong> Know that they can take steps to protect eye What can I do to protect myself from DR and prevent vision loss?</td>
</tr>
</tbody>
</table>

<sup>a</sup>Leaflet content (antecedent leaflet text in brackets illustrates context)
### Performance Objectives (PO) and Change Objectives

<table>
<thead>
<tr>
<th>Panel No.</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
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</thead>
<tbody>
<tr>
<td>A.3.4</td>
<td>Adopt personal responsibility for retinal screening</td>
</tr>
<tr>
<td></td>
<td>(Lucas, aged 34, diagnosed with type 2 diabetes 2 years ago)</td>
</tr>
<tr>
<td></td>
<td>&quot;I'm a busy person and my family depend on me.&quot;</td>
</tr>
<tr>
<td></td>
<td>Leaflet heading: Who is looking after your eyes?</td>
</tr>
<tr>
<td>NB.3.4</td>
<td>Believe that similar others take responsibility for their own eye health</td>
</tr>
<tr>
<td></td>
<td>Images: mother and daughter, smiling couple selfie, young man</td>
</tr>
<tr>
<td></td>
<td>of indeterminate cultural origin, Asian female (a.k.a. ‘Jenny’)</td>
</tr>
<tr>
<td>BS.3.4</td>
<td>Be confident they have the tools to act on personal responsibility</td>
</tr>
<tr>
<td></td>
<td>Leaflet sub-heading: Your guide to preventing vision loss from diabetes eye disease</td>
</tr>
<tr>
<td></td>
<td>Protect your sight for life</td>
</tr>
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</table>

### PO.4 YOUNG ADULTS WITH T2D WILL PROACTIVELY ENGAGE WITH THE HEALTHCARE SYSTEM AND THEIR HEALTHCARE TEAM

<table>
<thead>
<tr>
<th>Panel No.</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
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</thead>
<tbody>
<tr>
<td>K.4.1a</td>
<td>Know that GP should be involved in monitoring diabetes-related eye health</td>
</tr>
<tr>
<td></td>
<td>Either way, discuss your results with your GP or your diabetes specialist</td>
</tr>
<tr>
<td>K.4.1b</td>
<td>Know that an eye examination for DR is different to a standard eye check</td>
</tr>
<tr>
<td></td>
<td>(What is a diabetes eye health check?)</td>
</tr>
<tr>
<td></td>
<td>It is different to a standard eye check because it specifically looks to see whether diabetes is affecting your eyes.</td>
</tr>
</tbody>
</table>
### Performance Objectives (PO) and Change Objectives

<table>
<thead>
<tr>
<th>Panel No.*</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.4.1</td>
<td><strong>Anticipate a positive social and emotional experience</strong>&lt;br&gt;&quot;I had a lovely optometrist and she really put me at ease.&quot;</td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>NB.4.1</td>
<td><strong>Believe that similar others approve of, and recommend, sharing their diabetes diagnosis with optometrist</strong>&lt;br&gt;&quot;Discuss with the optometrist what to expect, what you should be aware of and so on.”</td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>BS.4.1a</td>
<td><strong>Prompt GP contact</strong>&lt;br&gt;Either way, discuss your results with your GP or your diabetes specialist</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>BS.4.1b</td>
<td><strong>Be confident in sharing diabetes diagnosis with optometrist</strong>&lt;br&gt;(Getting a diabetes eye health check is easy. You don’t need a referral from your GP. You can book an appointment directly with an optometrist.)&lt;br&gt;When you do, be sure to tell them you have diabetes.</td>
</tr>
<tr>
<td>6</td>
<td></td>
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</tbody>
</table>
| PO.4.2    | **Understand treatment benefits and options**<br>**K.4.2 Know treatment trajectory**<br>What happens next?<br>If they see any signs of damage to the back of your eye, your optometrist will either monitor it or arrange treatment with an ophthalmologist (medical eye specialist).<br>(What happens if I have DR?)<br>In the early stages, treatment may not be needed, but you may be asked to have eye
### Performance Objectives (PO) and Change Objectives

<table>
<thead>
<tr>
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<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
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<tbody>
<tr>
<td>88</td>
<td>A.4.2 Understand benefits of early treatment</td>
</tr>
<tr>
<td></td>
<td>If DR progresses, you may need to take tablets or have specialist treatment (usually laser therapy)</td>
</tr>
<tr>
<td></td>
<td>(What happens if I have DR?)</td>
</tr>
<tr>
<td>5</td>
<td>B.4.2 Know that they will receive expert advice</td>
</tr>
<tr>
<td></td>
<td>What happens if I have DR?</td>
</tr>
<tr>
<td></td>
<td>Your eye health professional will advise you of your treatment options</td>
</tr>
<tr>
<td>2</td>
<td>K.4.3a Know how to find more information (e.g. optometrist, diabetes or DR)</td>
</tr>
<tr>
<td></td>
<td>To find an optometrist in your area</td>
</tr>
<tr>
<td></td>
<td>Scan the QR code to download the free Diabetes Australia app</td>
</tr>
<tr>
<td></td>
<td>Visit Optometry Australia</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.optometry.org.au/find-an-optometrist/">www.optometry.org.au/find-an-optometrist/</a></td>
</tr>
<tr>
<td></td>
<td>For more information on eye health and diabetes management</td>
</tr>
<tr>
<td></td>
<td>Visit diabetesvic.org.au, or call the Info line on 1300 136 588</td>
</tr>
<tr>
<td></td>
<td>Multilingual infoline 1300 801 164 multiculturalportal.ndss.com.au</td>
</tr>
<tr>
<td>2</td>
<td>K.4.3b Know that information is available in other languages</td>
</tr>
<tr>
<td></td>
<td>Image: national interpreter symbol</td>
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### Performance Objectives (PO) and Change Objectives

<table>
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<tr>
<th>Panel No.*</th>
<th>Performance Objective</th>
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<tbody>
<tr>
<td>1.4.3</td>
<td>Form intention to access credible information about DR and screening</td>
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<table>
<thead>
<tr>
<th>Panel No.*</th>
<th>Leaflet content (antecedent leaflet text in brackets illustrates context)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Images: smart phone, QR codes</td>
</tr>
<tr>
<td></td>
<td>'Proudly sponsored by [stakeholder logos]'</td>
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</tbody>
</table>

PO=Performance Objective, DR=diabetic retinopathy, GP=general practitioner. *Panel number in Figure 3.

^See Table 5 for full list of Performance Objectives and sub-objectives; see Additional file (Table 20) for complete list of Change Objectives.

K=Knowledge, A=Attitudes, NB=Normative Behaviour, I=Intention, BS=Behavioural Skills
CHAPTER 5. What is the effect of a tailored leaflet intervention on diabetic retinopathy screening among young adults with type 2 diabetes? A randomised controlled trial.\textsuperscript{10}
5.1 Authorship statement

1. Details of publication and executive author

<table>
<thead>
<tr>
<th>Title of Publication</th>
<th>Publication details</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amelia J. Lake</td>
<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td><a href="mailto:alake@acbrd.org.au">alake@acbrd.org.au</a></td>
</tr>
</tbody>
</table>

2. Inclusion of publication in a thesis

Is it intended to include this publication in a higher degree by research (HDR) thesis? | Yes | If Yes, please complete Section 3. If No, go straight to Section 4. |

3. HDR thesis author’s declaration

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
</tr>
</thead>
<tbody>
<tr>
<td>As above</td>
<td>Australian Centre for Behavioural Research in Diabetes; School of Psychology</td>
<td>Reducing risk of vision loss for young adults with type 2 diabetes</td>
</tr>
</tbody>
</table>

If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

The thesis author made substantial contribution to the evaluation methodology and design and protocol development, developed the ethics application, led the recruitment of study participants and managed all aspects of the study. She also led liaison with the National Diabetes Services Scheme to enable dissemination of leaflet to intervention group participants. The thesis author conducted data analysis and interpretation and prepared the first and subsequent drafts of the manuscript.
4. Description of all author contributions

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Jessica L. Browne</td>
<td>Provided substantial input into data analysis and interpretation. Made substantial contribution to evaluation methodology and design. Provided substantial intellectual input reviewing the first and subsequent drafts.</td>
</tr>
<tr>
<td>School of Psychology, Deakin University, Geelong, VIC Australia; The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, VIC Australia</td>
<td></td>
</tr>
<tr>
<td>Dr. Gwyneth Rees</td>
<td>Made substantial contribution to evaluation methodology and design. Provided substantial intellectual input into manuscript.</td>
</tr>
<tr>
<td>Centre for Eye Research Australia, Royal Victorian Eye and Ear Hospital, Melbourne, VIC Australia; Ophthalmology, Department of Surgery, University of Melbourne, Melbourne, VIC Australia</td>
<td></td>
</tr>
<tr>
<td>Professor Jane Speight</td>
<td>Provided substantial input into data analysis and interpretation. Made substantial contribution to evaluation methodology and design. Provided substantial intellectual input reviewing the first and subsequent drafts.</td>
</tr>
<tr>
<td>School of Psychology, Deakin University, Geelong, VIC Australia; The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, VIC Australia; AHP Research, Hornchurch, United Kingdom</td>
<td></td>
</tr>
</tbody>
</table>

5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:
vi. that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,

vii. that there are no other authors according to these criteria,

viii. that the description in Section 4 of my contribution(s) to this publication is accurate,

ix. that the data on which these findings are based are stored as set out in Section 7 below.

If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin University and, if the higher degree is awarded, the subsequent publication of the thesis by the university (subject to relevant Copyright provisions).

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Jessica L Browne</td>
<td></td>
<td>23 October 2017</td>
</tr>
<tr>
<td>Dr. Gwyneth Rees</td>
<td></td>
<td>19 October 2017</td>
</tr>
<tr>
<td>Professor Jane Speight</td>
<td></td>
<td>19 October 2017</td>
</tr>
</tbody>
</table>

6. Other contributor declarations

I agree to be named as a non-author contributor to this work.

<table>
<thead>
<tr>
<th>Name and affiliation of contributor</th>
<th>Contribution</th>
<th>Signature* and date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td></td>
<td></td>
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</tbody>
</table>

* If an author or contributor is unavailable or otherwise unable to sign the statement of authorship, the Head of Academic Unit may sign on their behalf, noting the reason for their unavailability, provided there is no evidence to suggest that the person would object to being named as author.

7. Data storage

The original data for this project are stored in the following locations. (The locations must be within an appropriate institutional setting. If the executive author is a Deakin staff member and data are stored outside Deakin University, permission for this must be given by the Head of Academic Unit within which the executive author is based.)

<table>
<thead>
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<th>Data format</th>
<th>Storage Location</th>
<th>Date lodged</th>
<th>Name of custodian if other than the executive author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data files are stored in electronic format</td>
<td>Deakin University secure network</td>
<td>N/A</td>
<td>Professor Jane Speight</td>
</tr>
</tbody>
</table>

If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
5.2 Abstract

Aims: Diabetic retinopathy is the leading cause of blindness and vision loss in working-age adults. Retinal screening is a crucial preventative measure, yet many young adults with type 2 diabetes (18-39 years) do not screen in a timely manner. We evaluated the effectiveness of a tailored, evidence-based leaflet designed to promote retinal screening uptake and improve identified modifiable behavioural determinants, using a randomised controlled trial (RCT, ACTRN1261400111067). Methods: Eligible participants were randomised to leaflet intervention or no-leaflet control, stratified by engagement with retinal screening (yes/no). Primary (screening uptake) and secondary (social cognitive) outcome data was collected pre-intervention and four weeks post-intervention. Results: A total of 129 young adults with type 2 diabetes (26% no retinal screen) provided baseline data; 101 completed follow-up. A significant intervention effect was observed for knowledge of DR ($p=.03$) with moderate effect ($\eta^2=.05$); no other intervention effects were observed. Power to test intervention effect on the primary outcome was curtailed. Conclusions: This study confirms that a well-designed retinal screening leaflet can increase knowledge of diabetic retinopathy, an important retinal screening predictor. Nonconventional alternatives to RCT designs should be considered for hard-to-reach populations.
5.3 Introduction

Increasing incidence of type 2 diabetes (T2D) in young adults (aged 18-39 years) and associated high morbidity and mortality has generated significant concern over the past decade (Yeung et al., 2014; Zimmet, Magliano, Herman, & Shaw, 2014). Clinical and population-based studies highlight the aggressive nature of the condition, with affected individuals experiencing considerable diabetes-related complications by mid-life (Al-Saeed et al., 2016).

The most common complication is diabetic retinopathy (DR), the leading cause of vision loss and blindness in working-age adults worldwide (Sivaprasad, Gupta, Crosby-Nwaobi, & Evans, 2012). Younger age of T2D onset is an independent risk factor for the development of DR (Wong, Molyneaux, Constantino, Twigg, & Yue, 2008). Retinal screening (henceforth ‘screening’) is crucial for early detection of asymptomatic DR and timely treatment thereafter can significantly reduce risk of vision loss (Arun, Al-Bermani, Stannard, & Taylor, 2009; Ferris, 1993).

Australian guidelines recommend screening uptake at diagnosis of T2D, repeated a minimum of every two years thereafter (Mitchell & Foran, 2008). Once initiated, screening is generally sustained (Lee et al., 2000). However, younger age is also an independent risk factor for low screening uptake (Sachdeva, Stratton, Unwin, Moreton, & Scanlon, 2012; Scanlon et al., 2016) with increased risk of vision-threatening retinopathy when screening is eventually initiated (Scanlon et al., 2016).

Only 55% of young Australian adults with T2D report screening for DR (compared to 76% of young adults with type 1 diabetes, and 77% of the general
adult diabetes population, reported at around the same time), (Diabetes Australia, 2006; Tapp et al., 2004). Consequently, clinicians and policy makers have called for the development of early intervention strategies for this priority population (Dabelea et al., 2017; Wilmot & Idris, 2014).

A systematic review of the effectiveness of interventions to promote retinal screening confirmed that a range of interventions targeting patients or populations are effective, and that the majority focussed on increasing knowledge and awareness of DR (Zhang et al., 2007). However, lack of specification of the effective elements of many existing interventions has hindered implementation of strategies to promote screening uptake (Lawrenson et al., 2016).

Effective interventions to promote health behaviour change, including for diabetes self-management, have shared elements: underpinned by theoretical constructs, grounded in evidence and data, targeting modifiable behavioural determinants associated with the behaviour (e.g. attitudes, normative beliefs, intentions), and tailoring to the priority population (Ayling, Brierley, Johnson, Heller, & Eiser, 2015; Bartholomew Eldredge et al., 2016). The Information-Motivation-Behavioural skills (IMB) model, which cites three broad, underlying constructs, has utility for identification of modifiable behavioural determinants (Fisher, Fisher, & Harman, 2003).

The IMB model posits information (knowledge) is a key determinant of behaviour change, but insufficient on its own, and requires the integration of motivational and behavioural skills elements In essence, an individual who is well-informed about their health risk(s) and the target health behaviour,
REducing risk of vision loss for young adults with type 2 diabetes

*personally and socially motivated* to perform the behaviour, and who has the appropriate *behavioural skills*, will be more likely to initiate and maintain the behaviour (Figure 8).

![Information-Motivation-Behavioural skills model](image)

*Figure 8: Information-Motivation-Behavioural skills model*

The IMB model has been validated in relation to diabetes for self-care behaviours and medication-taking (Mayberry & Osborn, 2014; Osborn & Egede, 2010). In the current study, the IMB model was used as a theoretical foundation for identification of modifiable behavioural determinants and as a framework for evaluating the effect of the leaflet on secondary outcome data.

The aim of this study was to assess the effectiveness of a retinal screening promotion leaflet tailored to young adults with T2D. Overall, the leaflet sought to promote screening uptake for those who had not previously engaged in the behaviour, and to improve modifiable behavioural determinants (associated with the behaviour) which had been identified in a comprehensive needs assessment (Lake et al., Unpublished results; Lake, Browne, Rees, & Speight, 2017).
5.4 Participants, Materials and Methods

5.4.1 Study design and registration. This parallel-group randomised controlled trial (RCT) was retrospectively registered with the Australian New Zealand Clinical Trials Registry (ACTRN12614001110673, UTN No.: U1111-1161-9803). Ethics approval was obtained from the Deakin University Human Research Ethics Committee (2014-156); all participants provided informed consent.

5.4.1.2 Sample size and trial design considerations. Informed by previous studies among young adults with T2D (Nguyen et al., 2014; Zeitler, Chou, Copeland, & Geffner, 2015), we anticipated low recruitment (10%; Browne, Nefs, Pouwer, & Speight, 2014) low screening rate (50%; Diabetes Australia, 2006; Wang et al., 2017) and high attrition (40%; Nguyen et al., 2014).

Initially, a four-group design was selected to account for anticipated bias (Solomon, 1949), but lower than expected recruitment (particularly of participants who had never screened for DR, henceforth ‘unengaged’), indicated high risk of lack of power at follow-up. On advice from a senior biostatistician, the trial design was modified to a two-arm (intervention / control) RCT. Explanation of initial sample size calculation, number of recruitment invitations, and subsequent changes to methods after trial registration are provided in 5.8 Additional information (Section 5.8.4). Using the revised design, 25 unengaged participants per condition were required to provide sufficient power at follow-up (80%, significance level 0.05, two-tailed).
5.4.2 Participants. Eligible participants were young adults with T2D (aged 18-39 years), who had been registered with the National Diabetes Services Scheme (NDSS) in the previous three years (registration date was used as a proxy for diabetes diagnosis). The NDSS is an Australian Government initiative, which supports people with diabetes to self-manage their condition by providing subsidised access to products (e.g. needles, blood glucose testing strips) and services (e.g. information, education and advice). With approximately 86% of Australians with T2D registered, the NDSS is considered the “best available source to monitor type 2 diabetes in children and young people in Australia” (Australian Institute of Health and Welfare, 2014, p.36). Exclusion criteria were: non-proficiency in English, other diabetes types (e.g. type 1, gestational).

Of the approximately 32,000 young adults with T2D registered on the NDSS, 36% (N=5,354) were eligible and had consented to be contacted for research purposes. To protect registrant confidentiality, the NDSS managed invitation mail-out, with one reminder posted four weeks later. Study recruitment was conducted over a 7-week period. Two incentives were offered; a chance to win one of three iPad minis at registration, and AUD$20 upon completion of follow-up questionnaire. In order to minimise the possibility of resistance from unengaged NDSS registrants (who may opt not to participate in a study specifically focussed on retinal screening), invitees were initially masked to the purpose of the study, which was advertised more broadly as research about “diabetes self-management”.
5.4.3 **Procedure.** Data collection was managed via Qualtrics, a secure online survey platform (Qualtrics, 2014).

5.4.3.1 **Baseline data collection.** To ensure that private information (postal addresses) were only collected for intervention participants, baseline data was collected in two phases, with randomisation conducted in-between.

**Phase 1 (study registration):** participants provided consent and demographic data (e.g. diabetes management, including screening status to provide an indication of the number of unengaged participants; family history of T2D, health comorbidities), see Appendix D for survey items. At the end of the recruitment period, participants were randomly allocated to one of two conditions (leaflet intervention, no-leaflet control) using an online random number generator (Dallal, 2008). Unengaged participants were stratified in a 1:1 ratio to ensure balanced representation into both conditions. **Phase 2:** participants provided baseline social cognitive data (to assess secondary outcome) and retinal screening status (intended for primary outcome assessment to allow for the possibility that participants may have engaged in screening since phase 1 study registration). Those allocated to the leaflet intervention condition were also asked to provide their postal address so that they could be sent a “leaflet about diabetes self-management” (see Appendix E for survey items).

5.4.3.2 **Post-intervention data collection.** Four weeks after the leaflet intervention mail-out (and six months after study commencement), all participants were invited to provide follow-up outcome data (screening status, modifiable behavioural determinants - Appendix E). To check assumptions
regarding the accessibility of optometry services, we conducted a nationwide dummy booking exercise. Using the online Optometry Australia ‘find an optometrist’ service, we contacted 11 large and small-scale providers located in the same postcodes as leaflet intervention participants. We called each provider, requesting an appointment for an eye check, stating that a diabetes diagnosis had been made. We declined the first available appointment, asking instead for alternate appointment times including out of standard business hours. All optometrists surveyed could offer appointments during business hours within five days, and most could offer out-of-hours appointments within seven days, confirming that the four-week timeframe between leaflet mail-out and follow-up data collection was appropriate. At the end of the follow-up survey, control group participants were invited to receive the eye health leaflet.

5.4.4 Summary of leaflet development. The aim of the leaflet was twofold: promote screening uptake for young adults with T2D, and improve modifiable behavioural determinants of screening behaviour. Leaflet development process is described in detail elsewhere (Lake et al., Unpublished results) and publicly available online (Diabetes Victoria; Vision 2020 Australia, 2017).

In brief, leaflet development was guided by intervention mapping (IM), a systematic framework for developing and evaluating behaviour change interventions specific to the needs and characteristics of a priority population (Bartholomew Eldredge et al., 2016). Following IM processes, leaflet design was informed by comprehensive needs assessment which highlighted five modifiable behavioural determinants associated with screening behaviour: knowledge,
attitudes, normative beliefs, intention and behavioural skills (Lake et al., Unpublished results; Lake et al., 2017). A range of targeted, persuasive messaging was developed, written to recommended literacy standards and incorporated into a leaflet alongside engaging and appropriate imagery. The leaflet was piloted and reviewed by a range of stakeholders, including five young adults with T2D who provided essential patient and public involvement (PPI) throughout.

5.4.5 Outcomes. Primary and secondary outcome data were collected post-randomisation and at follow-up. The primary outcome was uptake of retinal screening for unengaged participants; secondary outcomes were change in the five modifiable behavioural determinants noted in Section 5.4.4. All data were collected via self-report online questionnaire which was pilot-tested online by PPI members (aged 29-37 years) prior to implementation.

5.4.5.1 Primary outcome. Unengaged participants were asked if they had engaged in an “eye health check since you completed the last ... questionnaire” at phase 2 baseline and at post-intervention data collection points. The term “eye health check” was used in preference to “retinal screening”, informed by feedback from young adult PPI members. The following definition was used to minimise reported confusion between standard vision check and screening for DR (Hipwell et al., 2014):

“An eye health check is usually done by an optometrist or eye specialist who will check the blood vessels at the back of your eye for signs of diabetes-related eye damage. They do this by taking a photo or using a lamp and they may use eye drops to dilate your pupil”.
5.4.5.2 Secondary outcome. 54 items were developed in broad consultation with key stakeholders to assess the three IMB constructs, with wording derived from existing valid and reliable IMB-based questionnaires (Fishbein & Ajzen, 2010; Fishbein et al., 2001; Osborn, Amico, Fisher, Egede, & Fisher, 2010; Osborn & Egede, 2010). Item categories are summarised below; related items were summed to create a composite score (full item detail provided in Table 24, Section 5.8.2 - 5.8.2 Supplementary materials, including item wording, score range and internal validity for composite scores; full questionnaire provided in Appendix E).

Information: Information was assessed with 16 items across three categories: (i) link between diabetes and vision loss, (ii) knowledge of DR, and (iii) knowledge of retinal screening. Responses were scored dichotomously (correct / incorrect). Items were aggregated to form a composite score with higher scores indicating greater knowledge.

Motivation: Motivation was assessed with 27 items across three behavioural determinant categories: (i) attitudes (e.g. towards retinal screening, risk perception and anticipated regret); (ii) normative beliefs (e.g. approval of others); (iii) intention to screen for DR. Responses were scored on either a 5- or 7-point Likert scale, with higher scores representing stronger agreement (items reverse scored where necessary).

Behavioural skills: Behavioural skills were assessed using 11 items across two behavioural determinant categories: (i) perceived control (e.g. ability to seek and attend retinal screening); (ii) overcoming barriers (e.g. ability to identify and address common environmental and psychosocial barriers). Responses were
scored on a 5-point Likert scale with higher scores representing greater confidence.

5.4.5.3 Demographic data. Demographic data included: age, gender, country of birth, main language spoken at home, socio-economic status, employment, level of education and relationship status. Health information included: age at diagnosis of T2D, family history of T2D, primary diabetes management and health comorbidities. To reduce the risk of overestimation due to social desirability bias (Hwang, Rudnisky, Bowen, & Johnson, 2015), the retinal screening item was embedded within a suite of six items which assessed engagement with healthcare: “Since you were diagnosed with diabetes, have you had your ...(1) cholesterol, (2) blood pressure, (3) average blood glucose (HbA1c), (4) kidney function, (5) eye health, and (6) feet checked?“.

5.4.6 Assessment of adverse effects. To determine any negative impact of the intervention on emotional well-being, participants completed a brief, validated depression screening tool, the Patient Health Questionnaire (PHQ-2; Kroenke, Spitzer, & Williams, 2003) at baseline and follow-up. Using the PHQ-2, respondents rate how often, over the past two weeks, they had experienced “little interest or pleasure in doing things” and “feeling down, depressed or hopeless” on a 4-point scale (0=not at all to 3=nearly every day). Responses are summed (range: 0 - 6), with higher scores indicating more depressive symptoms. In addition, participants were invited to provide qualitative feedback.

5.4.7 Intervention fidelity We included an item in the follow-up questionnaire asking intervention group participants whether they received the
leaflet, and if so, whether they had read it.

5.4.8 Statistical analyses. We analysed data using the Statistical Package for Social Sciences (SPSS, IBM Corp, Armonk, NY; Ver.23, 2015). To assess factors associated with loss to follow-up, chi-square and independent t-tests (two-tailed) were used to compare baseline demographic characteristics and scores on modifiable behavioural determinants between those who completed and did not complete the study.

We were unable to perform inferential statistical analyses on the primary outcome, thus only descriptive statistics are reported for the numbers of participants in each study arm who were engaged versus unengaged pre- and post-intervention. To assess intervention effects on secondary outcomes, we created change scores by subtracting baseline score (pre-) from follow-up (post-) for each composite score. Then, we conducted independent samples t-tests (two-tailed) on the change scores to assess between-group differences, and paired-samples t-tests to assess within-group changes over time. Effect sizes are described with partial eta squared ($\eta^2$, range: 0-1); guidelines for interpretation are: $\eta^2=0.01$ (small), $\eta^2=0.06$ (moderate), and $\eta^2=0.14$ (large effect), (Cohen, 2013).

Although intention-to-treat and per-protocol analyses were planned, unusually high attrition precluded reliable analysis. Consequently, we elected to exclude cases with missing secondary outcome data pairwise (there were no missing data on the primary outcome), restricting results to complete cases only for each individual behavioural determinants composite score. Data are
presented as mean ± standard deviation (SD), median (interquartile range) or n (%), as appropriate.
5.5 Results

5.5.1 Participant flow and timeline of study activities. Of the 5,354 young adults with T2D who were invited to participate, 273 (5%) visited the study website and completed eligibility screening. Of those, 227 (4%) were eligible, consented to participate, completed phase 1 baseline questionnaire (demographic data), and were randomised. However, only 129 (57%) provided both phase 1 and 2 baseline data, and 101 (44% of original 227 registrants) provided follow-up data (Figure 9).

There was considerable attrition over the course of the study, the majority of which occurred post-randomisation but before collection of phase 2 baseline data (n=98, 45%). A further 22% of participants (n=28) did not complete the post-intervention, follow-up questionnaire. Although there was no evidence of differential attrition between treatment groups (all \( p > .05 \)), those who completed the study differed significantly from those who did not on four variables: country of birth, language spoken at home, number of health comorbidities and relationship status. Of those, country of birth was the only significant contributor to loss to follow-up at both of the stages noted above. Compared to non-completers, completers were significantly more likely to be Australian-born (65% vs 50%, \( p < .01 \) and 71% vs 43%, \( p < .05 \), respectively).

Finally, the leaflet was received and read by the majority of intervention group participants (n=43, 86%); seven (four unengaged, three engaged) either did not receive, or did not read, the leaflet due to “lack of time” and were excluded from outcome analyses. The final sample comprised 94 participants (n=43 intervention; n=51 control).
Figure 9: CONSORT diagram detailing participant flow through the trial, and project timeline

Invitations mailed to eligible NDSS registrants (N=5,354)
Assessed for eligibility (n=273)
Excluded (n=46):
- Not meeting inclusion criteria (n=9)
- Decline to participate (n=9)
- Incorrect email address (n=28)
Randomised (n=227)

Allocated to leaflet intervention (n=114)
Baseline analysis (n=67)
- Lost to follow-up (n=47)\(^a\)

Allocated to no leaflet control (n=113)
Baseline analysis (n=62)
- Lost to follow up (n=51)\(^b\)

Follow-up analysis (n=50)
- Excluded from outcome analysis (n=7)\(^c\)
- Lost to follow-up (n=17)\(^d\)

Follow-up analysis (n=51)
- Lost to follow-up (n=11)\(^e\)

\(^a\) Did not commence survey (n=44), withdrew (no reason given, n=3)
\(^b\) Did not commence survey (n=48), withdrew (no reason given, n=3)
\(^c\) Leaflet not received (n=5), leaflet received but not read (n=2)
\(^d\) Did not commence survey (n=12), withdrew (no reason given, n=1), invalid email address (n=1), no postal address provided (n=2), other (n=1)
\(^e\) Did not commence survey (n=11)
5.5.2 Baseline characteristics. The average age of the total study sample (N=227) was 34±4 years (range: 19-39 years), and more than half (n=126, 56%) were women. Most (n=177, 78%) spoke English at home, and more than half (n=131, 58%) were born in Australia, with a substantial minority (n=64, 29%) born in Asia. Participants reported short average duration of diabetes (1.6±2.5 years). Two-thirds of participants (n=150, 66%) managed their diabetes with oral hypoglycaemic agents and a high proportion (197, 87%) reported having engaged with four or more diabetes-related health and complication checks since their diagnosis. Almost three-quarters (n=164, 72%) reported engagement with retinal screening since their diabetes diagnosis.

One hundred and twenty-nine participants provided full baseline demographic and social cognitive data (Table 22). Overall, participants’ knowledge of an association between diabetes and vision loss was high (1.96±.20); but more detailed knowledge of DR and screening was low (6.46±2.12 and 1.47±.63, respectively). Participants reported high baseline intention to engage in screening (18.45±5.01) and strong perceptions of others’ approval (normative beliefs, 13.26±2.12), but only moderate perception of personal risk and anticipated regret at missing screening (12.78±4.38 and 24.64±6.39, respectively). Finally, participants reported moderately positive attitudes to screening at baseline (46.14±6.44), perceived control in attending screening and overcoming barriers (23.87±5.17 and 19.57±4.41, respectively).
### Table 22: Baseline demographic and behavioural determinants for total sample and by treatment group

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Total (N=129)</th>
<th>Intervention (n=67)</th>
<th>Control (n=62)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic variables (range)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, years</td>
<td>34.13 (4.46)</td>
<td>33.57 (4.58)</td>
<td>34.74 (4.28)</td>
<td>.135</td>
</tr>
<tr>
<td>Gender: women</td>
<td>77 (60)</td>
<td>40 (60)</td>
<td>37 (60)</td>
<td>1.00</td>
</tr>
<tr>
<td>Australian born</td>
<td>84 (65)</td>
<td>41 (61)</td>
<td>43 (69)</td>
<td>.431</td>
</tr>
<tr>
<td>Main language spoken at home:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>108 (84)</td>
<td>57 (85)</td>
<td>51 (82)</td>
<td>.846</td>
</tr>
<tr>
<td>Relationship status:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In a relationship</td>
<td>83 (64)</td>
<td>44 (66)</td>
<td>39 (63)</td>
<td>.885</td>
</tr>
<tr>
<td>Level of education:</td>
<td></td>
<td></td>
<td></td>
<td>.718</td>
</tr>
<tr>
<td>Secondary</td>
<td>28 (22)</td>
<td>13 (20)</td>
<td>15 (24)</td>
<td></td>
</tr>
<tr>
<td>Trade or certificate</td>
<td>49 (38)</td>
<td>25 (37)</td>
<td>24 (39)</td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>52 (39)</td>
<td>29 (43)</td>
<td>23 (37)</td>
<td></td>
</tr>
<tr>
<td>In paid employment</td>
<td>77 (60)</td>
<td>37 (55)</td>
<td>40 (65)</td>
<td>.371</td>
</tr>
<tr>
<td>Socioeconomic status:</td>
<td></td>
<td></td>
<td></td>
<td>.142</td>
</tr>
<tr>
<td>SEIFA score^</td>
<td>989.71 (64.6)</td>
<td>981.7 (7.38)</td>
<td>998.4 (68.3)</td>
<td></td>
</tr>
<tr>
<td>T2D duration, years</td>
<td>1.51 (1.95)</td>
<td>1.53 (2.11)</td>
<td>1.48 (1.78)</td>
<td>.877</td>
</tr>
<tr>
<td>Primary diabetes management:</td>
<td></td>
<td></td>
<td></td>
<td>.024</td>
</tr>
<tr>
<td>Lifestyle only</td>
<td>26 (20)</td>
<td>10 (15)</td>
<td>16 (26)</td>
<td></td>
</tr>
<tr>
<td>Oral medication</td>
<td>87 (67)</td>
<td>44 (66)</td>
<td>43 (69)</td>
<td></td>
</tr>
<tr>
<td>Insulin</td>
<td>16 (12)</td>
<td>13 (19)</td>
<td>3 (5)</td>
<td></td>
</tr>
<tr>
<td>Family history of T2D</td>
<td>94 (73)</td>
<td>47 (70)</td>
<td>47 (76)</td>
<td>.600</td>
</tr>
<tr>
<td>Diabetes-related health check (range: 0-6)</td>
<td>4.63 (1.41)</td>
<td>4.67 (1.31)</td>
<td>4.60 (1.5)</td>
<td>.762</td>
</tr>
<tr>
<td>Engaged with retinal screening at baseline: yes</td>
<td>92 (71.3)</td>
<td>48 (72)</td>
<td>44 (71)</td>
<td>1.00</td>
</tr>
<tr>
<td>Number of health comorbidities#</td>
<td>1.77 (1.38)</td>
<td>1.79 (1.33)</td>
<td>1.75 (1.45)</td>
<td>.881</td>
</tr>
<tr>
<td>Depressive symptoms: PH-2 (range: 0-6)</td>
<td>2.42 (2.08)</td>
<td>2.67 (2.15)</td>
<td>2.15 (1.98)</td>
<td>.150</td>
</tr>
</tbody>
</table>
Table 22: Baseline demographic and behavioural determinants for total sample and by treatment group (Cont.)

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Total (N=129)</th>
<th>Intervention (n=67)</th>
<th>Control (n=62)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social cognitive behavioural determinants (range)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>diabetes/vision link (range: 0-2)</td>
<td>1.96 (.20)</td>
<td>1.97 (.18)</td>
<td>1.94 (.23)</td>
<td>.554</td>
</tr>
<tr>
<td>diabetic retinopathy (range: 0-11)</td>
<td>6.46 (2.12)</td>
<td>6.28 (2.20)</td>
<td>6.66 (2.03)</td>
<td>.325</td>
</tr>
<tr>
<td>retinal screening (range: 0-3)</td>
<td>1.47 (.63)</td>
<td>1.46 (.56)</td>
<td>1.48 (.70)</td>
<td>.902</td>
</tr>
<tr>
<td><strong>Attitudes:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>retinal screening (range: 11-55)</td>
<td>46.16 (6.44)</td>
<td>46.19 (5.62)</td>
<td>46.12 (7.31)</td>
<td>.956</td>
</tr>
<tr>
<td>risk perception (range: 4-28)</td>
<td>12.78 (4.38)</td>
<td>13.23 (4.46)</td>
<td>12.26 (4.27)</td>
<td>.225</td>
</tr>
<tr>
<td>anticipated regret (range: 6-42)</td>
<td>24.64 (6.39)</td>
<td>24.73 (6.19)</td>
<td>24.53 (6.65)</td>
<td>.859</td>
</tr>
<tr>
<td>Normative beliefs (range: 2-14)</td>
<td>13.26 (2.12)</td>
<td>13.41 (1.96)</td>
<td>13.09 (2.29)</td>
<td>.411</td>
</tr>
<tr>
<td>Intention (range: 3-21)</td>
<td>18.45 (5.01)</td>
<td>18.31 (4.78)</td>
<td>18.60 (5.29)</td>
<td>.757</td>
</tr>
<tr>
<td><strong>Behavioural skills:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>perceived control (range: 6-30)</td>
<td>23.87 (5.17)</td>
<td>23.58 (5.11)</td>
<td>24.20 (5.27)</td>
<td>.516</td>
</tr>
<tr>
<td>overcoming barriers (range: 5-55)</td>
<td>19.57 (4.41)</td>
<td>19.41 (4.25)</td>
<td>19.75 (4.61)</td>
<td>.672</td>
</tr>
</tbody>
</table>

^Some missing data: range 3-10 dependent upon variable. Data are number (%) or mean (SD). Chi-square and independent t-tests (two-sided); p<0.05.

^Index of Relative Socio-economic Advantage and Disadvantage (IRSAD),

5.5.3 **Primary and secondary outcomes at follow-up.** Baseline, follow-up and change scores are presented for outcome variables, by treatment condition in Table 23.

*Table 23: Primary and secondary outcome variables at follow-up, by condition*

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Time point</th>
<th>Intervention (n=8)</th>
<th>Control (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary outcome variable:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retinal screening uptake</td>
<td>Baseline</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>since baseline for unengaged participants</td>
<td>Follow-up</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>% increase</td>
<td></td>
<td>63</td>
<td>25</td>
</tr>
<tr>
<td><strong>Secondary outcome variables (range)†</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge: diabetes/vision link (0-2)</td>
<td>Baseline</td>
<td>1.97 (.17)</td>
<td>1.96 (.21)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>1.97 (.17)</td>
<td>1.98 (.15)</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>0.00</td>
<td>0.02</td>
<td></td>
</tr>
<tr>
<td>Knowledge: diabetic retinopathy (0-11)</td>
<td>Baseline</td>
<td>6.43 (2.38)</td>
<td>6.78 (2.00)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>7.64 (1.97)</td>
<td>6.86 (2.10)</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>1.21**</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Knowledge: retinal screening (0-3)</td>
<td>Baseline</td>
<td>1.45 (.55)</td>
<td>1.42 (.70)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>1.70 (.72)</td>
<td>1.72 (.70)**</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>0.25</td>
<td>0.30</td>
<td></td>
</tr>
<tr>
<td>Attitudes: retinal screening (11-55)</td>
<td>Baseline</td>
<td>46.29 (4.99)</td>
<td>46.28 (6.17)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>46.61 (5.70)</td>
<td>45.85 (5.4)</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>0.32</td>
<td>-0.43</td>
<td></td>
</tr>
<tr>
<td>Attitudes: risk perception (4-28)</td>
<td>Baseline</td>
<td>13.49 (4.24)</td>
<td>12.30 (4.08)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>13.64 (3.91)</td>
<td>12.17 (3.57)</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>0.15</td>
<td>-0.13</td>
<td></td>
</tr>
<tr>
<td>Attitudes: anticipated regret (6-42)</td>
<td>Baseline</td>
<td>24.62 (5.96)</td>
<td>24.79 (5.55)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>30.67 (5.85)</td>
<td>29.40 (7.16)</td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>6.05</td>
<td>4.62</td>
<td></td>
</tr>
</tbody>
</table>
Table 23: Primary and secondary outcome variables at follow-up (Cont).

<table>
<thead>
<tr>
<th>Secondary outcome variables (range)#</th>
<th>Intervention (n=43)</th>
<th>Control (n=51)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Normative beliefs (2-14)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>13.26 (2.28)</td>
<td>13.43 (1.44)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>13.10 (2.34)</td>
<td>13.02 (2.66)</td>
</tr>
<tr>
<td>Change</td>
<td>-0.15</td>
<td>-0.40</td>
</tr>
<tr>
<td><strong>Intention (3-21)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>18.51 (4.61)</td>
<td>18.72 (5.22)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>18.46 (4.01)</td>
<td>18.83 (4.36)</td>
</tr>
<tr>
<td>Change</td>
<td>-0.05</td>
<td>0.11</td>
</tr>
<tr>
<td><strong>Behavioural skills: perceived control (6-30)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>24.72 (4.10)</td>
<td>24.5 (4.38)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>25.28 (4.24)</td>
<td>24.11 (4.97)</td>
</tr>
<tr>
<td>Change</td>
<td>0.56</td>
<td>-0.39</td>
</tr>
<tr>
<td><strong>Behavioural skills: overcoming barriers (5-25)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>20.21 (3.27)</td>
<td>19.91 (4.08)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>20.08 (3.43)</td>
<td>19.15 (4.17)</td>
</tr>
<tr>
<td>Change</td>
<td>-0.13</td>
<td>-0.77</td>
</tr>
<tr>
<td><strong>PHQ-2 (0-6)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>2.38 (2.42)</td>
<td>1.94 (1.96)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>2.05 (2.04)</td>
<td>2.00 (2.01)</td>
</tr>
<tr>
<td>Change</td>
<td>-0.33</td>
<td>0.06</td>
</tr>
</tbody>
</table>

Primary outcome data: number who reported receiving and reading leaflet.

Secondary outcome data: mean (standard deviation)

Change score = follow-up score minus baseline score.

# some missing data: range 3-10 dependent upon variable.

* Significant between-condition difference in change scores;

b Significant within-condition difference in change scores.

*p<.05, ** p<.001, ***p<.001
5.5.3.1 Screening uptake for unengaged participants. Overall, an insufficient number of unengaged participants provided follow-up data (n=24, and 12 in each condition) and the study was underpowered to detect meaningful change on the primary outcome. Further, of the 24 unengaged participants who provided outcome data, four intervention group participants reported that they either did not receive, or did not read, the leaflet and were excluded from analysis. Among the remaining intervention group participants, there was a proportionally higher screening uptake than among those in the (no-leaflet) control group (n=5 and n=3 respectively).

5.5.3.2 Social cognitive variables. At follow-up, the leaflet intervention group reported greater knowledge of DR relative to the control group \( t(72) = -2.213, p < .05; CI = -2.14 \text{ to } -.11 \), with moderate effect size \( \eta^2 = .05 \). There were no other significant between-group differences (all \( p > .05 \)). Both groups reported a significant increase (from baseline to follow-up) in their knowledge of retinal screening and a significant increase in anticipated regret (all \( p < .05 \)).
5.6 Discussion

5.6.1 Summary of findings. This is the first randomised controlled trial to evaluate an evidence-based retinal screening promotion leaflet tailored to young adults with T2D. The leaflet targeted screening behaviour, as well as associated modifiable behavioural determinants identified in an earlier needs assessment (Lake et al., Unpublished results). Trends in the expected direction suggested that those unengaged participants who received the leaflet were more likely to initiate screening than those who did not, however caution is required in interpreting these findings given the small sample size, and in particular the smaller-than-anticipated number of unengaged participants. The subsequent underpowered study precluded assessment of intervention effect on screening behaviour, the primary outcome. As such, no firm conclusions about the impact of the leaflet on screening uptake can be drawn.

Effect of the leaflet on secondary outcomes was also promising. The intervention group demonstrated significantly greater improvement in knowledge of DR than the control group, an important retinal screening predictor associated with increase in screening in the general diabetes population (Zhang et al., 2007). The moderate effect size observed in the current study is consistent with effect sizes found in the behavioural sciences (Cohen, 2013; Johnson, Scott-Sheldon, & Carey, 2010).

Although the leaflet intervention did not independently impact other targeted social cognitive behavioural determinants, study involvement was associated with change in both knowledge (increased knowledge of retinal screening) and attitudes (increased anticipated regret). The latter is a likely
randomised controlled trial (RCT) (Kooman et al., 2019). A co-primary endpoint was the primary outcome in all treatment arms. Additional, exploratory endpoints included intermediate and health outcomes.

5.6 Discussion

5.6.1 Implications for Practice and Research

The study findings have implications for the development of effective vision screening programmes for people with type 2 diabetes. Key messages include:

- Little is known about the acceptability of the retinal screening programme among people with type 2 diabetes, particularly young adults. This information is crucial for the development of strategies to promote screening uptake.
- The high participant baseline screening rates in this study (72%) may not be representative of the general (non-Indigenous) diabetes population in Australia’s first national eye health obesity and vision study (NEOHANTS) (Collins et al., 2019).

5.6.2 Limitations

The key limitation was lack of power to detect change in the primary outcome. Contributing factors were low recruitment, high baseline screening rate and high baseline scores (ceiling effect) for some of the behavioural determinant variables. Despite careful planning, broad consultation and a nationwide recruitment program, only 4% of eligible NDSS registrants were recruited to the study. It is likely that low recruitment resulted from a confluence of commonly reported barriers for this group (e.g. disproportionately high representation of ethnic/racial minorities, social disadvantage and complex psychosocial needs), (Lake et al., 2017; Nadeau et al., 2016; Nguyen et al., 2014; Zeitler et al., 2015). Additional, context-specific barriers such as study ‘fatigue’ from high number of concurrent research opportunities (personal communication, D. Rae, National Inventory Manager, NDSS) may also have affected recruitment.

The high participant baseline screening rate (72%) is lower than that the general (non-Indigenous) diabetes population in Australia’s first national eye health obesity and vision study (NEOHANTS) (Collins et al., 2019).
health survey (78%) (Foreman et al., 2017). However, reports from other sources indicate that the true young adult screening rate is likely to be closer to 50% (Diabetes Australia, 2006; Wang et al., 2017), indicating that the study may have missed recruiting the more disengaged members of the priority population. The low average number of health comorbidities and high average number of diabetes-related health and complication checks despite earlier, contradictory findings (Browne et al., 2014), support this assertion.

Possible explanations for recruitment bias, which favours high self-reported screening rates, include: self-selection bias, whereby those who choose to participate in research have higher self-efficacy and are more engaged in their diabetes care (Müller, Lamoureux, Bullen, & Keeffe, 2006), and social desirability and recall bias, both of which risk overestimation of retinal screening (Foreman et al., 2017). Although self-report of retinal screening behaviour is commonly used as an outcome measure for intervention effectiveness, previous research has reported overestimation when compared with medical record data (Beckles et al., 2007; MacLennan, McGwin, Searcey, & Owsley, 2013).

Despite efforts to conceal the true nature of the study, asking about self-management behaviour from the outset may have elicited a social desirability bias, of which younger people are considered particularly susceptible (Johnson et al., 2010). Accuracy of self-report is also vulnerable to recall bias, particularly in the light of acknowledged confusion regarding the difference between screening for DR and a standard eye check (Hipwell et al., 2014). Future studies could overcome the threat of bias from these sources by not only including definition
of retinal screening (as was done in the current study), but also corroboration of self-report with medical record data.

Finally, moderate-to-high baseline scores for many behavioural determinant variables indicated favorable retinal screening beliefs and attitudes in the priority population, prior to the intervention. This ceiling effect was observed for variables within each of the three IMB constructs: Information (knowledge of diabetes/vision link); Motivational factors (attitudes, normative beliefs, and intentions) and Behavioural skills factors (perceived control, overcoming barriers). Thus potential to detect treatment effect on the secondary outcome variables was limited. Further, as we would expect to see the greatest change in those who had not previously screened for DR, low representation of unengaged young adults with T2D may have exacerbated this issue.

Additional sources of bias included the inability to mask participants to the experimental condition (i.e. they either did or did not receive the leaflet) and high loss to follow-up. Although inability to mask participants is a common issue for health behaviour change interventions (Tarquinio, Kivits, Minary, Coste, & Alla, 2015), possible consequences of this include performance or ascertainment bias, potentially affecting subjective reporting of study outcomes. Further, we experienced considerable loss to follow-up, the majority of which occurred prior to intervention implementation. However, the majority of demographic characteristics of those lost to follow-up did not differ from those who completed the entire study with the important exception of country of birth.
5.6.3 Implications for future research. In addition to the need to redouble efforts to recruit and ensure retention of non-Australian born members of this cohort from the outset (possibly via collaboration with community-based organisations which represent culturally and linguistically diverse groups) as suggested by Zhang et al. (2007) in their systematic review of retinal screening promotion interventions, this study also highlights implications for the evaluation of retinal screening interventions.

Considering that participant recruitment was conducted with the support and involvement of leading eye health and diabetes stakeholders, and that invitations were extended nationwide to over 5,000 eligible young adults with T2D, utilising an appropriate platform (NDSS database), our experience suggests that replication is not a practical option and that alternate evaluation designs should be considered.

In recent years, clinical trials targeting youth/young adults with T2D have highlighted the challenges faced in the context of limited sample size and culturally diverse populations (Nadeau et al., 2016; Nguyen et al., 2014; Zeitler et al., 2015). Solutions proposed by those conducting large-scale trials include “realistic and efficient” study designs, development of collaborative networks, and a consortium approach to simultaneously evaluate medical treatments while sharing the one placebo arm (Nadeau et al., 2016; Zeitler et al., 2015).

However, this may not be feasible for smaller-scale behavioural interventions, such as the current study. Instead, both MRC guidance and recent literature suggest alternatives to the conventional parallel-group randomised controlled trial. Dependent upon a variety of factors (e.g. cost, time, priority
population characteristics, intervention setting and risk of selection bias), alternate evaluation approaches which maintain randomisation include dynamic wait-listed (DWL) and stepped wedge designs, while quasi-experimental designs include interrupted time-series (ITS) and regression point displacement (Craig et al., 2008; Fok, Henry, & Allen, 2015; Wyman, Henry, Knoblauch, & Brown, 2015). Despite improvements in study design, statistical and data measurement approaches which maximise efficiency and statistical power, each of the non-conventional options cited above have inherent limitations, such as inflexibility due to time-limited parameters (DWL), long wait times (stepped-wedge), potential for high cost and participant burden (ITS), and potential for low power (regression point displacement), (Fok et al., 2015; Wyman et al., 2015).

In their systematic review, Zhang and colleagues (2007) noted that retinal screening promotion intervention studies with non-RCT designs were conducted in more diverse populations than RCT designs. However, the benefits of the former need to be weighed against challenges with respect to achieving sufficient power, rigour and generalisability of findings. Thus, in the context of future screening interventions for young adults with T2D, we recommend that researchers explore nonconventional alternatives to the traditional parallel groups RCT, while giving close consideration to the limitations noted above. However, if a conventional, gold standard RCT design is desired, we recommend use of a Solomon 4-group design to account for the likely presence of QBE. Furthermore, an RCT would need to overcome issues identified above, preferably via a highly proactive, community-based recruitment and engagement strategy.
5.6.4 Conclusion. Despite careful study design and proactive recruitment and implementation initiatives, we faced many of the challenges experienced in ‘real-world’ health behaviour change intervention studies conducted with diverse or disadvantaged groups, including low recruitment from small population base, high loss to follow-up, and subsequent lack of statistical power. Notwithstanding its limitations, this study has made an important contribution by demonstrating that a tailored, evidence-based leaflet can improve knowledge of DR, a key screening facilitator, among young adults with T2D. A trend towards enhanced screening engagement as a result of the intervention was also observed, suggesting the leaflet has the potential to increase retinal screening rates among young adults with T2D.
5.7 References


eye examinations among adults with diabetes in managed care. *Medical Care, 45*(9), 9.


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5.8 Additional information

5.8.1 Acknowledgements. We thank the study participants for their contribution, insights and experiences. For their professional input, we thank: Carolyn Hines (Diabetes Education Manager, Diabetes Victoria) and Dee Tumino (Vision Initiative Manager, Vision 2020 Australia). For advice on QBE and the Solomon 4-group trial design, we thank Prof Charles Abraham (Exeter University, UK). For advice on website development, we thank Dr Steve Trawley (ACBRD). For their statistical advice, we thank Dr Elizabeth Holmes-Truscott (ACBRD) and Deakin University Faculty of Health biostatistics team (Dr Lucy Busija, Assoc Prof Liliana Orellana, Dr Mohammadreza Mohebbi).

Finally, we thank Mr. Darren Rae, National Operations Manager and staff at the NDSS for their advice and guidance, registration statistics and for managing participant recruitment.
5.8.2 Supplementary materials

Table 24: Supplementary materials - questionnaire items assessing modifiable behavioural determinants associated with retinal screening

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>No. of items</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INFORMATION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge: diabetes/vision loss link</td>
<td>2</td>
<td>0-2</td>
</tr>
<tr>
<td>Diabetes can lead to vision loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All people with diabetes are at risk of DR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge: diabetic retinopathy (DR)</td>
<td>11</td>
<td>0-11</td>
</tr>
<tr>
<td>Prevalence rates of DR amongst people with diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR can cause vision loss or blindness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR can develop without symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high blood pressure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high cholesterol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR is treatable if detected early via an eye health check</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR is more likely to develop the longer you have diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR is influenced by high blood glucose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early DR is asymptomatic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended target HbA1c*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended target blood pressure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge: retinal screening</td>
<td>3</td>
<td>0-3</td>
</tr>
<tr>
<td>Which health professional would you most likely to see for a DR examination?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When should a person with diabetes have their first eye examination?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommended eye examination frequency if no DR present?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 24: Questionnaire items assessing modifiable behavioural determinants associated with retinal screening (Cont.)

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>No. of items</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MOTIVATION</strong>&lt;sup&gt;b,c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attitudes: retinal screening</strong>&lt;sup&gt;c&lt;/sup&gt; (α=.86)</td>
<td>11</td>
<td>11-55</td>
</tr>
<tr>
<td>For me to have an eye health check for DR would...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be a good idea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...(not)&lt;sup&gt;“&lt;/sup&gt; be ‘unpleasant’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be wise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...(not)&lt;sup&gt;“&lt;/sup&gt; be ‘difficult’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...(not)&lt;sup&gt;“&lt;/sup&gt; be ‘frightening’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...(not)&lt;sup&gt;“&lt;/sup&gt; be ‘unnecessary’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be reassuring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be beneficial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be comfortable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...be empowering</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attitudes: risk perception</strong>&lt;sup&gt;b&lt;/sup&gt; (α=.70)</td>
<td>4</td>
<td>4-28</td>
</tr>
<tr>
<td>I believe I will develop DR due to my diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I expect to be diagnosed with DR at my next eye check</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I believe I can reduce my risk of vision problems if</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...I manage my diabetes well</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I believe I will develop vision problems due to diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attitudes: anticipated regret</strong>&lt;sup&gt;b&lt;/sup&gt; (α=.87)</td>
<td>6</td>
<td>6-42</td>
</tr>
<tr>
<td>If I did NOT have an eye health check for DR, I would feel...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...indifferent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...concerned</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...fearful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...worried</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...regretful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...guilty</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 24: Questionnaire items assessing modifiable behavioural determinants associated with retinal screening (Cont.)

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>No. of items</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MOTIVATION&lt;sup&gt;b,c&lt;/sup&gt; (Cont.)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normative beliefs&lt;sup&gt;b&lt;/sup&gt; (α=.93, Pearson’s r=.87)</td>
<td>2</td>
<td>2-14</td>
</tr>
<tr>
<td>My family/close friends would approve of me attending an eye health check...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My health professionals would approve of me attending an eye health check...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional item: Most people I know with diabetes have regular eye health checks&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1</td>
<td>0-7</td>
</tr>
<tr>
<td>Intention&lt;sup&gt;b&lt;/sup&gt; (α=.98)</td>
<td>3</td>
<td>3-21</td>
</tr>
<tr>
<td>I plan to attend an eye health check...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I will make an effort to have an eye health check...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I intend to have an eye health check...</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BEHAVIOURAL SKILLS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived control&lt;sup&gt;d&lt;/sup&gt; (α=.87)</td>
<td>6</td>
<td>6-30</td>
</tr>
<tr>
<td>How confident are you that you...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...know what steps you can take to reduce the risk of developing DR?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...will have regular eye health checks?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...know how to make the appointment for an eye check?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...will remember to have an eye health check in the next four weeks OR when it is next due?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...will attend the eye health check that you have booked?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...can reschedule the eye health check to a different time or day if needed?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 24: Questionnaire items assessing modifiable behavioural determinants associated with retinal screening (Cont.)

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>No. of items</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overcoming barriers&lt;sup&gt;d&lt;/sup&gt; (α=.76)</td>
<td>5</td>
<td>5-25</td>
</tr>
</tbody>
</table>

How confident are you that you...

...can talk to your doctor about your eye health?

...can find the time to attend an eye health check in the next four weeks OR when it is next due?

...will mention you have diabetes when you make the eye check appointment?

...can resume your normal activities immediately after the eye health check?

...can afford to pay for the eye health check, if there is a charge?

~Cronbach’s alpha was generated for all motivational and behavioural skills constructs; Pearson’s r generated for 2-item construct.
*Indicator of glycaemic control (measure of average blood glucose levels over the past 8-12 weeks).
DR: diabetic retinopathy, #responses reverse coded.

**Scoring for individual items:**

<sup>a</sup> incorrect / correct;

<sup>b</sup> 1 (Strongly disagree) to 7 (Strongly agree),

<sup>c</sup> 1 (Strongly disagree) to 5 (Strongly agree),

<sup>d</sup> 1 (Not at all confident) to 5 (Extremely confident).
5.8.3 Trial registration. Australian and New Zealand Clinical Trials registry ACTRN12614001110673

5.8.4 Changes to methods after trial commencement. Based on experience from an earlier qualitative study (Lake, Browne, Rees, & Speight, 2017), the original design for this project addressed a potential source of bias known as question-behaviour effect (QBE). Common to socially desirable behaviours, QBE is a phenomenon whereby answering questions about a specific behaviour can influence an individual’s cognitions, emotions and subsequent behaviour (Spangenberg et al., 2012). QBE has been detected in relation to a range of health-related behaviours, including blood donation, cervical screening, uptake of influenza vaccination and health checks (Conner, Godin, Norman, & Sheeran, 2011; Godin, Germain, Conner, Delage, & Sheeran, 2013; Sandberg & Conner, 2009).

Researchers have highlighted QBE as a source of bias in health behaviour change interventions (McCambridge, 2015), urging caution in the use of pre-test measures (Sandberg & Conner, 2009). In an attempt to account for QBE, we originally selected a Solomon 4-group study design (Solomon, 1949), which randomly assigns participants to a combination of four pre-test/intervention groups in a 2x2 factorial design. In a Solomon 4-group design, half of all participants within each condition receive baseline questionnaires and the other half do not, permitting assessment of both the intervention and the interaction of pre-test items. If pre-test sensitisation, or QBE, is present, the effect would be expected to be larger than ‘no pre-test plus intervention’.
Informed by previous studies among young adults with T2D (Nguyen et al., 2014; Zeitler, Chou, Copeland, & Geffner, 2015), we anticipated low recruitment (10%) (Browne, Nefs, Pouwer, & Speight, 2014; Johnson, Niles, & Mori, 2015) estimated a low previous retinal screening rate (50%) (Diabetes Australia, 2006; Wang et al., 2017) and high attrition (40%) (Nguyen et al., 2014). Sample size calculation was computed using input parameter of an effect size of 0.3 (Johnson, Scott-Sheldon, & Carey, 2010), which required 200 participants not engaged with screening (50 per condition in the 4-group design) at follow-up for 80% power, using a significance level of 0.05 (two-tailed).

To fulfil this requirement, it was estimated that we would need to mail recruitment invitations to 3,400 eligible NDSS registrants. However, subsequent discussions with representatives from the NDSS suggested that recruitment rates would be lower than reported in the literature due to a high number of invitations to concurrent research opportunities being disseminated by the NDSS. Consequently, the planning team agreed to send recruitment invitations to all eligible NDSS registrants who had consented to be contacted for research (N=5,354).

At the end of the seven-week recruitment period, and after an additional reminder invitation was mailed, only 63 unengaged young adults had registered for the study; below the required minimum sample size. A senior biostatistician reviewed the study design and advised to replace the Solomon 4-group design with a standard 2-group RCT design (leaflet intervention vs no-leaflet control). A second power analysis confirmed that the effect of the leaflet on the primary
outcome could be assessed with a sample size of 50 per condition (including 25 ‘unengaged’ per condition); power and significance levels remained the same.

The RCT design modification received Deakin University Human Research Ethics Committee approval in November 2014 and was added to trial registration ACTRN12614001110673.

5.8.4.1 References for changes to methods after trial commencement


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CHAPTER 6: Discussion

The overall aim of this program of PhD research was to develop a public health intervention to promote uptake of retinal screening among young adults with type 2 diabetes (T2D). To achieve this aim, three objectives were defined: i) identify modifiable factors impacting retinal screening behaviour among young adults with T2D; ii) develop an individual-level, theoretically-grounded, psycho-educational retinal screening promotion intervention, tailored to this priority population; and iii) evaluate the effectiveness of the intervention in increasing self-reported uptake of retinal screening and changing modifiable behavioural determinants in a fully powered randomised controlled trial (RCT).

This chapter comprises five sections. The first summarises key findings by objective, and discusses the original contribution of this program of PhD research to existing knowledge. The second section discusses study implications, particularly with regard to clinical practice and a proposed nationally coordinated retinal screening program in Australia. Section three discusses implications for future research, such as utilisation of the leaflet as a foundation for similar resources, and lessons learned for future research. Strengths and limitations are discussed in Section four, followed by a brief conclusion (Section five).
6.1 Overview of Key Findings and Contribution to Current Knowledge

Although younger age is an independent risk factor for both diabetic retinopathy (DR) and low retinal screening uptake (Scanlon et al., 2016; Zoungas et al., 2014), no study has previously explored in-depth, the underlying, individual-level factors impacting retinal screening uptake among young adults with T2D (Forward, Hewitt, & Mackey, 2012; Hessler, Fisher, Mullan, Glasgow, & Masharani, 2011). Furthermore, no previous studies have developed a retinal screening promotion intervention tailored to this priority population.

6.1.1 Objective 1: Identify modifiable factors impacting retinal screening behaviour among young adults with type 2 diabetes.

Previous research has demonstrated that young adults with T2D face a range of clinical and psychosocial barriers to diabetes self-management (Auslander, Sterzing, Zayas, & White, 2010; Brouwer et al., 2012; Browne, Nefs, Pouwer, & Speight, 2014; Browne, Scibilia, & Speight, 2013a; Hessler et al., 2011; Savage, Dabkowski, & Dunning, 2009; Sillars, Davis, Kamber, & Davis, 2010; Waitzfelder et al., 2011). Chapters 3 and 4 of this thesis report the conduct and findings of a mixed-methods needs assessment, which confirmed that young adults with T2D experience multiple barriers and facilitators to retinal screening, and identified key behavioural determinants of this important behaviour.

Using the Theoretical Domains Framework (TDF) as a theoretical foundation to data collection and interpretation (Cane, O'Connor, & Michie, 2012), the qualitative in-depth interview study (described in Chapter 3) demonstrated that many barriers and facilitators experienced by young adults with T2D are shared with their older adult T2D counterparts for whom the
majority of existing self-management resources are designed. Shared barriers include lack of knowledge of DR and retinal screening guidelines (see Section 3.5.2 for more detail). However, the study also identified factors of greater salience to young adults with T2D, including lack of financial and time resources, and lack of engagement with existing diabetes information and support services, highlighting the need for tailored retinal screening promotion materials. To illustrate, members of the older adult comparator group commonly stated that they engaged in retinal screening to preserve their independence, while those young adults with T2D who had screened for DR commonly reported fear of the impact of vision loss on the family unit as a motivating factor.

Using the Information-Motivation-Behavioural skills model as a framework for data collection and interpretation (Fisher, Fisher, & Harman, 2003), the nationally-conducted online quantitative survey (described in Section 4.4.1.2.2), further explored barriers and facilitators, and highlighted multiple modifiable behavioural retinal screening determinants to be targeted in the intervention, including several key differences between the young adults with T2D who had and had not engaged in retinal screening. To illustrate, young adults with T2D who had never screened for DR demonstrated significantly lower knowledge (e.g. that all people are at risk of DR, and that individuals should initiate retinal screening at diabetes diagnosis), than their similar aged counterparts who had engaged in retinal screening. Similarly, where the in-depth qualitative interview study highlighted social influence and support as a key retinal screening facilitator for both the young adults with T2D, and their older adult counterparts (Section 3.5.2.1), the quantitative survey findings confirmed
that young adults with T2D who had previously screened were significantly more likely to agree that significant others (i.e. family/friends, healthcare team) would approve of screening (Table 12, Section 4.4.1.2).

**Summary of retinal screening barriers and determinants.** The findings from the mixed-methods needs assessment studies indicated that many clinical and psychosocial barriers which apply to diabetes self-management (Browne et al., 2013a; Diabetes Australia, 2006), apply to retinal screening behaviour. Taken in combination with the literature study described in Section 4.8.1, these include:

- absence of symptoms from diabetes-related complications, which typically manifest 10 years post diagnosis (Dart et al., 2014; Delamater, Jacquez, & Patino-Fernandez, 2009);

- added burden of multiple health comorbidities at a young age, including obesity which is commonly cited by young adults with T2D as their main health concern (Auslander et al., 2010; Dabelea et al., 2017; Nguyen et al., 2014);

- lack of encouragement to screen for DR from general practitioner (GP), potentially due to uncertainty about how to manage younger onset T2D, or clinician misconception that the condition is low risk (Song, 2015; Zafar, Stone, Davies, & Khunti, 2014);

- time and financial constraints associated with life stage, which include parenting, full time work and study (Arnett, 2000; Sachdeva, Stratton, Unwin, Moreton, & Scanlon, 2012; Strutton, Du Chemin, Stratton, & Forster, 2016);
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- low health literacy and low appreciation of long-term consequences of diabetes, exacerbated by low rates of diabetes self-management education, an important screening predictor (Bailey et al., 2014; MacLennan, McGwin, Heckemeyer, & et al., 2014);

- disengagement with existing diabetes services and support networks, due to lack of perceived ‘age-appropriate’ materials and resources, and denial of diabetes diagnosis (Diabetes Australia, 2006);

- fatalism about the inevitability of diabetes complications, due to family history of T2D (Turner et al., 2015), and

- perception of stigma and negative judgment due to having a condition usually associated with older adults (Savage et al., 2009).

Similarly, the mixed-methods needs assessment identified that many retinal screening determinants were psychosocial in origin (e.g. knowledge, attitudes, health and normative beliefs, intentions and self-efficacy), and were similar to those identified in studies examining the uptake of other screening behaviours, such as breast and cervical cancer (Burgess et al., 2008; Byrd et al., 2012; Magai, Consedine, Neugut, & Hershman, 2007; Sadler, Albrow, Shelton, Kitchener, & Brabin, 2013; Vernon et al., 2008), colorectal cancer (Dharni, Armstrong, Chung-Faye, & Wright, 2017), hepatitis B (Van Der Veen, Van Empelen, & Richardus, 2012), and sexual health screening by young people (Newby et al., 2017; Theunissen et al., 2013; Tilson, Sanchez, Ford, & Smurzynski, 2004; Wolfers, de Zwart, & Kok, 2012).
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For example, although positive attitudes regarding the benefit of retinal screening, and expectations of a positive outcome, facilitated the behaviour, youth-related perceptions of invulnerability and low personal risk impeded it, lowering perception of need and decreasing prioritisation of retinal screening over competing activities (MacLennan et al., 2014). Further, although social normative factors, such as social support, beliefs about others’ approval, and awareness of the screening behaviour of similar others, facilitated retinal screening (as they also influence other screening behaviours), a crucial difference is that many young adults with T2D did not know anyone else with the condition and therefore, did not know whether similar others screened for DR, or whether others approved of the behaviour (Mulvaney et al., 2006).

Similarly, health beliefs (e.g. unrealistic optimism, fatalism, fear of adverse effects, misconceptions regarding eye health as an ‘older person’s’ concern) were demonstrated to influence young adults’ eye health behaviour, as they did for cancer screening initiatives (Sadler et al., 2013; Shickle et al., 2014). Intention to screen for DR was high among the priority population, even for those who had not screened, highlighting low actual prioritisation of the behaviour; a similar finding for young women and breast cancer screening (Sadler et al., 2013). Finally, low self-efficacy represented by low confidence in ability to screen for DR due to competing ‘life stage’ demands, was an important and distinct barrier contributing to the confluence of factors impacting retinal screening behaviour for young adults with T2D.

In addition to identifying salient barriers, facilitators and behavioural determinants, the most potent factor impeding retinal screening behaviour for
young adults with T2D appeared to be clustering of barriers, rather than one
over-riding specific factor. The hypothesis that an accumulation of barriers
impedes retinal screening was raised in earlier, qualitative work (Lindenmeyer et
al., 2014). Thus, in contrast to the discrete focus on increasing knowledge and
awareness, which was customary to many earlier retinal screening promotion
interventions (Livingston et al., 1998; Zhang et al., 2007), this program of PhD
research has highlighted the imperative of targeting and addressing a range of
salient factors when developing retinal screening promotion interventions
tailored to young adults with T2D. Further, given that the TDF was used to
identify barriers and facilitators to retinal screening, the findings from this study
have the potential to contribute to the systematic review currently being
conducted by Graham-Rowe et al. (2016), described in Section 2.1.2.

In summary, the findings of the mixed methods needs assessment
demonstrated that this priority population faces a converging range of
psychosocial and other barriers to retinal screening, many of which distinguish
them from their older adult counterparts. Consequently, a tailored intervention
is warranted in order to target appropriate underlying factors, and engage this
priority population in retinal screening.

6.1.2 **Objective 2: Develop an individual-level, theoretically-grounded,
psycho-educational retinal screening promotion intervention,
tailored to young adults with type 2 diabetes.** Chapter 4
reported on the use of Intervention Mapping (IM) as a framework to develop a
theoretically-grounded and evidence-based intervention tailored to the
expressed needs of young adults with T2D. Using causal modelling, modifiable
determinants (summarised in Section 4.4.1.2.3) and non-modifiable determinants (e.g. socioeconomic status, cultural diversity, general and health literacy, life stage demands, multimorbidity and complex treatment regimen) were integrated to identify both pathways of problem causation (i.e. from personal and environmental determinants, to consequent impact on health and quality of life; Section 4.4.1.3), and pathways of problem rectification (i.e. from the intervention to program objectives and outcomes, to anticipated health and quality of life improvements; Section 4.4.2.2).

Expected cognitions, behaviour and intervention outcomes were identified, and more than 40 evidence-based persuasive messages were developed systematically and mapped to theory-based behaviour change techniques (BCTs, Abraham & Kools, 2012; Abraham & Michie, 2008). In collaboration with a multidisciplinary project planning team, the messages were embedded in an engaging, individual-level, print-based intervention and paired with cohort-appropriate imagery. The final product, entitled 'Who is looking after your eyes?', was piloted widely among stakeholders, including members of the priority population.

As reported in Section 4.4.1.1, a highly engaged group of young adults with T2D remained with the study throughout the entire process, providing input and feedback on all key processes and expressing satisfaction at their involvement. The benefit of involving young adults with T2D was demonstrated when priority population feedback prompted inclusion of more information about treatment options (illustrated in Table 18, Section 4.4.4.2), ensuring an
accurate and relevant resource, which could be used readily in real-world conditions.

The process of formative research and development of empirically and theoretically-grounded psycho-educational materials that are culturally relevant and age-appropriate is consistent with UK Medical Research Council (MRC) guidance for developing health behaviour change interventions (Craig et al., 2008). However, as highlighted in Section 2.3.2, and in the broader literature (Abraham, Southby, Quandte, Krahé, & van der Sluijs, 2007; Lawrenson et al., 2016; Zwarenstein et al., 2014), many health behaviour change leaflets (including those that promote retinal screening uptake) are not developed in a systematic, evidence-based and rigorous manner; nor do they explore barriers or attempt to change the clearly identified, underlying modifiable determinants of health behaviour.

Furthermore, lack of specificity of theory- and evidence-based content in previous work has impeded our understanding of the effective components of various interventions (Michie & Abraham, 2008), including existing interventions to promote retinal screening (Graham-Rowe et al., 2016; Lawrenson et al., 2016; Zhang et al., 2007). In utilising IM as an overarching intervention development framework, and in clearly specifying each step of intervention development, this program of PhD research demonstrated a rigorous approach, providing a clear, replicable procedure upon which future program planners can build (Hoffmann et al., 2014). Further, in clearly specifying the underlying mechanisms for retinal screening uptake and systematically developing age- and contextually-appropriate persuasive messaging linked to evidence-based BCT, with the active
participation of members of the priority population, the ‘Who is looking after your eyes?’ leaflet has since been used to illustrate ‘best practice’ in health behaviour change intervention development (Abraham, 2017).

However, although IM was a useful framework for intervention development, the process was both time and resource intensive; an issue raised across a range of IM-based studies, (Ball, Mushquash, Keaschuk, Ambler, & Newton, 2017; Lloyd, Logan, Greaves, & Wyatt, 2011; Suzuki et al., 2012; Voogt, Poelen, Kleinjan, Lemmers, & Engels, 2014); the implications of which are discussed in Section 6.3.2.3 below.

In summary, development of a high-quality, print-based retinal screening promotion leaflet under real-world conditions, is a novel and valuable contribution to provision of age-appropriate resources for this priority population.

6.1.3 **Objective 3: Evaluate the effectiveness of the intervention in increasing self-reported uptake of retinal screening and improving modifiable behavioural determinants.** Chapter 5 reported the conduct and findings of an RCT evaluation to assess the effectiveness of the ‘Who is looking after your eyes?’ leaflet in increasing self-reported uptake of retinal screening (primary outcome) and improving modifiable behavioural determinants (secondary outcomes). Although the study was ultimately underpowered to detect improvement in the primary outcome, trends were apparent, with a slightly larger proportion of intervention group participants initiating screening compared to their control group counterparts (n=5 and n=3, respectively) in the four-week, post-intervention follow-up period.
In terms of secondary outcomes, the only differences between those in the leaflet intervention group and the control group at follow-up were that the former had a significant improvement in their knowledge of DR. Given that knowledge is a significant barrier to retinal screening, this finding is promising and has the potential to make a contribution to the systematic review currently being conducted by Lawrenson et al. (2016), described in Section 2.1.2. Further, as noted in a meta-synthesis of 62 health behaviour change meta-analyses (Johnson, Scott-Sheldon, & Carey, 2010), health behaviour change interventions typically report small-to-moderate effect, and effect sizes for those that focus on ‘Improving participation in health services’ is typically even lower. As such, the moderate effect size observed in the current study was an encouraging finding.

The improvement in knowledge is consistent with a small review of print-based information specific to screening programs (N=9), which found that the most common significant outcome was increase in knowledge, but not necessarily measurable behaviour (Fox, 2006). This is also consistent with the broader experience of print-based interventions focussing on young people. For example, a leaflet targeting uptake and determinants of sun protection behaviour for young women (N=97, mean age 18±2 years) reported increase in knowledge of skin cancer, but no change in beliefs, or increase in sun protection behaviour (Castle, Skinner, & Hampson, 1999).

In similar circumstances to the RCT reported in this program of PhD research, an evaluation of a condom promotion leaflet designed for secondary school students (N=404, age range: 16-18 years), was underpowered to detect effect on the primary outcome (i.e. self-reported uptake of condom use with new
partner), with the authors suggesting that opportunity to measure effect was curtailed due to high attrition and limited follow-up time. The study reported an increase in previously identified behavioural determinants (e.g. attitudes, beliefs, self-efficacy), but did not measure knowledge directly (Hill & Abraham, 2008).

Knowledge is a crucial factor in individual health behaviour, and a key underlying component of health behaviour and self-management theories (Fisher et al., 2003; Serlachius & Sutton, 2009). Unsurprisingly, knowledge is also a key factor in successful diabetes self-management (Speight & Bradley, 2001), including for uptake of retinal screening (Zhang et al., 2007). As young adults with T2D are under-researched, and arguably one of the most challenging diabetes populations to reach and engage, the findings from the evaluation conducted in this program of PhD research are novel. Further, considering that studies focussing on correlates of health promoting behaviours for young people have found that knowledge is a weaker correlate than social cognitive antecedents, such as attitudes, self-efficacy, risk perception and intentions (Abraham, Krahe, Dominic, & Fritsche, 2002; Bengel, Belz-merk, & Farin, 1996; DiClemente, 1991), the identification of motivational and behavioural skills based factors impacting retinal screening makes an important contribution to our understanding of this priority population.

As noted in Section 2.3.1, previous print-based retinal screening interventions have reported only moderate improvement in retinal screening rates with relative risk (RR) ranging from 1.02 (CI 0.94-1.10) to 1.13 (CI 1.04-1.23), (Burnett et al., 1998; Halbert, Kwan-Moon, Nichol, & Legorreta, 1999; Lafata, Baker, Divine, McCarthy, & Xi, 2002; Prela, Smilie, McInerney, Harwell, &
Helgerson, 2000). Importantly for this program of PhD research, all but Halbert et al. (1999) included people who had previously screened for DR but who were overdue. Further, moderation analyses reported by Prela et al. (2000), (closest in design to the current study), reported that the intervention was not effective for participants who had not screened in the previous two years.

Thus, despite the study being underpowered and the primary outcome not being achieved, the finding that single presentation of an evidence-based leaflet can increase knowledge of DR among those who have never engaged in retinal screening, and who therefore may be resistant to the behaviour (Strutton et al., 2016; Zhang et al., 2007), is promising.

6.1.4 Summary. In summary, this program of PhD research achieved the overall aim of developing and evaluating an evidence-based public health intervention to promote uptake of retinal screening, tailored to the needs and characteristics of young adults with T2D. As no previous research has explored, in-depth, the factors impacting retinal screening behaviour for young adults with T2D and no retinal screening promotion interventions have been developed to address the unique characteristics of the priority population, this novel program of PhD research makes several original empirical contributions.

In identifying factors influencing retinal screening uptake for young adults with T2D, the first study (described in Chapter 3) laid the foundation for an evidence-based health behaviour change intervention. In utilising IM to inform the development of a tailored retinal screening promotion intervention, the second study (described in Chapter 4) not only produced a promising intervention that can be used to promote screening, but also provided a ‘best-
‘practice’ illustration of evidence-based, tailored resource development. Finally, in assessing the effectiveness of the leaflet intervention in a two-arm RCT, the third study (described in Chapter 5), used rigorous, ‘gold standard’ methods for evaluation. While the RCT was ultimately underpowered (compromised by low recruitment and attrition), the study demonstrated that the ‘Who is looking after your eyes?’ leaflet can significantly increase knowledge of DR; and with trends in the expected direction, suggests that a well-designed, print-based intervention (developed with and endorsed by the target group) has the potential to improve key retinal screening facilitators in a priority population at high risk of vision loss from DR, who are traditionally considered ‘hard-to-reach’.
6.2 Implications for Clinical Practice and Health Policy

I've been to [diabetes advocacy organisations information event] ... this year ... and I think when I went there, the one thing I found is that probably 95% of the room comprised of 60-plus year olds. So there was only a handful, literally, 10 people out of 300 that were my age group. Being in that kind of environment felt a bit strange to me.

ID 39, 37 years, diabetes duration 9 years

Young-onset T2D has been described as a complex condition with heightened risk of sub-optimal long-term health outcomes (Wilmot & Idris, 2014). Clinical practice guidelines recommend “comprehensive management [including] early and aggressive control of diabetes complications ... to reduce lifetime risk of morbidity and early death” (Zeitler et al., 2014, p.41). The needs assessment findings reported in this program of PhD research highlighted key differences in psychosocial retinal screening barriers and facilitators between young adults with T2D and their older-onset counterparts (for whom the majority of diabetes information and services are developed), and provided timely evidence that young adults with T2D have a lower than average retinal screening rate when compared to the broader Australian population (72% and 78%, respectively; Foreman et al., 2017). These findings confirm that young adults with T2D represent a demographic ‘pocket’, warranting targeted and tailored health behaviour change intervention, to improve retinal screening rates and reduce the risk of vision loss from DR.

In order to promote optimal health care, including diabetes self-management, ‘best practice’ health behaviour change intervention development requires that interventions “take account of socioeconomic and cultural context
and strengths and skills of target groups ... anticipate barriers to change [and] ensure that ... content is evidence-based” (Abraham, Kelly, West, & Michie, 2009, p.3). Although there have not been any previous retinal screening interventions developed specifically for young adults with T2D (print-based or other formats), recent reviews of other health promotion leaflets targeting young adults and ophthalmic information leaflets demonstrate that content often does not take into account the criteria noted above (Abraham et al., 2002; Abraham et al., 2007; Muir & Lee, 2010).

Health education resources that do not suit the characteristics and literacy levels of the target group not only represent a missed opportunity for inclusion of key persuasive messages, and correspondence with evidence, but they also risk loss of engagement, unmet information needs, and lost opportunity to increase the reader’s motivation or skills to achieve the target behaviour (Abraham & Kools, 2012). Further, they may be counterproductive, including information that may be misunderstood or rejected (Doak, Doak, & Root, 1996) or worse, elicit feelings of stigma or shame (Parikh, Parker, Nurss, Baker, & Williams, 1996). Exemplified by the quotation at the start of this section derived from the current study, and as noted in previous studies (Browne et al., 2013a; Diabetes Australia, 2006; Dunning & Savage, 2013; Savage et al., 2009), young adults with T2D perceive a lack of age-appropriate diabetes self-management services and resources, resulting in loss of engagement and feelings of isolation.

The ‘Who is looking after your eyes?’ leaflet satisfies the criteria outlined by Abraham et al. (2009) and represents a crucial first step in age- and context-
appropriate engagement of young adults with T2D in their diabetes self-management. The leaflet has already had a sustained impact. Since completion of the RCT evaluation in mid-2015, the leaflet has been distributed statewide to all eligible NDSS registrants, periodically reviewed and updated, as per ‘best practice’ (Coulter, Entwistle, & Gilbert, 1999), and is freely available online, on diabetes and eye health websites (Diabetes Victoria; Vision 2020 Australia, 2017b). Furthermore, plans are underway for inclusion of the leaflet in the NDSS starter pack,\textsuperscript{11} a resource which is well-accepted by young adults with T2D (Dunning, Savage, & Dabkowska, 2009).

6.2.1 Implications for clinical practice. Two logical implications for clinical practice proceed from this work. First, given that India and China (both associated with increased risk of young-onset of T2D; Yeung et al., 2014), are represented in the top four countries of birth for Australian immigrants, and that Asian-born immigrants have a lower median age at immigration compared to their European counterparts (35 and 59 years, respectively; Australian Bureau of Statistics, 2016), Australia is very likely to experience increased incidence of young-onset T2D in coming years. Therefore, cultural adaptation and translation of the leaflet resource into the most commonly spoken languages of the priority population is warranted. As non-Australian born members of the priority population were well represented in both the in-depth qualitative and online

\textsuperscript{11}The starter pack is a collection of diabetes self-management and support information sent to all people with diabetes when they are registered on the NDSS (typically at or soon after diagnosis) by their treating practitioner.
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quantitative needs assessment studies (40% in-depth qualitative interviews, 42% quantitative online survey), it is likely that a cognitive debriefing (i.e. active ‘think aloud’ evaluation among members of the cultural group) would be sufficient to ensure comprehension, relevance and engagement for the priority population (Woods et al., 2000).

Second, in addition to DR, young adults with T2D are at increased risk of progression of a range of micro- and macro-vascular complications, highlighting an imperative for the development of a range of diabetes self-management resources tailored to young adults with T2D, in order to engage them in other aspects of diabetes self-management. For example, young adults with T2D have higher prevalence of diabetic peripheral neuropathy compared to similar aged young adults with type 1 diabetes (T1D), (22% vs 7%, respectively; Jaiswal et al., 2017), and concerns have been raised with regard to albuminuria (an indicator of chronic kidney disease) and cardiovascular disease (Al-Saeed et al., 2016; Bjornstad, Cherney, Maahs, & Nadeau, 2016; Deconinck, Mathieu, & Benhalima, 2017; Wilmot et al., 2014).

In summary, this program of PhD research corroborated the findings of earlier studies; that young adults with T2D are a heterogeneous population with complex and specific healthcare needs that are not being met, including for self-management resources (Amed et al., 2014; Browne et al., 2013a; Diabetes Australia, 2006; Dunning et al., 2009; Twigg & Wong, 2015). As concern for the burgeoning population of young adults with T2D has grown, leading clinicians and researchers have called for targeted psychological support and patient empowerment initiatives to promote behaviour change for this priority
population (Song, 2012; Wilmot & Idris, 2014; Zhang & Ning, 2014). The ‘Who is looking after your eyes?’ leaflet represents the first step in the development of evidence and theory-based age-appropriate resources for this priority population. However, there exists a broad imperative to develop a range of self-management resources and education programs for this emerging, heterogeneous population.

6.2.2 Implications for health policy. Retinal screening for the early detection of DR satisfies the criteria for a screening program outlined by the World Health Organisation (Scanlon, 2008; Wilson & Jungner, 1968). Despite the challenges associated with their establishment (Hazin, Colyer, Lum, & Barazi, 2011; Scanlon, 2017), systematic, nationwide retinal screening programs are effective in increasing screening rates and decreasing the frequency of vision threatening DR (Forster et al., 2013; Liew, Michaelides, & Bunce, 2014). Furthermore, the economic case for retinal screening programs is well-established, with systematic programs more cost-effective than opportunistic screening (Javitt & Aiello, 1996; Jones & Edwards, 2010; Raikou & McGuire, 2003). In Australia, cost per participant was considered competitive when 80% coverage is reached (Mitchell & Foran, 2008); in the UK, the current minimum acceptable level is 70%, with 80% diabetes population coverage considered achievable (Moreton, Stratton, Chave, Lipinski, & Scanlon, 2017). Significantly, the review by Raikou and McGuire (2003) singled out younger-aged people with T2D as the main beneficiaries, because “they had the most QALYs (Quality-Adjusted Life Years) to gain” (p.550).
Australia does not currently have a nationally coordinated retinal screening program. However, key stakeholders (Vision 2020 Australia, Diabetes Australia and Centre for Eye Research Australia) have recently proposed a pathway for a coordinated approach, which utilises the NDSS database as a foundation ‘registry’ database (Australian Diabetes Blindness Prevention Initiative; Vision 2020 Australia, 2017a). Should the Australian Diabetes Blindness Prevention Initiative (ADBPI) receive government support, the ‘Who is looking after your eyes?’ leaflet has the potential to be incorporated (in its current format) into coordinated retinal screening promotion initiatives targeting all young adults with T2D who have not screened or who are overdue for DR screening.

Further, the leaflet is just one means of delivering the evidence-based messages developed during this program of PhD research. The identification of effective knowledge-based messages contained in the leaflet enables their use in other formats as prompts and reminders, including “emails and text messages, social and traditional media and channels” suggested by the ADBPI (Vision 2020 Australia, 2017a). This strategy is concordant with the conclusions of systematic reviews of interventions to promote retinal screening, and of strategies to facilitate exposure of young adults to internet-delivered health behaviour change interventions, which noted that the most commonly used, effective strategies were a combination of tailored communication with the use of reminders and incentives (Crutzen et al., 2011; Zhang et al., 2007).
6.3 Future Research

Implications for future research that relate to specific components of the study (e.g. mixed-methods needs assessment, leaflet development, RCT evaluation) have been discussed within each of the relevant chapters. The implications discussed below relate, more broadly, to the entire program of PhD research and fall into two categories: utilisation or adaptation of the ‘Who is looking after your eyes?’ leaflet for other populations at risk of low retinal screening uptake, and lessons learned from this program of PhD research.

6.3.1 Utilisation of the ‘Who is looking after your eyes?’ leaflet as a foundation for other populations at risk of low retinal screening uptake. With the combined benefits of low cost, broad reach, consistency of message and wide acceptance, health promotion leaflets and other printed materials are ideally placed for dissemination of public health messages, and are broadly assumed to represent a cost-effective health behaviour change strategy (Abraham et al., 2007; Fox, 2006). There are several populations at risk of low retinal screening, each of which warrant targeted intervention. Other at risk-populations include: young adults with T1D, those living in socio-economically deprived areas, and individuals from minority ethnic and Indigenous populations (Foreman et al., 2017; Moreton et al., 2017; Paksin-Hall, Dent, Dong, & Ablah, 2013; Shi, Zhao, Fonseca, Krousel-Wood, & Shi, 2014).

As the ‘Who is looking after your eyes?’ leaflet is demonstrably evidence-and theory-based, it has the potential to be used as a foundation for development of similar eye health or other diabetes-complication resources. For example, considering that similar aged younger adults with T1D face the same
life-stage challenges as their T2D counterparts (Arnett, 2000), it is likely that this leaflet could be adapted to suit the young adults with T1D population. Intervention mapping provides clear guidance on the process required for adaption of evidence-based interventions for new populations and settings (Bartholomew Eldredge et al., 2016) and an example is available in the peer-reviewed literature (Highfield et al., 2015).

6.3.2 Lessons learned and recommendations for future research. The challenges associated with recruiting young adults with T2D to the needs assessment studies, and using IM to develop the ‘Who is looking after your eyes?’ leaflet have been discussed in earlier chapters (see Sections 3.6.3, 4.5.1 and 5.6.2, respectively).

This section revisits both issues from a broader perspective, to discuss lessons learned and suggest improvements for future program planners.

6.3.2.1 Recruiting young adults with T2D into research. Historically, it has been challenging to recruit individuals with younger-onset T2D into clinical trials and behavioural research (Browne et al., 2014; Browne et al., 2013a; Nadeau et al., 2016; Nguyen et al., 2014; Walders-Abramson et al., 2016; Zeitler, Chou, Copeland, & Geffner, 2015). Low recruitment rate and high attrition rate have had considerable consequences, including inability to successfully complete clinical trials (Nguyen et al., 2014; Zeitler et al., 2015), lack of power to conduct complex statistical analyses or detect effect (Browne et al., 2014), and reduced generalisability of findings (Zeitler et al., 2015).

Strategies used to boost recruitment and retention for hard-to-reach groups, including for this priority population, have included: leveraging social
media (Valdez et al., 2014); promoting the study via credible sources (Close, Smaldone, Fennoy, Reame, & Grey, 2013); use of monetary and material incentives (Nguyen et al., 2014; Walders-Abramson et al., 2016); collaborative partnerships with clinicians and/or communities (Vangeepuram, Townsend, Arniella, Goytia, & Horowitz, 2016); maintaining consistency of study personnel, establishing rapport with participants and prioritising flexibility of study participation (Leerlooijer et al., 2014; Newby et al., 2017; Nguyen et al., 2014; Walders-Abramson et al., 2016; Wolfers et al., 2012).

Many of the above strategies were utilised for the in-depth qualitative interview study (see Section 3.4.2). However, despite a six-month recruitment period, only 10 young adults with T2D participated, nine of whom responded to Diabetes Victoria postal invitations. Building on this experience, a direct mail out in collaboration with the NDSS was utilised for the quantitative, online survey (see Section 4.4.1.2.2). This strategy was not without precedent, as an earlier study following similar procedure with the same priority population achieved a modest response rate for a postal survey (12%; Browne et al., 2013a). Despite this, only 227 (4%) eligible young adults with T2D completed the baseline survey and only 129 (2%) completed follow-up.

Lessons learned in this program of PhD research reflect the experience of public health researchers working to promote uptake of other health behaviours such as sexual health checks and cancer screening among young adults. These studies have faced the same recruitment, attrition, and engagement challenges experienced in this program of PhD research. Consequently, published evaluation methodologies for uptake of screening or public health activities targeting young
adults are randomised controlled trials (cluster or stepped wedge, underpowered, published as pilot or feasibility studies), or pre-post design, without a control group (Fuller et al., 2015; Reisner et al., 2016; Town et al., 2016; Willis et al., 2018; Wolf et al., 2017).

Consequently, the three key recommendation for future researchers focus on increasing recruitment and engagement and minimising attrition among this priority population. First, there is no guaranteed recruitment pathway for young adults with T2D and the experience of this program of PhD research reinforced earlier findings that promotion via social media, including Facebook, does not necessarily represent a solution, despite wide adoption of the medium by the priority population (Nguyen et al., 2014; Sensis, 2017; Valdez et al., 2014). Importantly, previous research that identified the desire of young adults with T2D for credibility of information source over medium (Diabetes Australia, 2006; Dunning et al., 2009), appears also to be relevant for study recruitment. As such, the endorsement by and involvement of diabetes advocacy organisations (in this case Diabetes Victoria, NDSS and Diabetes Australia) was beneficial. Inclusion of an introductory letter from the diabetes advocacy organisation to their members/registrants immediately established credibility and promoted trust between study participants and organisers. The only drawbacks of this strategy were the potential for recruitment of individuals highly engaged with such organisations (and therefore, potentially, in their diabetes self-management), and ‘study fatigue’ due to the large number of concurrent studies being promoted by the NDSS, which may have contributed to the lower than anticipated response rate (Section 5.6.2).
Second, efforts to maintain a good rapport with participants were valuable in sustaining involvement throughout the mixed-methods needs assessment studies. This was also of crucial importance when involving members of the priority population in development of the leaflet resource. Although interactions with participants did not raise the issue of appropriate boundaries, which have been faced by other studies (Valdez et al., 2014), it was a time-consuming process. Thus, it is recommended that future researchers make sufficient allowance for this necessary activity in their project planning.

Third, although the use of study incentives (described in Section 4.4.1.2), were age-appropriate and not excessive, there was a noticeable spike in study withdrawals after the winners of the technology-based incentive (three iPad minis) were announced at the end of the recruitment period for the quantitative online survey. This suggests that the order of study incentives should have been reversed, so that the most valuable (yet probabilistic) incentive was awarded upon completion of the entire study.

6.3.2.2 Study designs for hard-to-reach populations. In a cautionary note on appropriate study design, the MRC framework suggests that randomisation may be unsuitable if “the changes are very small or take a very long time to appear” (Craig et al., 2006, p.11). Given the experience of this and other trials (Nadeau et al., 2016; Nguyen et al., 2014; Zeitler et al., 2015), there is an imperative to consider alternate study designs and data collection methods for evaluations that focus on young adults with T2D.

Options for randomised and non-randomised study design options were briefly discussed in Section 5.6.3 and two are explored further here, in the
context of greater use of non-randomised study designs for hard-to-reach populations (Zhang et al., 2007). An alternate, non-randomised, qualitative approach is ‘think aloud’ cognitive interviewing (Willis, 2005). The think aloud approach asks interviewees to verbalise their thoughts about a resource as they read it, allowing for detection of patterns or changes in cognitions, using a much smaller sample. In the current context, a think aloud study could recruit a small sample of the priority population who did not have DR and were ‘naïve’ (i.e. had not participated in) to the retinal screening process. The procedure has been utilised successfully to explore how participants evaluate and interpret other print-based screening information materials, and in diabetes self-management (Kelly, Brandom, & Mattick, 2015; Smith et al., 2013). Further, considering that young adults with T1D are the population closest in experience to the priority population in this program of PhD research, this strategy could potentially represent a cost-effective way to evaluate the components of the ‘Who is looking after your eyes?’ leaflet that require adaptation to promote change in cognition in that population.

A second alternate study design and data collection method could utilise the population-based approach adopted by Vision Initiative, which focussed intervention on a specific geographic location (see Section 2.1.1). Effect of a retinal screening promotion leaflet could then be determined via pre-/post-assessment of medical record and ophthalmic data in that locality, which is considered an accurate approach (MacLennan, McGwin, Searcey, & Owsley, 2013), or via comparison of two geographic locations, such as discrete Local Government Areas.
The former design has been used in earlier studies (Zwarenstein et al., 2014), with the obvious benefit being that it circumvents the need to recruit a priority population traditionally considered hard-to-reach. However, without a coordinated retinal screening database, such as the one proposed in Section 6.2.2, this procedure presents other recruitment concerns because it relies on study contact with all GPs and ophthalmologists in the locality. Furthermore, this type of design does not allow for evaluation of the impact of an intervention on behavioural and psychological determinants, which are key factors in understanding the processes underlying health behaviour change (Craig et al., 2008) but not typically collected in registries.

6.3.2.3 Utility of IM in development of ‘best practice’ public health intervention. Interventions underpinned by an evidence base and theoretical constructs are both recommended (Craig et al., 2008; Department of Health, 2004) and overall, more efficacious than those with no explicit theoretical basis (Gage et al., 2004; Hampson et al., 2000). However, such interventions are complex and time-consuming to develop and implement, presenting a considerable challenge to research, clinical and community settings (Leventhal, Weinman, Leventhal, & Phillips, 2008; Song, 2012).

The time and resource-intensive nature of IM (which has variously been described as complex, elaborate, tiresome, expensive, and time consuming; Kok, Peters, & Ruiter, 2017) has implications for the capacity of health services to develop ‘best practice’ resources. Essential yet burdensome activities included the iterative nature of the process, heavy emphasis on process documentation and wide-ranging consultative model, including formation of “at least one”
multidisciplinary planning team comprising a wide range of expertise, such as health practitioners and educators, behavioural scientists (to “link the relevant elements of a given problem to useful theories”, p.59), and representatives from potential implementation and dissemination organisations (Bartholomew Eldredge et al., 2016).

The time and resources required to develop and implement health behaviour change interventions are crucial barriers because health services research is invariably conducted in resource-poor research or clinical environments (Dieppe & Ades, 2008). This issue is of particular relevance to psychosocial and behavioural studies in diabetes, which receive minimal resource allocation in comparison to biomedical research (Jones, Vallis, Cooke, & Pouwer, 2016). The current lack of published evaluations and cost-effectiveness studies for IM-based projects (see Section 2.4.2.2) must also be addressed if the framework is to remain a relevant and appropriate intervention development method (Garba & Gadanya, 2017).

Prudent strategies advanced by others to assist future program planners wishing to maintain IM as a foundation for intervention development, include: a focus on general principles, processes and concepts rather than the minutiae (Gillison et al., 2012), and adaptation of existing, evidence-based health behaviour change programs into new contexts utilising a simplified version of IM, such as IM Adapt (Bartholomew Eldredge et al., 2016; Highfield et al., 2015).
6.4 Strengths and Limitations

This program of PhD research has several strengths and limitations, many of which have been discussed in previous chapters because they relate to the specific study components (e.g. Section 3.6.3, in-depth qualitative interview study; Section 4.5.1, mixed-methods needs assessment and leaflet development; Section 5.6.2, RCT evaluation). The strengths and limitations discussed below relate, more broadly, to utilisation of IM and development of a health behaviour change intervention within a real-world context.

6.4.1 Strengths. An important strength of this study is that the ‘Who is looking after your eyes?’ leaflet was developed and piloted within real-world conditions and with the involvement of young adults with T2D throughout, ensuring that the outcome is compatible with, and tailored to, the developmental stage and life context of the priority population (Abraham, Johnson, De Bruin, & Luszczynska, 2014). In pursuing a rigorous, best-practice development process, the study avoided commonly cited causes of limited effectiveness of previous health behaviour change leaflets.

The appointment of a multi-disciplinary project planning team facilitated involvement of key agency stakeholders (Vision 2020 Australia, Diabetes Victoria, Centre for Eye Research Australia and The Australian Centre for Behavioural Research in Diabetes), ensuring engagement, collaboration and contextual insights across a range of fields (Kok et al., 2017). In-depth exploration of barriers, facilitators and determinants of retinal screening behaviour provided a thorough evidence-base by which to understand the problem and pathways of causation (Abraham & Kools, 2012).
Reduction of vision loss for young adults with type 2 diabetes

Clear mapping of persuasive messaging to behavioural determinants and theory-based BCTs, ensured that the messages contained in the leaflet accurately targeted factors impacting the clearly-specified behaviour (Abraham et al., 2007). Detailed pilot and review, which included consideration of literacy demand, contextual and cultural appropriateness (including piloting with young adults with T2D), ensured that the content was engaging, easily understood, and relevant to both the target behaviour and the priority population (Coulter et al., 1999; Payne, Large, Jarrett, & Turner, 2000). Finally, inclusion of fidelity checks for intervention delivery and/or engagement ensured that the intervention reached the priority population and that the evaluation was accurately conducted (Walton, Spector, Tombor, & Michie, 2017).

6.4.2 Limitations

6.4.2.1 Constraints of predetermined study components. Although there were considerable benefits to conducting the program of PhD research under real-world conditions, each of the predetermined study components (e.g. eligibility criteria, timeline, intervention format and delivery medium, see Section 2.1.1) potentially impacted negatively on the ability of the study to detect effect. For example, strict eligibility criteria were applied (to meet the purpose of the suite of Vision Initiative projects), in order to reach those who were most likely to benefit from the intervention. However, in restricting the priority population to those young adults with T2D who had registered with the NDSS in the previous three years, and in restricting evaluation criteria to those who had not screened for DR, the pool of eligible participants was reduced considerably.
Furthermore, the strict timeline applied to all Vision Initiative projects potentially impacted the ability to detect change during the evaluation phase of the project. By necessity, time to follow-up for the leaflet evaluation was four weeks, a period confirmed as suitable by a ‘dummy’ booking exercise (Section 5.4.3.2). However, the four-week time to follow-up was far shorter than that reported by earlier retinal screening intervention evaluations (see Table 1, Section 2.3.1), and in a meta-analytic review of 57 tailored, print-based health behaviour change interventions (Noar, Benac, & Harris, 2007), with average follow-up time noted as 37 weeks and 23 weeks, respectively.

Given that one of the most salient barriers to retinal screening and other health behaviours for young adults is ‘lack of time’ (Browne et al., 2013a; Burgess et al., 2015; Diabetes Australia, 2006; Savage et al., 2009; Wilmot & Idris, 2014), and that this was the only reason given by study participants for not reading the leaflet, longer follow-up or an additional follow-up period six months later, would have been beneficial. That said, it is well-established that ‘lack of time’ and other practical barriers are often the verbalised reasons for not undertaking an activity for which the individual experiences other psychological barriers. These include denial of risk of diabetes complications, perception of stigma and negative judgement from having a condition usually associated with ‘older’ adults and high rates of diabetes related distress (Browne et al., 2013a; Browne, Ventura, Mosely, & Speight, 2013b; Horigan, Davies, Findlay-White, Chaney, & Coates, 2017; Mulvaney et al., 2006).

Finally, the predetermined nature of both the format and delivery medium potentially limited intervention reach. As described in Section 2.1.1, the
NDSS database primarily records registrant postal addresses and consequently, the intervention was, by necessity, print-based in a format that could be posted to participants at their home address. Although previous research into the education and information needs of young adults with T2D reported the acceptability of printed materials (Savage et al., 2009), greater flexibility of intervention format would have provided opportunity to broaden the reach and sustain message impact. This is particularly relevant for the 18-39 year age group, where utilisation of social media is “almost universal” in Australia (Sensis, 2017).

**6.4.2.2 Impact of small sample size on study design and identification of effective change processes and techniques.** Two principal elements of experimental research design theory are the control of known, potentially confounding variables, and the randomisation of study participants to intervention or control conditions, to determine intervention effect. Although study design was initially planned to uphold both (see Section 5.8.4 for detail of Solomon 4-group design), the design had to be adapted due to small sample size, exposing the study to the potentially confounding influence of question-behaviour effect (McCambridge, 2015).

Small sample size, particularly of those who had never engaged in retinal screening, also limited the ability to evaluate whether change processes were impacted by the leaflet (Abraham, 2012; Moore et al., 2015). Mediation analyses (i.e. evaluation of whether the targeted determinants were changed by the intervention) were conducted in this program of PhD research via assessment of
secondary outcomes (Section 5.5.3.2), and established that the leaflet was successful in improving knowledge of DR, a key screening facilitator.

However, moderation analyses (i.e. evaluation of whether an intervention is differentially successful with sub-groups within the same target population), were precluded by small sample size and consequent lack of power to analyse sub-groups. Given the heterogeneity of the priority population, sub-groups of interest would have been country of birth (e.g. Australian versus non-Australian born) and age, as the range of 18-39 years encompasses a number of life-stage, physical and psychological changes from ‘emerging adulthood’ (18-25 years; Arnett, 2000), to approaching mid-life. A clearer understanding of whether the leaflet intervention was effective for key sub-groups would have contributed to resource planning for this priority population.

Finally, although a limited process evaluation was conducted (see Section 5.4.7), which confirmed that the leaflet was received and read by 86% of intervention group participants, and that key messages were qualitatively recalled (data not reported), predetermined contractual limitations meant that a more in-depth theory-based process evaluation was not conducted. Lack of detailed theory-based process evaluation, which is designed to explore the mechanisms through which specific behaviour change occurs, as well as identify implementation problems (Moore et al., 2015) impeded a deeper understanding of the underlying processes of retinal screening behaviour (Michie & Abraham, 2004).
6.5 Conclusion

This program of PhD research was initiated in response to a well-articulated need for age-appropriate retinal screening promotion resources to reduce risk of vision loss for young adults with T2D. It is the first study to specifically explore factors affecting retinal screening uptake for young adults with T2D, and the first to develop an age-appropriate, evidence-based retinal screening resource tailored to this priority population.

Utilising an approach consistent with the MRC framework on developing complex interventions (Craig et al., 2008), the rigorous, step-by-step intervention development process outlined in Chapter 4 facilitates replication, providing a template for development of theory-based messages for future health behaviour change interventions. Utilising gold-standard RCT evaluation, the leaflet was found to be effective in increasing knowledge of DR, a key retinal screening facilitator. Discussion of leaflet development constraints and limitations within a real-world context allows future researchers to benefit from these learnings and insights (Michie & Abraham, 2004).

Preventing DR in young adults with T2D requires a broad, system-level approach incorporating early multidisciplinary intervention, and a nationally coordinated approach to retinal screening. As the product of a comprehensive, mixed-methods needs assessment, the evidence-based ‘Who is looking after your eyes?’ leaflet has the potential to be incorporated within the proposed nationally coordinated screening program, to enable systematic and targeted promotion of the program to young adults with T2D, and others who have not engaged in retinal screening for the early detection of DR.
6.6 References


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Appendices
Appendix A: List of other works arising from this program of PhD research

The following peer- and non-peer reviewed works (letters to the editor, conference presentations, posters and reports) chronicle the author’s contribution within diabetes, health behaviour change and public health forums.


Conference presentations

• Lake, A. (2015). Engaging young adults with type 2 diabetes in retinal screening: Do they need information, motivation or skills? Invited symposium. ADS-ADEA annual scientific meeting, Adelaide


Conference posters

• Lake, A.J., Browne, J.L., Rees, G., Abraham, C., Speight, J. (2015). Developing tailored messages to reduce the risk of vision loss for adults with younger-


**Non-refereed report**

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Appendix C: In-depth interviews - Participant interview guide (Chapter 3)

Warm up questions

Q. Perhaps we can start with you telling me about what happened when you found out that you had type 2 diabetes. (Prompts: were you initially advised to have eyes examined? By whom? What did it mean to you? Did you do anything about it at the time? Did you follow advice?)

1. On a scale of 0 to 10, how much does your diabetes affect your life? Where 0 is ‘No affect at all’ and 10 is ‘Severely affects my life’

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Can you please tell me why you nominated ____________________________? Why did you pick x and not 0? ____________________________ Why did you pick x and no 10? ____________________________

2. On a scale of 0 to 10, where 0 is ‘Not at all confident’ and 10 is ‘Very confident’, how confident are you that you can take care of your diabetes in the longer term?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
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<th>10</th>
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<tbody>
<tr>
<td>Not at all confident</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Very confident</td>
</tr>
</tbody>
</table>

Can you please tell me why you nominated ____________________________? Why did you pick x and not 0? ____________________________ Why did you pick x and no 10? ____________________________

3. Thinking about diabetes in the longer term, what is it that concerns you the most? (prompt: complications, greatest fear?)

________________________________________________________________

4. I am going to list 5 possible complications of diabetes. Please rate in order of concern to you:

- Nephropathy (kidney damage)
- Retinopathy (vision loss)
- Heart disease
- Amputation (due to nerve damage)
- Stroke

What was your reason for choosing ___ as most concern? ____________________________

What was your reason for choosing ___ as least concern (ie: 5)? ____________________________

Interviewer: I would like to focus the rest of the questions on one area of long term care, which is care of your eyes and your vision

Knowledge

5. Are you aware of a connection between diabetes and eye health? If Y: in your own words, can you please tell me what it is? ____________________________

Optimism
6. Do you think that you are likely to experience vision problems due to diabetes? Can you tell me why?

Knowledge

7. Have you previously heard of diabetic retinopathy? If Y: in your own words, can you please tell me what it is?

Interviewer: provide brief, simple explanation of retinopathy, if appropriate

8. Do you know of anything that a person can do to reduce their risk of getting retinopathy, or of slowing its progress? If Y: in your own words, can you please tell me?

9. I am going to list 5 things that people do, to lower the risk or slow the progression of diabetic retinopathy in the longer term. Please rate in order of importance to you.

☐ Keeping HbA1c levels in target
☐ Keeping blood pressure in target
☐ Having regular eye examination
☐ Keeping cholesterol at target
☐ Keep a regular check on blood glucose levels

What was your reason for choosing ___ as most important (ie: 1)?
What was your reason for choosing ___ as least important (ie: 5)?

Interviewer: “I would like to focus most of the rest of the questions on having regular eye examinations. These eye exams are usually done by putting drops in your eyes, which dilate your pupil. A photo is then taken of the inside of your eye, to look for damage to your retina. The rest of the questions will be about this kind of eye exam. Some of the questions may sound repetitive, but please answer all questions to help us best understand your point of view.

Beliefs about consequences

10. What are the positive benefits to having eye exams?

Are there are any negatives or ‘down sides’ to having eye exams? Does one outweigh the other?

Reinforcement

11. (If previous eye exam) Did the experience of having an eye examination make it more or less likely that you would have another one in the future? Why?

Beliefs about consequences

12. What do you expect will happen immediately after having an eye examination? (Hypothetically) if you were diagnosed with DR, how do you think you would feel?
13. What do you expect will happen if you don’t have regular eye examinations?

**Knowledge**

14. Do you know the recommended target for blood glucose (HbA1c) to prevent complications like retinopathy?

[Interviewer: HbA1c is an indicator of a patient’s individual control over blood glucose levels in the past 90-120 days. [For patients with diabetes, the HbA1c target should be less than 7%. Every 1% reduction in HbA1c lowered the risk of DR by 30–40%]

15. Do you know the recommended target for blood pressure to prevent complications like retinopathy

[Interviewer: the target for systolic blood pressure should be less than 130 mmHg or 130/80 mmHg]

16. Do you know of any recommendations or guidelines that say how often people with diabetes should have their eyes examined? If Y: please describe.

**Skills, Knowledge**

17. Can you please describe how you would go about getting an eye examination?

**Social/Professional Role and Identity**

18. Are you comfortable with people knowing that you have type 2 diabetes? How did people react when you told them? Is there anyone you wouldn’t want to know that you have diabetes?

19. What does having eye examinations mean to you? (Prompt: what kind of person are they?)

20. Do you belong to any diabetes support groups or forums? (Prompt for full list)

**Social Influence**

21. Have you been prompted by someone to have an eye examination? (Prompt: for full list) What was your response?

22. If anyone could influence your decision to have an eye examination, who would it be? (Prompt: for full list) Why would their views influence you?

23. Has anyone you know had an eye examination for DR? How did that make you feel?
24. Do you know of anyone who has experienced vision problems or lost their vision because of diabetes or diabetic retinopathy? How does that make you feel?

Knowledge
25. What steps would you take if you did notice changes in your vision (spots or blurred vision)?

Goals
26. Considering your other priorities, on a scale of 0 to 10, with 0 being ‘not at all important’ 10 being ‘very important’, how important is it for you to maintain your current vision?

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<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>Not at all important</td>
<td>Very important</td>
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</table>

(If not 10) What are higher priorities and why?

Intentions
27. Considering your other competing priorities, on a scale of 0 to 10, with 0 being ‘not at all likely’, and 10 being ‘extremely likely’, how likely is it for you to have regular eye examinations when they are next due?

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<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all likely</td>
<td>Extremely likely</td>
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</table>

(If not 10) What are higher priorities and why?

[Interviewer to state: the major benefit of regular eye examinations is early detection of DR before people experience symptoms of vision loss. Once DR is detected, treatment to slow the progression of the condition can begin.]

28. Now that I have explained the benefits of eye examinations, on a scale of 0 to 10, where 0 is ‘not at all likely’ and 10 is ‘extremely likely’, how likely are you to have an eye examination when it is next due?

<table>
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<tr>
<th>0</th>
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<tr>
<td>Not at all likely</td>
<td>Extremely likely</td>
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</tbody>
</table>

If the two values are different: explore Why? (Prompt: for detail)

Beliefs about capabilities
29. One a scale of 0 –10, where 0 is ‘not at all confident’ and 10 is ‘very confident’, how confident are you that you can talk to your GP or diabetes educator about eye examinations?

<table>
<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td>Very confident</td>
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</table>

What makes it easy/hard? What do you think would help you to overcome these problems?

Emotion
30. Can you please imagine/think back to, receiving a reminder for your regular eye examination, what feelings would you/did you have?
31. Can you please imagine/think back to when you are having an eye examination, what thoughts or feelings would you/did you, have?

32. Please imagine the time immediately after you have an eye examination, what thoughts or feelings do you have?

33. One a scale of 0 – 10, where 0 is ‘not at all concerned’ and 10 is ‘extremely concerned’, do thoughts of vision loss worry or concern you?

<table>
<thead>
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<th>7</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Not at all concerned</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Extremely concerned</td>
</tr>
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</table>

Interviewer to explore

**Behavioural regulation**

34. Eye examinations don’t have to be done as often as other diabetes self-management tasks, such as taking medication or checking blood glucose. If you want to have an eye examination, how do you think you will remember (or remind yourself)? *(Prompt: for detail)*

**Memory, attention and decision processes**

35. Have you ever forgotten, or delayed, an eye examination when it was due? If Y: do you know why? *(Prompt for detail)*

36. Making the decision to have an eye exam:
   If previously had an eye exam: Please step me through how you made the decision to have an eye examination?
   If not previously had eye exam: Did you consciously decide against going for an eye exam? What went through your mind when you made that decision? *(Prompt: Please step me through thought process)*

**Environmental context and resources**

37. Sometimes our plans are hindered by things outside of our control. What things, outside of your control, could make it harder for you to have regular eye exams? *(Prompt: list)*
   What things could make it easier? *(Prompt: list)*

38. How/where do you get information regarding diabetes management? *(Prompt: What have you found useful? Preferred format? Suggest improvements)*

39. How/where do you get information regarding eye examinations and diabetic eye conditions? *(Prompt: What have you found useful? Preferred format? Suggest improvements)*

**Closing**

Thank you very much for taking part in our study. Is there anything else about this topic that you would like to mention?
Appendix D: Online survey - Baseline (phase 1)

Instructions: Please complete this short questionnaire which asks about you and your background. All responses are confidential; please select the option that best suits your situation.

1. What is your gender?
   ☐ Woman  ☐ Man  ☐ Prefer not to say

2. What age were you when you were diagnosed with type 2 diabetes? ____________(years)

3. What is your postcode? ______________

4. Were you born in Australia?
   ☐ Yes  ☐ No, I was born overseas (please state) ______________

5. Do you identify as Aboriginal or Torres Strait Islander?
   ☐ Yes  ☐ No

6. What ethnic group do you identify with the most?
   ☐ Australian  ☐ Other (please state) ______________

7. What is the main language you speak at home?
   ☐ English  ☐ Other (please state) ______________

8. What is the highest qualification you have completed?
   ☐ No formal qualifications  ☐ Trade / apprenticeship (eg. Hairdresser, Chef)
   ☐ Primary school  ☐ Certificate / diploma
   ☐ High school to Year 10 (or University degree equivalent)
   ☐ High school to Year 12 (or Higher University degree (Grad Dip, Masters, PhD))

9. Which of the following best describes your current employment?
   ☐ Paid full-time work  ☐ Student  ☐ No paid work
   ☐ Paid part-time work  ☐ Retired  ☐ Other (please state) ______________

10. What is your total household income (before tax)?
   ☐ Up to $18,200  ☐ $18,201 – $37,000
11. Which of the following best describes your current relationship status?
   □ Married/De Facto   □ Separated/Divorced   □ Single
   □ In a steady relationship   □ Widowed   □ Other (please state)

Instructions: This section asks about your health, your general diabetes knowledge and self-management activities. Please select the option that you think is correct, but don’t spend too long on any question.

12. How do you currently manage your diabetes? (Select all that apply)
   □ Diet and physical activity (lifestyle only)
   □ Blood glucose-lowering tablets (e.g. Metformin)
   □ Non-insulin injectable (e.g. Byetta)
   □ Insulin injections
   □ Insulin pump
   □ Other: __________________________

13. The HbA1c or haemoglobin A1c test is:
   □ The fasting blood glucose test that you do in the mornings
   □ A measure of your average blood glucose over the last 2-3 months
   □ The blood glucose monitoring that you do throughout the day
   □ Not sure

14. What is the HbA1c goal for most people with diabetes?
   □ Less than or equal to 7%
   □ Less than or equal to 10%
   □ It doesn’t matter if you are on medication
   □ Not sure

15. What is the blood pressure goal for most people with diabetes?
   □ As low as possible
   □ 130/80 or lower
   □ It doesn’t matter if you are on medication
   □ Not sure

16. Have either of your parents, or any of your brothers or sisters been diagnosed with type 2 diabetes?
   □ Yes    □ No    □ Don’t know

17. Do you currently have any of the following health or medical conditions?
   □ Cardiovascular disease (heart disease)   □ Cerebrovascular disease (stroke)
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

- Peripheral vascular disease (arterial disease)
- Polycystic ovary syndrome
- High blood pressure (hypertension)
- Sleep apnoea
- High cholesterol (triglycerides/lipids)
- Diabetic retinopathy (eye disease)
- Sexual dysfunction
- Peripheral neuropathy (nerve damage)
- Nephropathy (kidney damage)
- Something else associated with diabetes? (please state)

18. Since you were diagnosed with diabetes have you had:
   - Your cholesterol checked?
   - Your blood pressure checked?
   - Your average blood glucose (HbA1c) \(^1\) checked?
   - Your kidney function checked because of your diabetes?
   - Your eyes examined because of your diabetes?
   - Your feet checked because of your diabetes?

Response options for each:
- Yes
- No
- Not sure

If Yes, how long ago? _________________(months)

What was the last reading (%) _________________

Don’t remember

Instructions: This section asks how you’re feeling in general about living with and managing diabetes. There are no right or wrong answers, so please select the option that you think is correct and don’t spend too long on any question. For the following questions, please select the number that best corresponds to your views.

19. How much does diabetes affect your life?
   0 1 2 3 4 5 6 7 8 9 10
   No affect at all <———> Severely affects my life

20. How long do you think your diabetes will continue?
   0 1 2 3 4 5 6 7 8 9 10
   A very short time <———> Forever

21. How much control do you feel you have over your diabetes?
   0 1 2 3 4 5 6 7 8 9 10
   Absolutely no control <———> Extreme amount of control

22. How much do you think your treatment can help your diabetes?
   0 1 2 3 4 5 6 7 8 9 10
   Not at all <———> Extremely helpful

23. How much do you experience symptoms from your diabetes?
   0 1 2 3 4 5 6 7 8 9 10
No symptoms at all ← Many severe symptoms

24. How concerned are you about your diabetes?
0 1 2 3 4 5 6 7 8 9 10
Not at all concerned ← Extremely concerned

25. How well do you feel you understand your diabetes?
0 1 2 3 4 5 6 7 8 9 10
Don’t understand at all ← Understand very clearly

26. How much does your diabetes affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)
0 1 2 3 4 5 6 7 8 9 10
Not at all affected emotionally ← Extreme affected emotionally

Instructions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and select the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle “1.” If it is very bothersome to you, you might circle “6.”

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Not a Problem</th>
<th>Moderate problem</th>
<th>Serious problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling overwhelmed by the demands of living with diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling that I am often failing with my diabetes regime.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Over the past 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</table>

Thank you for completing the questionnaire. We will contact you by email when the next stage is ready. Would you like to leave a comment about any part of the study so far?
Appendix E: Online survey - Baseline (phase 2)

Instructions: Many of the questions in this survey use of rating scales with either 5 or 7 options. For each question, please select the number that best describes your opinion or experience.

As you go through the questionnaire, you may notice that some of the questions are similar to others; this is because we are keen to understand your diabetes self-management from a number of perspectives.

We are going to start with some general questions about diabetes.

1. Which of the following senses can be damaged by diabetes?
   (Select all that apply)
   - Vision
   - Hearing
   - Touch
   - Taste
   - Smell
   - All of the above
   - Don’t know / Not sure

[Qualtrics survey flow instruction: If Vision selected]
1a. Where did you learn that diabetes affects eye health? (Select all that apply)
   - My health professionals (e.g. doctor, diabetes nurse educator, endocrinologist)
   - My pharmacy or chemist (in person or via mailed catalogue)
   - Printed information (poster/leaflet) or online health information (e.g. Better Health Channel)
   - Social media (e.g. facebook, twitter, blogs, Pintrest, tumblr)
   - Media campaign (e.g. radio, TV, newspaper)
   - My pathology centre (where I have my blood tests done)
   - My family, friends or work colleagues
   - Diabetes organisations (e.g. Diabetes Australia), National Diabetes Services Scheme
   - Other (please state): ________________________________
**Instructions:** The next question lists five possible complications of diabetes. Not everyone with diabetes develops these complications but we would like to know which concern you the most.

2. **How worried or concerned are you about each of the following possible diabetes complications?**

<table>
<thead>
<tr>
<th></th>
<th>Not at all concerned</th>
<th>Slightly concerned</th>
<th>Moderately concerned</th>
<th>Very concerned</th>
<th>Extremely concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney damage (nephropathy)</td>
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</tr>
<tr>
<td>Eye damage (retinopathy)</td>
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<tr>
<td>Heart disease</td>
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<tr>
<td>Stroke</td>
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<tr>
<td>Nerve damage (neuropathy)</td>
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</table>

**Instructions:** Please note: from this point onwards, we refer to ‘diabetic retinopathy (DR)’ and ‘eye health checks’. The next questions are about your knowledge of diabetes complications, such as diabetic retinopathy (DR) and eye health checks. Please answer each question to the best of your ability (but do not look up any answers).

*Definition: Diabetic retinopathy is a complication of diabetes that damages blood vessels at the back of the eye. If untreated it can cause vision loss. An eye health check is usually done by an optometrist or eye specialist who will check the blood vessels at the back of your eye for signs of diabetes-related eye damage. They do this by taking a photo or using a lamp and they may use eye drops to dilate your pupil.*

3. **Since you were diagnosed with diabetes have you been advised to have your eyes examined to check your eye health?**

- [ ] Yes
- [ ] No
- [ ] Don’t know / Not sure

[Qualtrics survey flow instruction: If yes selected]

3a. **Who advised you to have your eyes examined to check your eye health?**

(Select all that apply)

- [ ] My health professionals (i.e. doctor, diabetes nurse educator, endocrinologist)
- [ ] My pharmacy or chemist (in person or via mailed catalogue)
- [ ] My family, friends or work colleagues
- [ ] No one advised me to have my eyes examined to check my eye health
- [ ] Other (please state): ____________________
4. Which health professional do you think is most likely to do an eye health check for DR? (Select one)

- General practitioner (doctor)
- Diabetes nurse educator
- Optometrist
- Endocrinologist
- Don't know / Not sure

5. When should a person with diabetes have their first eye health check for DR? (Select all that apply)

- When they are first diagnosed with diabetes
- When they notice changes or problems with their vision
- If they regularly have blood glucose levels above the target recommended by their doctor
- When they are advised by their doctor
- Once they have had diabetes for longer than 10 years
- When they start taking tablets to treat their diabetes
- When they start taking insulin to treat their diabetes
- Once they are over 40 years of age
- All of the above
- Don't know / Not sure

6. If a previous eye health check showed their eyes to be healthy, a person with diabetes should have eye health checks for DR: (Select one)

- at least every 6 months
- at least every 12 months
- at least every 2 years
- at least every 3 years
- Don't know/ Not sure

Instructions: The next set of questions asks about your knowledge of DR and what you can do to reduce your risk of developing the condition. As before, we want to understand your current knowledge so please answer each question without referring to any information sources.

7. Please indicate whether you think that each of the following statements about DR are True, False, or whether you're not sure.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
<th>Don't know / Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least 1 in 4 people with type 2 diabetes have DR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR can cause vision loss or blindness</td>
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</tbody>
</table>
REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

DR can develop without symptoms
DR is influenced by high blood pressure
DR is influenced by high cholesterol
DR is influenced by high blood glucose
DR is treatable if detected early via an eye health check
DR is more likely to develop the longer you have diabetes

8. In the EARLY STAGES of DR, people can experience: (Select all that apply)
- blurry vision
- pain or discomfort in the eyes
- blood shot eyes
- itchy eyes
- spots or floaters in their vision
- loss of vision
- no symptoms at all
- All of the above
- Don't know / Not sure

9. What do you think is the HbA1c target to reduce the risk of DR? (Select one)
- Less than or equal to 7%
- Less than or equal to 10%
- It doesn't matter if you are on medication
- Don't know / Not sure

An HbA1c check is a blood test which provides an overall picture of average blood glucose levels over the past 3 months

10. What do you think is the blood pressure goal to reduce the risk of DR? (Select one)
- As low as possible
- 130/80 or lower
- It doesn't matter if you are on medication
- Don't know / Not sure
Instructions: The next questions are about your personal opinions on DR and eye health checks. There are no right or wrong answers; we are interested in your point of view, so please don’t take too much time on any one question or look up answers as you go. Occasionally the questions may seem repetitive, but please answer them all because we are trying to understand your views from different perspectives.

11. How much do you agree or disagree with these three statements about eye health checks for DR?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neither agree nor disagree</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I plan to attend an eye health check in the next four weeks OR when it is next due</td>
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</tr>
<tr>
<td>I will make an effort to have an eye health check in the next four weeks OR when it is next due</td>
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</tr>
<tr>
<td>I intend to have an eye health check in the next four weeks or when it is next due</td>
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</tbody>
</table>

12. Who do you believe is at risk of developing DR? (Select one only)

- Only people with type 1 diabetes
- Only people with type 2 diabetes
- Only people who use medications such as tablets or insulin to treat their diabetes
- Only people who have had diabetes for more than 10 years
- All people with diabetes
- Don’t know / Not sure
13. How much do you agree or disagree with these statements about eye health checks for DR?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Don’t know/not sure</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family/close friends would approve of me attending an eye health check in the next 4 weeks OR when it is next due</td>
<td></td>
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<tr>
<td>My health professionals would approve of me attending an eye health check in the next 4 weeks OR when it is next due</td>
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<tr>
<td>Most people I know with diabetes have regular eye health checks</td>
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</tr>
</tbody>
</table>

14. How much do you agree or disagree with each response?

For me to have an eye health check for DR in the next four weeks OR when it is next due would be:

<table>
<thead>
<tr>
<th>Response</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither disagree</th>
<th>agree</th>
<th>nor Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>...a good idea</td>
<td></td>
<td></td>
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<tr>
<td>...unpleasant</td>
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<tr>
<td>...wise</td>
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<tr>
<td>...difficult</td>
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<tr>
<td>...frightening</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>...unnecessary</td>
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</tr>
</tbody>
</table>
### REDUCING RISK OF VISION LOSS FOR YOUNG ADULTS WITH TYPE 2 DIABETES

14. For me to have an eye health check for DR in the next four weeks OR when it is next due would be....(Cont.)

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither disagree</th>
<th>agree</th>
<th>nor</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>...important</td>
<td></td>
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<tr>
<td>...beneficial</td>
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<td></td>
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<tr>
<td>...comfortable</td>
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<td></td>
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<tr>
<td>...empowering</td>
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</tr>
</tbody>
</table>

15 How much do you agree or disagree with these statements?

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neither nor disagree</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe I will develop DR due to my diabetes</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I believe I will develop vision problems due to my diabetes</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I expect to be diagnosed with DR at my next eye health check</td>
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</tr>
<tr>
<td>I believe I can reduce my risk of vision problems if I manage my diabetes well</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
16. How much do you agree or disagree with each response? If I did NOT have an eye health check, I would feel.....

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neither agree nor disagree</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>...indifferent?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>...concerned?</td>
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<td></td>
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<tr>
<td>...fearful?</td>
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<tr>
<td>...worried?</td>
<td></td>
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<td></td>
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<tr>
<td>...regretful?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>...guilty?</td>
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</tr>
</tbody>
</table>

**Instructions:** Next are some questions which ask about your confidence or ability to have eye health checks to check for signs of DR. As before, there are no right or wrong answers, so please select the option that best fits your experience / situation and don’t spend too long on any one question.

17 How confident are you that you ...

<table>
<thead>
<tr>
<th></th>
<th>Not at all confident</th>
<th>all</th>
<th>Slightly confident</th>
<th>Moderately confident</th>
<th>Confident</th>
<th>Extremely confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>....know what steps you can take to reduce the risk of developing DR?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>....can talk to your doctor about your eye health?</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>....will have regular eye health checks?</td>
<td></td>
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</tr>
<tr>
<td>....know how to make the appointment for an eye check?</td>
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<td></td>
</tr>
</tbody>
</table>
17. How confident are you that you ...(Cont.)

<table>
<thead>
<tr>
<th></th>
<th>Not at confident</th>
<th>Slightly confident</th>
<th>Moderately confident</th>
<th>Confident</th>
<th>Extremely confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>....can find the time to attend an eye health check in the next four weeks OR when it is next due?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>....will remember to have an eye health check in the next four weeks OR when it is next due?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>....will mention that you have diabetes when you make the eye check appointment?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>....will attend the eye health check that you have booked?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>....can reschedule the eye health check to a different time or day if needed?</td>
<td></td>
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</tr>
<tr>
<td>....can resume your normal activities immediately after the eye health check?</td>
<td></td>
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</tr>
<tr>
<td>....can afford to pay for the eye health check, if there is a charge?</td>
<td></td>
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</tr>
</tbody>
</table>
[Qualtrics survey flow instruction: next questions are for ‘unengaged’ study participants only]

18. Since you completed the last yourSAY questionnaire, have you had an eye health check?
   - Yes
   - No

18a. If you haven’t had an eye check yet, can you tell us the main reasons for not having one? (Select up to three reasons)
   - I didn’t receive a reminder/my doctor didn’t tell me to have one
   - I couldn’t afford it
   - I didn’t know that regular eye checks were important
   - I forgot to make an appointment
   - I forgot to attend the appointment
   - I was concerned that there would be something wrong with my eyes
   - Eye health checks are low on my list of priorities
   - I was away (e.g. on holidays or with work)
   - I haven’t noticed any changes to my vision
   - I don’t like to think about my diabetes
   - I didn’t have time
   - I felt tired or unwell
   - Other reason (please state):__________________

Instructions: This section asks about your general mood and how you feel about living with diabetes. There are no right or wrong answers, so please select the option that best fits your experience / situation and don’t spend too long on any one question. Over the past two weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Feeling down, depressed or hopeless?</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are two potential problem areas that people with diabetes may experience.

Consider the degree to which each of the two items may have distressed or bothered you DURING THE PAST MONTH and select the appropriate number. Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle “1.” If it is very bothersome to you, you might circle “6.”

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Not a Problem</th>
<th>Moderate problem</th>
<th>Serious problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling overwhelmed by the demands of living with diabetes.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Feeling that I am often failing with my diabetes regime.</td>
<td>1 2 3 4 5 6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire.

[Qualtrics survey flow instruction: next statement for ‘intervention group’ study participants only] The information that you have provided will be used to develop a leaflet about diabetes self-management which we will post to you in March 2015.

[All participants] We also welcome your feedback; please write any comments into the box below: