

# Adults with young-onset type 2 diabetes: Exploring factors affecting retinal screening uptake for diabetic retinopathy

Lake AJ<sup>1,2</sup>, Browne JL<sup>1,2</sup>, Rees G<sup>3,4</sup>, Speight J<sup>1,2</sup>

1. The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, Australia; 2. School of Psychology, Deakin University, Burwood, Victoria, Australia; 3. Centre for Eye Research Australia, Royal Victorian Eye and Ear Hospital, East Melbourne, Australia; 4. Department of Ophthalmology, Melbourne University, Parkville, Victoria, Australia.



## Background

- Early onset of type 2 diabetes (T2D) is an independent risk factor for the development of diabetic retinopathy (DR)<sup>1</sup>, a leading cause of blindness in working age adults<sup>2</sup>.
- Eye examinations are essential in detecting diabetic retinopathy. Once detected, timely treatment can significantly reduce the risk of vision loss<sup>2</sup>.
- Despite this, young adults with diabetes are more than three times more likely not to attend eye examinations than their older counterparts<sup>3</sup>.
- To date, there have been no Australian studies focusing on factors affecting uptake of eye examinations for young adults with T2D.
- There is a need for evidence based eye health resources tailored to young adults with T2D.

## Aim

- The qualitatively explore barriers and enablers to retinal screening uptake for young adults with T2D using the theoretical domain framework (TDF)<sup>4</sup>.
- This study is the first step in the development of a tailored psychoeducational retinal screening leaflet.

## Method

### Study Design

- A semi-structured interview guide was developed based on the TDF, a validated, consensus-based framework to systematically explore individual determinants of specific behaviours.
- 542 Diabetes Victoria members with T2D, aged 18-39 years were invited to participate.
- Semi-structured, in-depth interviews were conducted by phone in Sep-Dec 2013 (average 56 minutes). Interviews were audio-recorded and transcribed in full.

### Interview guide

- Existing literature on barriers/enablers was reviewed and mapped onto TDF domains.
- 13 behaviour change and/or TDF experts completed an online validation exercise, nominating which TDF domains each interview guide item represented.
- Items with low reviewer/TDF domain correspondence were reviewed by consensus and re-written or discarded.

### Analysis

- Using framework analysis, TDF behaviour change domains were compared based on retinal screening behaviour, highlighting barriers and enablers to the activity (see Table 1).

### Participants

- Ten Australian adults with early-onset T2D (2% response rate).
- Five (50%) had engaged in eye examinations since their diabetes diagnosis.
- Average age: 33.4 ± 2.6 years.
- Average duration of diabetes: 3.7 ± 5.1 years.
- Gender was equally distributed (5 female, 5 male).
- No participants reported a diagnosis of DR

*“The increasing frequency of type 2 diabetes in youth... is the most disturbing and worrisome aspect of the current diabetes epidemic”<sup>6</sup>*

*Dr. William Cefalu, Editor-in-Chief of Diabetes Care*

**Table 1: Theoretical Domain Framework themes and participant quotes**

Barriers	
Knowledge	“I would like to know more details about the retinopathy and how diabetes affects it and any timeline on how it’s going to progress with the diabetes. If he (GP) had told me that sometimes even before the (DR) diagnosis there could be retinopathy, that would definitely have an influence.” [ID #31 No eye exam]
Beliefs about capabilities	“You hear stories about... complications, and then the deeper you dig... they’re the ones who they’ve eaten the donuts every day and haven’t been taking an active sort of control over it...” [ID #36 No eye exam]
Social identity	“I feel a bit weird saying it because I’m so young and because I’m very, very self-conscious about my weight. I’m not huge, I think I’m 10 or 15 kg overweight and I think there’s a bit of an idea people have about diabetics and being fat.” [ID #38 No eye exam]
Emotion	“I’ve been to a Living Well with Diabetes event.....the one thing I found is that probably 95% of the room comprised of 60+ 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 Yes eye exam]
Environmental context and resources	“I was scared of what damage was done, I was scared of what would have to be done or if anything could be done, if there was damage. I was scared of losing my (driving) license, I mean that would really leave me in a pickle. Just scared I suppose of confronting the fact that my eyesight could be permanently damaged..... being confronted with what’s there.” [ID #32 No eye exam]
Enablers	
Social influence	“My wife (is) always encouraging me, she always reminds me. She’s always asking “are you due for an eye check. Have you done your eye check?” [ID #34, Yes eye exam]
Procedural knowledge	“I would arrange an eye check by going to my diabetes educator, or my doctor, and asking if there was a particular doctor in Geelong....that deals with the type of test that is required. If there wasn’t a particular doctor, just...explaining to the staff at the optometrist, and asking for the right kind of test.” [ID #41 No eye exam]
Reinforcement	“It was actually quite fun. I don’t know why I put it off. I was really scared going in but definitely not now. I’m not fazed by it at all. The thought that I can control this is quite reassuring.” [ID #32 No eye exam at start of study]
Beliefs about consequences	“I always think ‘If I don’t go, I won’t know’; but then I want to know because it could be worse next time.” [ID #40, Yes eye exam]

## Results

- All participants placed a high value on preserving their vision and expressed high intentions to have an eye examination.
- Five TDF domains were highlighted as barriers to retinal screening:
  - ◊ Lack of knowledge/awareness of DR and eye examinations (*Knowledge*)
  - ◊ Misconceptions regarding risk factors for DR (*Beliefs about capabilities*)
  - ◊ Perceptions of stigma and lack of engagement with existing diabetes support services (*Social identity*)
  - ◊ Fear of eye examination or outcome (*Emotion*)
  - ◊ Multiple demands on time and finances resulting in a lack of prioritisation of health care (*Environmental context and resources*)
- Four TDF domains were highlighted as enablers to retinal screening:
  - ◊ Support from family/friends (*Social influences*)
  - ◊ Knowledge of how to arrange an eye examination (*Procedural knowledge*)
  - ◊ Expectation of positive outcomes/proximal rewards (*Reinforcement*)
  - ◊ Anticipated regret if no eye examination (*Beliefs about consequences*)

## References

1. Wong J, et al. Timing is everything: age of onset influences long-term retinopathy risk in Type 2 diabetes, independent of traditional risk factors *Diabetes Care* 2008; 31(10): 1985-1990.
2. Fong DS, et al. Retinopathy in Diabetes *Diabetes Care* 2004; 27 (Suppl 1): S84-S87.
3. Orton E, et al. Equity of uptake in a diabetic retinopathy screening programme in a geographically and socio-economically diverse population *Public Health* 2013; 127(9): 814-821.
4. Cane J, et al. Validation of the theoretical domains framework for use in behaviour change and implementation research *Implementation Science* 2012; 7(1): 37.
5. Zeitler P, et al. Clinical trials in youth-onset type 2 diabetes: needs, barriers, and options *Current Diabetes Reports* 2015; 15(5): 1-8.
6. Cefalu, TW “TODAY” reflects the changing “faces” of type 2 diabetes, *Diabetes Care* 2013; 36(6): 1732-1734.

## Conclusion

- This elicitation research provides in-depth data on the factors affecting uptake of retinal screening for this under-researched group who are at risk of early development and rapid progression of DR.
- This study demonstrated that multiple psychological, social and environmental factors affect retinal screening uptake for young adults with T2D.
- The small sample size is indicative of the challenges associated with engaging young adults with T2D<sup>5</sup>.
- The TDF is a suitable foundation for identifying behaviour change domains associated eye examination behaviour.
- These domains can be targeted in an eye health and retinal screening health promotion leaflet.
- A larger study is required to quantify the cognitive and psychosocial determinants of retinal screening and provide baseline data for a subsequent evaluation.



## Enquiries

Amelia Lake: [alake@acbrd.org.au](mailto:alake@acbrd.org.au)

## Acknowledgements

This project is a designated Vision Initiative activity  
We thank the study participants for sharing their time and insights regarding diabetes and eye health