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# Barriers and enablers to diabetic retinopathy screening: a cross-sectional survey of young adults with type 1 and type 2 diabetes in the UK

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## ABSTRACT

**Introduction** Diabetic retinopathy screening (DRS) attendance in young adults (YAs) is consistently below recommended levels. The aim of this study was to identify barriers and enablers of DRS attendance among YAs in the UK living with type 1 (T1D) and type 2 diabetes (T2D).

**Research design and methods** YAs (18–34 years) were invited to complete an anonymous online survey in June 2021 assessing agreement with 30 belief statements informed by the Theoretical Domains Framework (TDF) of behavior change describing potential barriers/enablers to DRS.

**Results** In total, 102 responses were received. Most had T1D (65.7%) and were regular attenders for DRS (76.5%). The most salient TDF domains for DRS attendance were ‘Goals’, with 93% agreeing that DRS was a high priority, and ‘Knowledge’, with 98% being aware that screening can detect eye problems early.

Overall, 67.4% indicated that they would like greater appointment flexibility (*Environmental context/resources*) and 31.3% reported difficulties getting time off work/study to attend appointments (*Environmental context/resources*). This was more commonly reported by occasional non-attenders versus regular attenders (59.1% vs 23.4%,  $p=0.002$ ). Most YAs were worried about diabetic retinopathy (74.3%), anxious when receiving screening results (63%) (*Emotion*) and would like more support after getting their results (66%) (*Social influences*). Responses for T1D and T2D were broadly similar, although those with T2D were more likely have developed strategies to help them to remember their appointments (63.6% vs 37.9%,  $p=0.019$ ) (*Behavioral regulation*).

**Conclusions** Attendance for DRS in YAs is influenced by complex interacting behavioral factors. Identifying modifiable determinants of behavior will provide a basis for designing tailored interventions to improve DRS in YAs and prevent avoidable vision loss.

## INTRODUCTION

Despite evidence supporting the effectiveness of diabetic retinopathy screening (DRS) in reducing the risk of sight loss, attendance for screening in particular demographic groups is

### WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Younger adults (YAs) (<35 years) with diabetes have been identified as having longer time intervals before attending initial diabetic retinopathy screening (DRS) and are more likely to miss successive screening appointments.
- ⇒ Previous studies have explored modifiable influences on DRS attendance but often do not differentiate between population groups, particularly YAs.

### WHAT THIS STUDY ADDS

- ⇒ One of the main reported barriers to attending DRS was the lack of appointment flexibility and difficulty getting time off work/study to attend appointments.
- ⇒ This was compounded by the lack of integration of DRS with other diabetes appointments.
- ⇒ Most YAs were worried about diabetic retinopathy, anxious when receiving screening results and would like more support

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ A more tailored approach is needed to support YAs to attend DRS.
- ⇒ The findings of this research provide a basis for developing tailored interventions to increase screening uptake in this age group.

often below recommended levels.<sup>1</sup> Although adherence to screening recommendations is generally high in countries with universal health insurance coverage, there is considerable variability within population subgroups. For example, in Australia, DRS uptake in non-indigenous Australians was reported to be 53% compared with 78% of indigenous Australians.<sup>2</sup> Only 38% of recent immigrants to Canada had at least one screening visit within 1 year of diagnosis compared with 51% of long-term residents.<sup>3</sup>

Understanding modifiable barriers and enablers to DRS is essential to develop tailored intervention strategies to improve screening uptake. There have been many studies internationally that have investigated the factors influencing DRS attendance.<sup>4,5</sup> Barriers/enablers to attendance potentially operate at different levels, including the person with diabetes, the healthcare professional (HCP) or the healthcare system. Furthermore, factors influencing individual screening attendance are likely to differ according to the presence of variables that are known to impact on health equity, for example, type of diabetes, ethnicity or socioeconomic status.<sup>6–9</sup> However, studies have often considered people with diabetes as a homogeneous group and relatively few studies have addressed barriers/enablers in particular population subgroups.

Another demographic group where adherence to DRS consistently falls below recommended levels is young adults (YAs) with diabetes aged under 35 years.<sup>10–13</sup> Recent studies from the UK Diabetic Eye Screening Program (DESP) have shown that the time interval from registration with the screening program to DRS attendance is strongly age dependent.<sup>10,12</sup> Time to first screening was significantly longer for the 18–34 year age group, with 70% meeting the requirement for routine annual screening and approximately 20% remaining unscreened 3 years after registration.<sup>12</sup> In terms of ongoing attendance, it was reported that younger adults (<35 years) have a 75% reduction in the odds of attending annual DRS compared with those aged 60 years and over.<sup>12</sup> Furthermore, younger adults are more likely to miss three successive DRS appointments and present with sight-threatening retinopathy.<sup>13</sup>

YAs are a particularly hard to reach group and there has been little previous research to understand the reasons for poor DRS attendance in YAs.<sup>14</sup> A 2017 Australian study<sup>15</sup> conducted semistructured interviews with YAs, n=10 aged 18–39 years and older adults, n=20 aged over 40 years with type 2 diabetes (T2D). This study used a behavioral science framework, the Theoretical Domains Framework (TDF),<sup>16</sup> to explore the wide range of barriers and enablers to attendance. The TDF synthesizes constructs from 33 theories of behavior change into 14 domains, representing individual, sociocultural and environmental influences on behavior (eg, knowledge, emotions, social and professional identity, perceived consequences, intention, environmental context and resources). Although younger and older adults shared several screening behavior determinants, a number of TDF domains showed greater salience to YAs including misconceptions regarding diabetic retinopathy (*Knowledge*); social comparison with others; unrealistic optimism and perceived invulnerability (*Beliefs about consequences*); and lack of time and financial resources (*Environmental context and resources*).<sup>15</sup> We have recently completed the National Institute for Health and Care Research (NIHR)-funded ‘Enabling diabetic Retinopathy Screening: Mixed methods study of barriers and enablers to attendance (EROS study)’, which aimed to identify barriers and enablers to DRS attendance experienced by YAs with diabetes living in the UK. As part of this research, we conducted qualitative interviews with 29

YAs with type 1 diabetes (T1D) aged 18–34 years.<sup>17</sup> We have also conducted a cross-sectional survey of HCPs working in the UK National Diabetic Eye Screening Program.<sup>18</sup> We similarly applied the TDF to identify modifiable barriers and enablers to DRS attendance. In terms of the interviews, key influences fell within the TDF domains: *Knowledge*, for example, not understanding reasons for attending DRS or treatments available if diabetic retinopathy is detected; *Social support*, for example, lack of support following DRS results; *Social role and identity*, for example, not knowing other people their age with diabetes; feeling ‘isolated’ and being reluctant to disclose their diabetes; *Environmental context and resources*, for example, lack of appointment flexibility and options for rescheduling; and *Emotion*, for example, diabetes distress/burnout. Enablers included *Social influences*, for example, support of family/diabetes team; and *Goals*, for example, DRS regarded as ‘high priority’. Barriers/enablers were generally consistent across groups defined by patterns of attendance (regular attenders, occasional non-attenders, regular non-attenders).

In the current study, we used the results of the previous interview study<sup>17</sup> to further explore the research problem. Themes from the qualitative data informed the design of an online survey. The purpose of the survey was three-fold: (1) to assess the generalizability of the perceived barriers and enablers in a larger and more diverse sample of YAs with regard to particular demographic characteristics (eg, age, employment, gender, ethnicity, educational level); (2) to enable a qualitative investigation of differences in perceived barriers and enablers between YAs with T1D and T2D; and (3) to investigate differences in those that attend DRS regularly versus those who did not. The survey also allowed us to triangulate findings from qualitative and quantitative methods to gain a more complete picture of the factors that influence screening uptake in YAs.<sup>19</sup>

## RESEARCH DESIGN AND METHODS

### Design

A cross-sectional web-based survey.

### Participants and recruitment strategy

Eligible participants included YAs aged 18–34 years with diabetes. Previous studies have shown that people in this age group are least likely to attend DRS and have high rates of referable retinopathy.<sup>10,12,13</sup> As this was a descriptive survey, we did not have a predefined target sample size in mind and aimed to maximize response rate from as many YAs as possible. Two recruitment strategies were used:

1. A text (SMS) message with the link to the survey was sent to all YAs with T1D and T2D aged 18–34 on the register of a large DESP in London whose mobile number was available. Screening providers often use this mobile phone strategy to request feedback from patients about the care they receive.

2. The survey was also promoted via the web pages of the Juvenile Diabetes Research Foundation UK (JDRF UK) and Diabetes UK and further supported using the Facebook and Twitter accounts of these organizations (see online supplemental file S1 for examples of promotional material).

### Materials: questionnaire

The full survey is available in online supplemental file S2. In brief, the survey was developed based on guidance for conducting surveys using the TDF<sup>20</sup> and the findings of our previous interview study with YAs in the UK.<sup>17</sup> The survey was fully anonymous and divided into three sections:

- ▶ Section 1—Participant demographics: age, gender, ethnicity, geographical location, highest level of education; type and duration of diabetes; screening appointments missed in the last 3 years (either forgotten and rescheduled or deliberately not attended) (12 questions).
- ▶ Section 2—Perceived influences on DRS attendance: Participants were presented with 30 belief statements representing barriers and enablers to DRS attendance. These statements were developed based on the inductively generated themes based on frequency and elaboration from our semistructured interview study with YAs in the UK<sup>17</sup> (eg, the theme *‘Diabetic retinopathy is a concern’* was reflected in the belief statement *‘I worry about diabetic retinopathy’*). To ensure theoretical coverage and that the wide range of potential influences were considered, belief statements covered 13 of the 14 TDF domains (our earlier qualitative study<sup>17</sup> did not identify themes for the domain *Optimism*). Participants rated their agreement with each statement using a 5-point Likert scale (strongly agree→strongly disagree).
- ▶ Section 3: Free text question, ‘Please describe any other factors which influence your attendance at diabetic eye screening which we have not covered’.

To assess participant burden, clarity of questions and face validity, a draft questionnaire was sent to the project Patient and Public Involvement (PPI) panel consisting of four YAs with diabetes, who were asked to comment on the following:

- ▶ How long the survey takes to complete.
- ▶ If the survey items make sense, are appropriate and relevant.
- ▶ If there are any survey items which are ambiguous or unclear.

A final version based on the feedback was uploaded and pretested for technical quality prior to distribution.

### Procedure

The survey took place in June 2021. The questionnaire was hosted online using Qualtrics survey software (<https://www.qualtrics.com/uk/core-xm/survey-software/>). The survey was fully anonymous, and participants consented to participate in the survey by completing a

brief consent form on the survey home page. Respondents were offered an incentive in the form of the chance to win a £20 Love2shop voucher (we offered twenty £20 vouchers).

### Analysis

After the closure of the survey, all data were imported into an Excel spreadsheet. Data were summarized using descriptive statistics (percentages (n)). For the responses to the 5-point scale in Section 2, scores for ‘Strongly agree’ and ‘Somewhat agree’ were combined into an overall mean and percentage agreement score.

Statistical analysis for comparison between participants with T1D and T2D and pattern of attendance (regular attenders vs occasional non-attenders) was carried out using MedCalc statistical software V.18 (MedCalc Software, Ostend, Belgium; <http://www.medcalc.org>) in the form of  $\chi^2$  tests to determine differences in endorsed barriers and enablers. Occasional non-attenders were grouped as those who had either (1) unintentionally forgotten/missed previous appointments and rescheduled, or (2) actively chosen to not attend on at least one occasion.

A single investigator (JGL) coded each line of responses to the free-text question by adding a descriptive label. Codes representing similar thematic topics were then grouped together to identify common themes and concepts. A second investigator (FL) reviewed the thematic groupings and any discrepancies were resolved by discussion.

## RESULTS

### Respondent demographic characteristics

One hundred and two responses were received. Detailed respondent demographic characteristics are presented separately for respondents with T1D and T2D in [table 1](#) (two participants reported having an ‘other’ type of diabetes (eg, maturity onset diabetes of the young)). Almost all respondents (98.5%) were located in England. The greatest proportion of respondents were female (59.8%), had T1D (65.7%), were aged 30–34 (52.9%), identified as white British (57.8%), employed (76.4%) and educated to degree level or higher (60.8%).

Most respondents were regular attenders for eye screening, with 76.5% having not missed a DRS appointment in the last 3 years.

### Barriers and enablers

The results of agreement/disagreement with belief statements related to barriers/enablers to DRS are presented in [table 2](#). In this well-engaged population, the most salient TDF domain for DRS attendance was *Goals*, with 93% of respondents agreeing that DRS was a high priority in terms of diabetes management, with a clear intention to attend future eye screening appointments (TDF domain, *Intention*) (97%). The reason for attending was understood by almost all respondents,



**Table 1** Characteristics of persons with type 1 and type 2 diabetes

	Type 1 N=67	Type 2 N=33
Gender	n (%)	n (%)
Male	20 (29.9)	17 (51.5)
Female	45 (67.2)	16 (48.5)
Other	2 (3.0)	0 (0.0)
Age (years)		
18–23	13 (19.4)	1 (3.0)
24–29	25 (38.8)	5 (15.2)
30–34	28 (41.8)	25 (75.8)
Not reported	0 (0.0)	2 (6.1)
Number of years since diagnosis		
<3	4 (1.5)	11 (33.3)
3–9	18 (28.4)	19 (57.6)
10–14	12 (17.9)	3 (9.1)
15–19	15 (20.9)	0 (0.0)
>20	16 (23.9)	0 (0.0)
NR	1 (1.5)	0 (0.0)
Ethnicity		
White British	48 (71.6)	10 (30.3)
Other white background	8 (11.9)	0 (0.0)
Indian	3 (4.5)	8 (24.2)
Bangadeshi	1 (1.5)	6 (18.2)
Pakistani	1 (1.5)	4 (12.1)
Other	4 (6.0)	4 (12.1)
NR	2 (3.0)	1 (3.0)
Country of residence		
England	66 (98.5)	33 (100.0)
Wales	1 (1.5)	0 (0.0)
Area		
Urban	31 (46.3)	18 (54.5)
Suburban	35 (52.2)	14 (42.4)
Rural	1 (1.5)	0 (0.0)
NR	0 (0.0)	1 (3.0)
Occupational status		
Full-time job	46 (68.7)	18 (54.5)
Part-time job	7 (10.4)	3 (9.1)
Self-employed	2 (3.0)	2 (6.1)
Studying	6 (9.0)	2 (6.1)
Unemployed	4 (6.0)	5 (15.2)
Other/NR	2 (3.0)	3 (9.1)
Highest level of education		
Secondary	3 (4.5)	7 (21.2)
Further education	16 (23.9)	6 (18.2)
Degree or higher	45 (67.2)	17 (51.5)
Other/NR	3 (4.5)	3 (9.1)
Missed DRS appointments		

Continued

**Table 1** Continued

	Type 1 N=67	Type 2 N=33
None	51 (76.1)	27 (81.8)
Unintentionally	14 (20.9)	6 (18.2)
Intentionally	2 (3.0)	0 (0.0)

DRS, diabetic retinopathy screening.

with 98% being aware that DRS can help detect eye problems early (*'Knowledge'*). Conversely, 84% did not know what treatments were available if retinopathy was detected (*Knowledge*). Importantly, only 52% felt that diabetes education and training covered eye screening in detail (*Skills*).

In terms of the screening process itself, overall, 67.4% indicated that they would like to be offered more options for appointment days/times when booking DRS appointments (*Environmental context/resources*) and approximately one-third of respondents had difficulties getting time off work/study to attend DRS appointments (*Environmental context/resources*). Scheduling was compounded by retinopathy screening appointments being at a different time to other diabetes appointments for most respondents (*Environmental context/resources*) (75.2%). Comparison between regular attenders and occasional non-attenders ([table 2](#)) found that non-attenders were more likely to report more difficulty taking time off to attend appointments (59.1% vs 23.4%,  $p=0.002$ ) and felt that appointments took up too much of the day (50.0% vs 23.1%,  $p=0.015$ ).

Additional negative aspects of the screening process were acknowledged, for example, being upset by seeing older people with worse complications in the waiting room (*Emotion*) (40%) and the adverse effects of the dilating eye drops (*Beliefs about consequences*) (64%). Most respondents were worried about diabetic retinopathy (74.3%), reported anxiety when receiving screening results (*Emotion*) (63%) and would like more support and information after getting their results (*Social influences*) (66%).

Enablers of attendance included an awareness that DRS allows early detection of eye problems (*Beliefs about consequences*) (98%), feeling reassured by attending DRS (*Emotion*) (75%) and feeling comfortable disclosing diabetes to others (*Social identity*) (71.6%).

Percentage agreement between YAs with T1D and T2D were broadly similar ([table 2](#)). Statistically significant differences were found for only three statements. Persons with T1D were more likely to feel overwhelmed by their diabetes (76.9% vs 56.7%,  $p=0.046$ ) (*Emotion*). YAs with T2D were less comfortable in disclosing their diabetes to others (77.6% vs 57.6%,  $p=0.039$ ) (*Social identity*) and were more likely have developed

**Table 2** Mean scores and percentage agreement with belief statements representing barriers and enablers to diabetic retinopathy screening (DRS)

Belief statement (corresponding TDF domain)	Mean scores		% agreements						
	Mean (SD)	N	ALL	T1D	T2D	P value	RA%	ONA%	P value
<b>Knowledge</b>									
'I do not understand why diabetic eye screening is conducted'	4.36 (1.19)	101	6.9	4.5	12.1	0.166	5.1	13.6	0.168
'I do not know what treatments are available if diabetic retinopathy is detected'	1.81 (1.03)	100	84.0	87.9	78.1	0.209	85.9	77.3	0.334
<b>Skills</b>									
'Diabetes education and training covers eye screening in detail'	2.42 (1.46)	102	52.0	50.7	54.5	0.722	51.3	59.1	0.518
<b>Social/professional role/identity</b>									
'I feel comfortable disclosing to others that I have diabetes'	2.55 (1.48)	102	71.6	77.6	57.6	<b>0.039*</b>	68.8	81.8	0.233
'I would like to meet more young people with diabetes'	2.87 (1.04)	97	47.4	53.8	33.3	0.064	48.0	45.5	0.837
<b>Beliefs about capabilities</b>									
'I think that I manage my diabetes well'	2.63 (1.03)	97	64.9	69.2	53.3	0.135	64.0	68.2	0.718
<b>Beliefs about consequences</b>									
'Attending diabetic eye screening can help detect problems with my eyes early'	1.19 (0.75)	99	98.0	98.5	96.8	0.583	97.4	100.0	0.458
'The eye drops which dilate your pupils before screening are unpleasant'	2.47 (1.16)	100	64.0	65.2	59.4	0.578	64.1	63.6	0.966
<b>Reinforcement</b>									
'I feel pressured to attend my diabetic eye screening appointments'	3.80 (1.22)	97	19.6	21.5	16.7	0.561	18.7	22.7	0.679
<b>Intention</b>									
'I will attend all my future diabetic eye screening appointments'	1.24 (0.79)	101	97.0	98.5	93.9	0.211	97.5	95.5	0.625
<b>Goals</b>									
'Attending diabetic eye screening appointments would be a higher priority for me if I experienced problems with my eyes'	1.90 (1.05)	96	60.4	53.8	72.4	0.091	56.8	72.7	0.183
'Attending diabetic eye screening appointments is a high priority in terms of diabetes management'	1.46 (0.83)	101	93.1	92.4	93.9	0.785	92.4	95.5	0.614
<b>Memory, Intention, Decision-making</b>									
'It is easy to forget to attend diabetic eye screening appointments'	3.16 (1.34)	99	32.3	28.8	38.7	0.3320	28.2	47.6	0.093
'Reminders (eg, text messages, phone calls) about my diabetic eye screening appointments are helpful'	1.06 (0.25)	99	99	98.5	100.0	0.489	98.7	100.0	0.593
'I am not notified of my appointment (eg, by letter/text message)'	3.72 (1.59)	100	25.0	22.7	31.3	0.362	23.1	31.8	0.408
'Diabetic eye screening appointment letters are sent too far in advance'	3.38 (1.13)	100	25.0	27.3	21.9	0.567	25.6	22.7	0.782
<b>Environmental Context and Resources</b>									
'My diabetic eye screening appointments are at a different time and place to my other diabetes appointments'	1.97 (1.33)	101	75.2	58.5	54.8	0.733	74.7	77.3	0.804
'I am unable to get time off work/study to attend diabetic eye screening appointments'	3.44 (1.50)	99	31.3	30.8	31.3	0.960	23.4	59.1	<b>0.002*</b>
'I would like to be offered more options for appointment days/times when booking diabetic eye screening appointments'	2.00 (1.23)	95	67.4	65.6	69.0	0.749	66.2	71.4	0.656

Continued

Table 2 Continued

Belief statement (corresponding TDF domain)	Mean scores		% agreements						
	Mean (SD)	N	ALL	T1D	T2D	P value	RA%	ONA%	P value
'Diabetic eye screening appointments take up too much time in my day'	3.72 (1.30)	100	29.0	33.3	21.9	0.249	23.1	50.0	0.015*
'My doctors and nurses check whether I have attended my diabetic eye screening appointments and encourage me to attend'	2.61 (1.50)	98	58.2	58.5	54.8	0.733	55.3	68.2	0.283
<b>Social influences</b>									
'I find seeing older people with worse complications in the eye screening waiting room upsetting'	3.09 (1.28)	100	40.0	41.5	33.3	0.433	38.5	45.5	0.558
'I would like more support and information following my diabetic eye screening results'	2.38 (1.16)	100	66.0	69.7	59.4	0.314	67.9	59.1	0.444
'There is a lack of awareness among the general public that younger people can have diabetes'	1.67 (0.88)	97	82.5	81.5	86.7	0.589	88.0	63.6	0.009*
'I have had bad experiences when discussing diabetic eye screening with healthcare professionals'	4.22 (1.13)	100	16.0	19.7	9.4	0.198	12.8	27.3	0.083
<b>Behavioural regulation</b>									
'I have developed strategies to help me remember to attend my diabetic eye screening appointments'	2.00 (1.17)	101	46.5	37.9	63.6	0.019*	50.6	31.8	0.120
<b>Emotions</b>									
'I worry about diabetic retinopathy'	2.06 (1.12)	101	74.3	78.8	66.7	0.194	73.4	77.3	0.713
'I sometimes feel overwhelmed due to my diabetes'	2.70 (1.24)	97	97	76.9	56.7	0.046*	68.0	72.7	0.677
'I feel reassured by attending diabetic eye screening'	1.91 (1.09)	100	75.0	75.8	75.0	0.837	74.4	77.3	0.782
'I feel anxious about receiving my diabetic eye screening results'	2.56 (1.41)	100	63.3	63.6	62.5	0.920	62.8	63.6	0.946
The mean scores correspond to the extent to which participants agreed with each statement using a 5-point Likert scale (strongly agree=1; somewhat agree=2; neither agree nor disagree=3; somewhat disagree=4; strongly disagree=5). The p value represents the results of the $\chi^2$ test for differences between T1D and T2D subgroups and between RA and ONA. Highlighted values indicate statistically significant differences. ONA, occasional non-attender; RA, regular attender; T1D, type 1 diabetes; T2D, type 2 diabetes; TDF, Theoretical Domains Framework.									

strategies to help them to remember to attend their DRS appointments (63.6% vs 37.9%,  $p=0.019$ ) (*Behavioural regulation*).

### Other factors influencing attendance at DRS

Free text responses were received from 30 respondents. These covered the following areas: impact of the COVID-19 pandemic on scheduling DRS appointments ('*Last appointment later due to COVID-19*'); fear of vision loss ('*My mother in law lost her eye due to diabetic (retinopathy)*'); appointment inflexibility ('*They can also be inflexible-the nearest one to me only does Tuesday mornings*'); impact of eye drops and transport issues ('*They can be difficult to get to, especially as you cannot drive-in one occasion I had to get three buses which took nearly 2 hours-the return trip with dilated pupils wasn't fun*'), interactions with screening staff and issues with receiving screening results ('*I always receive letters that are extremely distressing and usually on a weekend when I cannot call anyone*'). The complete set of free text comments can be found in the online supplemental material.

## DISCUSSION

### Summary of findings

This study aimed to build on the findings of our earlier qualitative interview study to identify perceived barriers and enablers to DRS in YAs in the UK.<sup>17</sup> The results broadly confirmed our qualitative interview findings in YAs with T1D and converged with the findings from a qualitative study of YAs with T2D in Australia.<sup>15</sup>

Based on the level of agreement with each belief statement, the most salient TDF domains associated with DRS included 'Social influences', 'Intentions', 'Emotion', 'Environmental context/resources', 'Knowledge', 'Skills', and 'Goals'. However, the level of agreement with belief statements differed between respondents with T1D and T2D and between regular attenders and occasional non-attenders. This emphasizes the importance of understanding barriers/enablers for specific population subgroups.

Overall, survey respondents represented a well-engaged population, with approximately 78% reporting that they had not missed any screening appointments in



the last 3 years. This may explain the high level of understanding of the purpose of DRS, the high priority (*Goals*) given to this particular aspect of diabetes care and the strong intention to attend further screening appointments. However, despite a large majority understanding the purpose of DRS and the need for regular screening, there were specific knowledge gaps such as an awareness of the treatments available should sight-threatening retinopathy be detected.

Competing time demands and practical issues with making appointments have been previously shown to be important barriers to DRS attendance.<sup>4 9 15 17</sup> This was particularly pertinent among respondents who reported occasionally missing DRS appointments. Occasional non-attenders were more likely to agree with the belief statements: *'Diabetic eye screening appointments take up too much time in my day'* and *'I am unable to get time off work/study to attend diabetic eye screening appointments'*. Most survey respondents agreed that their DRS appointments were at a different time and place to their other diabetes appointments. Possible solutions could include evening and weekend appointments coupled with a flexible online booking system to allow them to schedule appointments more easily. Furthermore, the use of an integrated diabetes care in the form of a 'one-stop shop' clinic that combines several processes of diabetes care, including DRS, which would reduce the number of appointments. Although there is currently no high quality evidence from the UK that integrated diabetes clinics improves DRS uptake specifically in YA, 'collaborative case management', which coordinates processes of diabetes care, has been shown to improve diabetic retinopathy outcomes in clinical trials of a general adult population with diabetes.<sup>1</sup>

The eye drops used to temporarily dilate the pupils were perceived to be unpleasant by the majority of respondents. Free text comments also alluded to the impact of the eye drops on attendance due to not being able to drive to and from the screening venue and having to rely on family members or use public transport (*'With the drops you can't drive but it's also hard to then see where the train is. The drops knock me out for the rest of the day and really affect work and everything'*). Previous studies have also reported on barriers relating to dilating eye drops.<sup>49</sup> The National Screening Committee in the UK currently recommends pupil dilation (mydriasis) for all attendees for DRS based on the ease of organization and improvement in image quality; however, there is evidence that using mydriasis only when clinically necessary can be effective for DRS.<sup>21</sup>

Fear of diabetic retinopathy was identified as a cause for concern, with a high level of agreement that screening attendance provided reassurance. However, there was a particular anxiety associated with receiving screening results and a desire for more support and information on receiving results. The previous literature identified that while, for some, the fear of losing vision is a strong incentive to attend DRS, for others, the fear of a diagnosis of diabetic retinopathy may act as a barrier.<sup>17</sup> Interventions to address this could include

training suitably qualified screeners to give immediate feedback on the results of eye screening or the provision of more support after receiving results. This strategy is potentially acceptable to implement in practice, with a recent cross-sectional survey of HCPs working in the UK National Diabetic Eye Screening Program highlighting that screening providers would like to be more involved in discussing screening results with YAs and promoting diabetes self-management.<sup>18</sup>

A recommendation by a HCP has been shown to be an important enabler for DRS uptake and receiving a recommendation from a healthcare provider to attend screening is associated with improved attendance.<sup>4 15</sup> However, survey respondents reported that members of the diabetes team did not always check their DRS attendance record or encourage them to attend. This is clearly a missed opportunity to improve screening uptake in this population. Furthermore, the lack of integration of DRS with other diabetes services creates a further missed opportunity for screening providers to discuss general diabetes self-management, due to a lack of information on how attendees are managing their diabetes.<sup>18</sup>

T2D is increasingly prevalent in YAs. This trend is particularly pronounced in South Asian ethnic groups.<sup>22 23</sup> Previous research has established that YAs with T2D are at higher risk of developing diabetic retinopathy,<sup>24 25</sup> face unique barriers to diabetes self-management and have specific unmet psychosocial needs.<sup>26</sup> Although all participants in our earlier interview study<sup>17</sup> had T1D, 32% of respondents in the current study were YAs with T2D. The levels of agreement between these subgroups were very similar, with significant differences in agreement found for only three belief statements (*'I sometimes feel overwhelmed due to my diabetes'*; *'I feel comfortable disclosing to others that I have diabetes'*; *'I have developed strategies to help me remember to attend my diabetic eye screening appointments'*). Respondents with T1D were more likely to feel overwhelmed by their diabetes. YAs with T2D were less comfortable in disclosing their diabetes to others. Research in Australia suggests that young people with T2D are sensitive to stigmatizing attitudes.<sup>27</sup> Although there was no difference between respondents with T1D and T2D in terms of likelihood of forgetting to attend DRS appointments, respondents with T2D were more likely to have developed strategies to help them to remember to attend.

### Strengths and limitations of the current study

One of the strengths of the current study is that it addresses an important evidence gap. Although there are many studies that have reported modifiable barrier/enablers to DRS,<sup>2 3</sup> the majority of these studies tend to treat people with diabetes as a homogeneous group, and therefore, it is not possible to identify determinants of DRS uptake from the perspective of particular population subgroups. Relatively few studies have reported barriers from the perspective of YAs, who are at a high risk of developing sight-threatening retinopathy.<sup>12 24 25</sup>

Another strength of our approach is the use of a theory-informed methodology to identify barriers and enablers.<sup>14</sup> We used the TDF to guide data collection, which provides a basis for generating future behavior change strategies that can be tailored to YA to address barriers or enhance facilitators.

Although this hypothesis-generating study was limited in terms of its small sample size, we received responses from a demographically diverse sample of YA, including 33% of responses from YA with T2D. The results confirmed many of barriers and enablers identified in previous qualitative interview studies<sup>15 17</sup> and suggest that the determinants of screening attendance are broadly similar for YAs with T1D and T2D.

The main limitation was the difficulty experienced in recruiting non-attenders. Despite using a variety of recruitment strategies (see online supplemental material), only 20% of survey respondents had missed a DRS appointment in the last 3 years and nearly all of these had unintentionally missed the appointment (ie, they forget or were unable to attend). We were only able to recruit two participants who had made a deliberate decision not to attend DRS, which could impact on the generalizability of the findings to repeat non-attenders. Considering the study aimed to identify barriers and enablers of DRS attendance among YAs in the UK, a further limitation is that 98.5% of respondents were from England.

## CONCLUSIONS AND IMPLICATIONS FOR POLICY

Barriers identified in the current study included the lack of appointment flexibility, impact of the eye drops used to dilate the pupils and anxiety associated with the risk of developing diabetic retinopathy. More consistent checking of DRS attendance by the diabetes team and encouragement to attend could be an important enabler. These findings highlight recommendations for changing policy and practice, including pinpointing to specific intervention strategies that could potentially address identified barriers and enablers and increase attendance to DRS in this priority population group. Future research should address the challenges of engaging with socially disadvantaged and hard to reach groups to ensure that they are not excluded.

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