







RESEARCH NOTE

REVISED

Understanding the uptake of a national retinopathy screening programme: An audit of people with diabetes in two large primary care centres [version 2; peer review: 1 approved, 1 approved with reservations]

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Abstract

Background: Diabetic retinopathy (DR) affects 8.2% of the Irish population with type 2 diabetes over 50 years and is one of the leading causes of blindness among working-age adults. Regular diabetic retinopathy screening (DRS) can reduce the risk of sight loss. In 2013, the new national screening programme (RetinaScreen) was introduced in Ireland.

Maximising DRS uptake (consent to participate in the programme *and* attendance once invited) is a priority, therefore it is important to identify characteristics which determine DRS uptake among those with diabetes in Ireland. We report uptake in an Irish primary care population during the initial phase of implementation of RetinaScreen and investigate factors which predict consenting to participate in the programme.

Methods: In two primary care practices, data were extracted from records of people with diabetes (type 1 and type 2) aged ≥ 18 years who were eligible to participate in RetinaScreen between November 2013 and August 2015. Records were checked for a RetinaScreen letter. RetinaScreen were contacted to establish the status of those without a letter on file.







Multivariable Poisson regression was used to examine associations between socio-demographic variables and consenting. Adjusted incident rate ratios (IRR) with 95% CI were generated as a measure of association.


Results: Of 722 people with diabetes, one fifth ($n=141$) were not registered with RetinaScreen. Of 582 who were registered, 63% ($n=365$) had participated in screening. Most people who consented subsequently attended ($n=365/382$, 96%). People who had attended another retinopathy screening service were less likely to consent (IRR 0.65 [95%CI 0.5-0.8]; $p<0.001$). Other predictors were not significantly associated with consent.

Conclusions: Over one third of eligible participants in RetinaScreen had

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not consented. Research is needed to understand barriers and enablers of DRS uptake in the Irish context. Implementing strategies to improve DRS uptake, barriers to consent in particular, should be a priority.

Keywords

diabetes, retinopathy, screening, microvascular complication, primary care

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REVISED Amendments from Version 1

This improved version contains some minor revisions as suggested by peer-reviewers.

Throughout the manuscript, the following changes have been made:

Replaced 'patients' with 'people with diabetes' where appropriate

Referenced the RetinaScreen website URL and programme report

Within the Abstract we have clarified that the main barriers occur at the consent step, when people decide whether to participate in the programme, and that strategies to address this should be the priority.

Within the Introduction, we have explained the prevalence estimate cited is based on self-report. We also provide some additional estimates. We have added further references for uptake rates internationally.

Within the Methods, we have clarified that the appointments people receive are fixed time appointments, weekdays and working day only, but that they can reschedule the time and date.

Within the Discussion, we have explained that the appointments people receive are fixed time appointments, weekdays and working day only. We have clarified that people may find it difficult to attend such appointment, referring both to follow up qualitative work we conducted with patients and an international systematic review of barriers and enablers of screening attendance. We have also mentioned that people may prefer other screening providers which they may find more convenient. We also clarify that barriers occur at the consent stage and most people attend once consented. We have referenced several additional reviews and studies on barriers and enablers to screening attendance. We have revised the limitations section to emphasise the importance of other factors which could not be examined in our study, namely socio economic status (SES), self-management, and history of glycaemic control, and psycho-social factors (e.g. attitudes, beliefs and knowledge about DRS, and recommendations from a health care professional. We have included a recommendations section with reference to studies in the UK, Canada and Australia.

Any further responses from the reviewers can be found at the end of the article

Introduction

Diabetic retinopathy (DR) is the most common microvascular complication of diabetes. DR affects 8.2% of the Irish population over 50 years with type 2 diabetes¹ and is the leading causes of blindness among adults of working age². This estimate is based on self-report; studies among regional cohorts of primary care patients with type 1 and 2, based on objective data, have reported higher estimates (25–26%)^{3,4}. Regular diabetic retinopathy screening (DRS) leads to the earlier detection of retinopathy and treatment that can prevent or delay the development of diabetes-related blindness. Although DRS is found to be effective, few countries have established a population-based DRS programme. In 2013, the new national programme (Diabetic RetinaScreen) was introduced in Ireland offering free, regular retinopathy screening to people with diabetes.

Ensuring a high uptake of retinopathy screening is challenging⁵. Prior to the introduction of a national programme, there was variation in attendance at regional screening services in

Ireland, with attendance rates ranging from 49–80%^{3,4,6,7}. Screening uptake has also been identified as a challenge internationally; with attendance rates ranging from 28–92%^{8–14}. Non-attendance at screening has been identified as a risk factor for poor visual outcomes among those with diabetes¹⁵. Factors associated with non-attendance include, younger age^{9,11}, type 1 diabetes⁹, poor glycaemic control^{9,16} and lack of awareness of the benefits of DRS or the risk of DR among people with diabetes^{6,17}. A recommendation from a healthcare provider^{6,17} and fear of impaired vision¹⁷ have been shown to motivate attendance. Little is known about characteristics which determine the uptake of retinal screening among those with diabetes in the Irish context^{4,6}. The aim of this study was to identify factors associated with participation in a new national retinopathy screening service using data from primary care.

Methods

National Screening Programme

RetinaScreen is a government-funded programme providing free, annual retinal screening, and, if necessary, treatment, to anyone aged 12 years or older with diagnosed diabetes. The programme was commissioned in 2011 and rolled out in 2013 and 2014^{18,19}. The current study was conducted during the initial phase of the programme (2013–2015). In Ireland, there is no national register of people with diabetes. The programme register was populated in 2012 using information from existing national health schemes, specifically pharmacy claims data. GPs or by other healthcare professionals involved in diabetes care can also add people with diabetes to the register by directly contacting RetinaScreen. All those on the register are invited by letter to participate in the programme^{18,19}, after which they provide consent for the programme to hold and use their contact details and receive an appointment. Once consented they receive an appointment for a fixed time in their local screening centre. They can contact RetinaScreen to change the time and date of their appointment. Once consented they receive an appointment, after which they need to attend. [Figure 1](#) illustrates this process of registration, consenting to and attending the programme.

Population

Members of the target population were people with diabetes aged 18 years and over who were eligible to participate in RetinaScreen during the uptake period of interest, that is, diagnosed with diabetes four months before the end of the uptake period of interest (Practice A: between July 2014 and August 2015; Practice B between November 2013 and December 2014).

Research setting

Data collection was carried out across two large primary healthcare centres (Practice A and Practice B) located in two different Community Health Organisations in Ireland ([Figure 2](#)). Practice A had seven GPs with five practice nurses and approximately 22,000 patients. Practice B had eight GPs with four practice nurses and approximately 20,000 patients.

Data collection

The two primary care centres used the same computerised IT system, therefore data collection methods described were carried out across both sites. All adults aged ≥ 18 years with diabetes

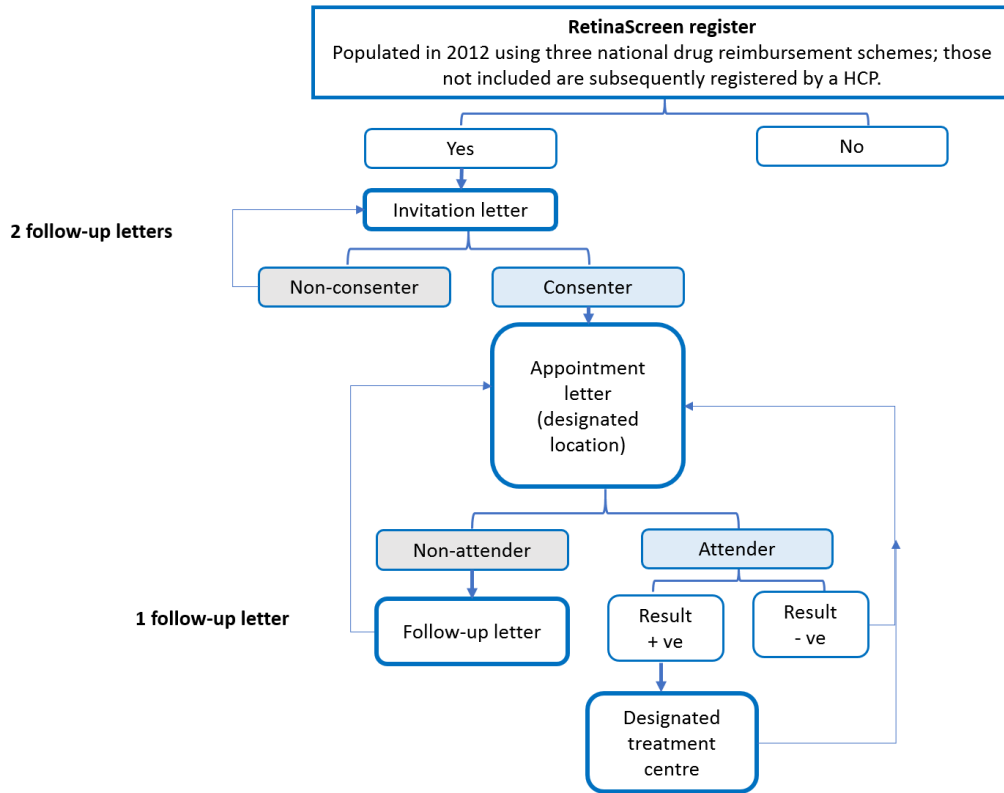


Figure 1. Flow diagram illustrating process of consenting and attending to the programme. HCP; Health Care Professional.

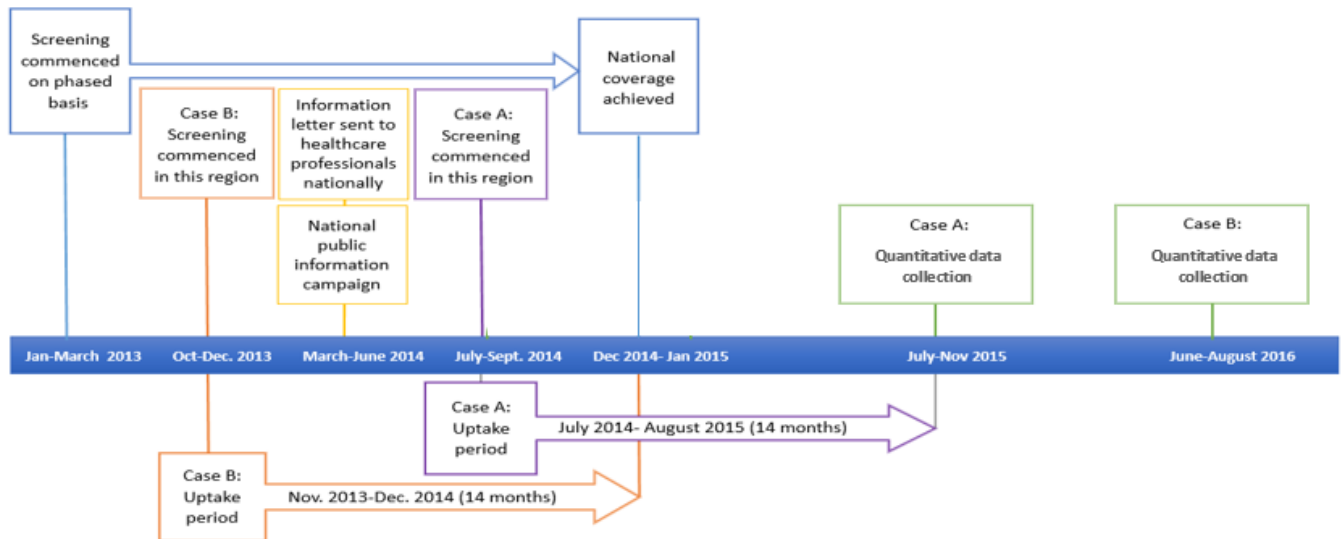


Figure 2. Timeline of the national programme, RetinaScreen, and data collection at study sites.

were identified via the practice database, using the International Classification of Primary Care, Second Edition (ICPC-2) codes for diabetes insulin dependent (T89) and diabetes non-insulin dependent (T90). Duplicates were removed and data were extracted from each individual medical record. Next, the following inclusion criteria were applied: age 18 years and older, community-dwelling, diagnosed with diabetes at least four months before the end of the uptake period of interest (Practice A: before May 2015; Practice B: before September 2014). Exclusion criteria were, a diagnosis of prediabetes or gestational diabetes or diabetes insipidus, no perception of light in both eyes (blindness) as documented in medical records, nursing home residence, visiting patient to the practice.

Data were extracted from eligible individual's medical record. Each medical record was checked for a RetinaScreen letter (results letter or did not attend letter). RetinaScreen was contacted to establish the status of those who did not have a letter on file. Individuals were then categorised into four groups:

1. Not registered (details were not listed on the RetinaScreen database),
2. Non-consenters (details were listed in the RetinaScreen database but did not respond to the RetinaScreen initial letter asking for individual's consent to hold and use their contact details),
3. Non-attenders (details were listed on the RetinaScreen database; they responded to the RetinaScreen invitation letter but did not attend screening appointment)
4. Attenders (details were listed on the RetinaScreen database, responded to the RetinaScreen invitation letter and attended appointment).

In each practice, the beginning of the uptake period was defined as the earliest date of the first screening results letter available on file (Figure 2). The end of the uptake period was defined as the last day of data collection; hence the uptake period for each practice was 14 months in duration.

Individual-level characteristics were also extracted from the patient's medical records and included: date of birth, gender, healthcare cover (medical card/private insurance), diabetes type (type 1/type 2), date of GP diabetes diagnosis (≤ 2012 vs. > 2012) and a previous doctor diagnosis of hypertension. A previous diagnosis of myocardial infarction, congestive cardiac failure, cerebrovascular accident and transient ischaemic attack were defined as macrovascular complications. A previous diagnosis of DR, diabetic neuropathy or diabetic nephropathy were defined as microvascular complications. Each medical record was checked for a results letter from existing retinopathy screening services; attendance at existing retinopathy screening services (for example a private ophthalmologist or previous regional initiative) was categorised into two groups: no evidence of attending existing retinopathy screening services ('none') and evidence of attending existing retinopathy screening services ('previous attendance').

Age (years) was calculated by subtracting year of birth from year of uptake period and was categorised into three age groups (18–39 years; 40–65 years; 65 years and over). Duration of diabetes diagnosis was calculated by subtracting year of GP diabetes diagnosis from year of uptake period and was categorised into three groups (0–4 years; 5–9 years; 10 years and over).

Data analysis

Analysis was carried out in Stata version 13 for windows (StataCorp, College Station, TX). Descriptive statistics were used to summarise characteristics of people with diabetes and were stratified according to outcome group. Uptake was calculated as the number of people who participated in the programme (consented *and* attended) and reported as a proportion of the total who were registered. Group specific differences in categorical variables were analysed using Pearson's chi-square test. The mean and standard deviation were reported if continuous data conformed to normality and the student t-test was conducted to compare mean differences. If data were skewed, the median with associated lower and upper quartile values was reported and the Kruskal Wallis test was utilised. Associations between predictor variables and programme outcomes were examined with multivariable Poisson regression. Adjusted incident rate ratios (IRR) with 95% CI were generated as a measure of association. Predictor variables were selected based on whether they had been reported in the literature as significant predictors of uptake to diabetic retinopathy screening.

Ethical considerations

Ethical approval for the study was obtained from the Clinical Research Ethics Committee for the Cork Teaching Hospitals (ECM 4 (o)). Patient consent for the use of their medical records was waived by the ethics committee as no patient records or identifiable data were removed from primary care centres. MT acted as a 'Data processor' on behalf of the general practitioner and a 'Data Protection and Confidentiality Agreement' was signed by the general practitioner and MT.

Results

Uptake of Diabetic RetinaScreen

A total of 722 people with type 1 and type 2 diabetes were identified during data collection (Figure 3). At the time of data collection, one fifth ($n = 140$) were not registered with RetinaScreen. A total of 582 people were registered and had been invited to participate in the screening programme. Of these, 66% consented to take part ($n = 382$), the majority of whom attended screening. Overall, 63% of those who were registered ($n = 365$), participated; i.e., consented *and* attended (Figure 3).

Most of the 217 who had not participated in the programme had not consented for the programme to hold and use their details ($n = 200$, 92%). While the uptake of RetinaScreen was 63% among those who were registered for the programme ($n = 365/582$), only half ($n = 365/722$) of the eligible population of people with diabetes had participated in the new national programme at the time of the study.

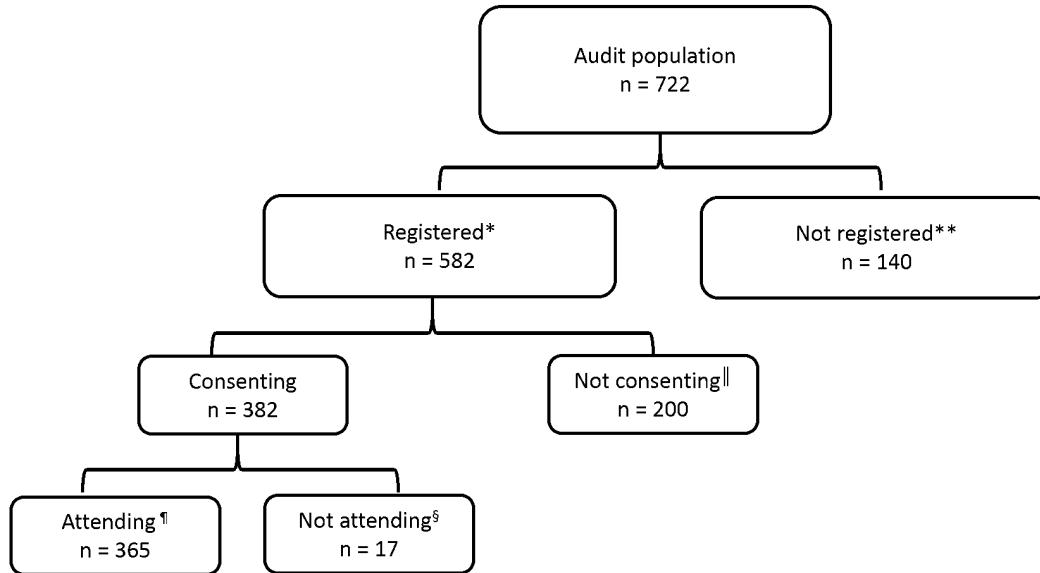


Figure 3. Outcome status of individuals identified during data collection. *Registered, details listed on the screening programme database; invitation letter to avail of screening sent. **Not registered, details not listed on the screening programme database. ||Not consenting, did not respond to invitation letters; ¶Attending, attended screening appointment. §Not attending, responded to invitation letter but did not attend screening appointment.

Characteristics of the target population

The characteristics of the 582 people who were registered with RetinaScreen are shown in Table 1. The mean age of patients was 63.0 years (SD 13.8), 61% were male and 91% had type 2 diabetes. Approximately half of the sample had evidence of attending existing retinopathy screening services in their medical record (52%).

Predictors of consenting to Diabetic RetinaScreen

Most people who consented to participate in the programme subsequently attended (n = 365/382, 95.6%). Therefore, consent to be invited to participate was the outcome of interest for the regression analysis. Table 2 presents the results from the Poisson regression analyses. Multivariable analysis indicated that people who had previously attended an existing retinopathy screening service (IRR = 0.65 [95% CI 0.5-0.8]; p<0.001) were less likely to consent.

Discussion

This study outlines uptake of DRS among people with diabetes in Ireland during the initial implementation of a new national screening programme. Over the 14-month period the overall uptake (consenting *and* attending) among people who were registered was 63%. This is similar to the most recent figures (61%) available from RetinaScreen; i.e., people sent a consent letter who attended²⁰, and higher than previously reported in some regional community-based screening initiatives^{3,4,6}. Consent was the outcome of interest as this is the first point of engagement with the programme before a patient can attend screening. Over one third of people eligible to participate in RetinaScreen had not consented, suggesting barriers may occur at this stage. Encouragingly, once consented, most people (96%, n = 365/382) attended their screening appointment.

National figures indicate that, in the first round of screening (March 2013 to December 2014), of the 134,513 people who were invited to participate (sent a consent letter), 57.1% consented to RetinaScreen¹⁸. This is lower than the proportion of people reported in the current study (66%). While previous studies have found factors such as age^{9,11}, type of diabetes and duration⁹ to be associated with DRS uptake, our analysis only found that previous attendance to an existing retinopathy screening service was significantly associated with non-consent. We may expect that people who already are aware of, and familiar with, DRS would be more inclined to attend the new national programme. A lack of awareness of DR and the risk has previously been reported as a barrier to attendance in the international literature^{6,17,21-23}. An Irish study conducted in 2015 which surveyed people with diabetes attending general practices and diabetes outpatient clinics about screening behaviours, reported 91% had never previously heard of RetinaScreen²⁴. However, since then the programme has introduced further advertising and may be more familiar to people with diabetes. Conversely, those attending another screening service may find it is more convenient. RetinaScreen appointments are offered on weekdays and during the working day. It is possible that people may find it difficult to attend appointments at these times. Our follow-up qualitative work with patients indicated competing demands, including work and family commitments were barrier to attendance. Similarly, a 2016 systematic review identified several individual, social, cultural and environmental barriers DRS attendance, including work commitments (e.g. finding it hard to take time off work)²¹.

We found one fifth of people with diabetes were not registered with RetinaScreen at the time of the study. The introduction of the Cycle of Care, in 2015, may improve RetinaScreen registration rates for those with a medical card as it provides financial

Table 1. Characteristics of the sample who were registered, stratified by outcome status (n = 582).

Variable	Registered (n = 582)	Consenting (n = 381)		Not consenting (n = 200)
	Overall (n = 582)	Attending (n = 365)	Not attending (n = 17)	
	N (%)	N (%)	N (%)	N (%)
Demographics				
Age years (mean, SD)	63.0 (13.8)	63.8 (12.8)	57.9 (17.6)	62.1 (15.1)
Gender [Male]	355 (61)	227 (62)	6 (35)	122 (61)
Medical card	406 (70)	252 (69)	12 (71)	142 (71)
Diabetes				
Type 2	531 (91)	341 (93)	14 (82)	176 (88)
Year of diagnosis ≤2012	533 (92)	337 (92)	14 (82)	182 (91)
Years since diagnosis (median, IQR)	8 (5–13)	8 (5–13)	6 (4–10)	9 (5–15)
Complications				
Microvascular	147 (25)	86 (24)	5 (29)	56 (28)
Macrovascular	75 (13)	47 (13)	2 (12)	26 (13)
Hypertension	294 (50)	189 (52)	7 (41)	91 (46)
Screening history*				
None	280 (48)	214 (59)	5 (29)	61 (31)
Previous attendance	301 (52)	151 (41)	12 (71)	138 (69)

*Evidence of retinopathy screening at existing screening provider in medical record

Table 2. Contextual predictors of consenting to RetinaScreen.

Variables	Crude IRR (95% CI) (n=582)	p	Adjusted ¹ IRR (95% CI) (n=582)	p
Demographics				
Age				
18–39 years	1 (ref)		1 (ref)	
40–64 years	1.7 (0.9-3)	0.10	1.4 (0.7-2.7)	0.34
65+ years	1.6 (0.8-2.8)	0.13	1.3 (0.6-2.6)	0.46
Gender				
Male	1 (ref)		1 (ref)	
Female	1.03 (0.82-1.3)	0.68	0.9 (0.8-1.2)	0.69
Healthcare cover				
Medical card	1 (ref)		1 (ref)	
Private	0.9 (0.8-1.2)	0.77	1.04 (0.8-1.3)	0.72
Medical factors				
Diabetes type				
Type 1	1 (ref)		1 (ref)	
Type 2	1.4 (0.9-2.1)	0.14	1.3 (0.8-1.3)	0.28
Years since diagnosis				
0–4 years	1 (ref)		1 (ref)	
5–9 years	0.9 (0.8-1.3)	0.89	0.9 (0.7-1.3)	0.89
10 + years	0.9 (0.7-1.2)	0.80	1.03 (0.8-1.4)	0.81
Attendance to existing retinopathy screening				
None	1 (ref)	<0.001	1 (ref)	<0.001
Existing	0.65 (0.5-0.8)		0.65 (0.5-0.8)	

¹variables entered into model: age, gender, healthcare cover, diabetes type, years since diagnosis, screening history

remuneration to General Practitioners (GPs) for providing structured care for people with type 2 diabetes who have a medical card. The structured review visit includes monitoring of key processes of care including screening attendance. In this study, 34% of those not registered would not be eligible for the Cycle of Care. Systems should be put in place to support professionals to register and encourage attendance among *all* people with diabetes. With routine management of type 2 diabetes taking place in the community, primary care professionals are well positioned to promote DRS attendance. A recommendation to attend screening from a primary care professional has been found to motivate attendance^{17,21,25}. In a survey of GPs in Ireland, 56% identified the time required to register patients as a barrier²⁴. Since this study, RetinaScreen have introduced a number of measures to facilitate registration and consent, including an online referral system (2015), and a single step registration and consent form which can be returned by people with diabetes directly to RetinaScreen (2019)^{19,26}. It is important to recognise that service innovations evolve as they become more embedded in everyday practice. As such, with new implementation strategies RetinaScreen may have addressed initial challenges and reasons for non-participation may change over time.

It is important to acknowledge the limitations of this study. First, as mentioned, the study was undertaken during the initial phase of an on-going implementation process. However, estimates from the current study are in line with more recent figures from the programme. People may be attending private providers, and we cannot assess this using the current data. Quantitative data were extracted using a standardised extraction template and relevant quality checks were applied to the data. We acknowledge that the completeness and accuracy of our study is dependent on the consistency and timely application of codes in each practice. However, both practices have systems in place to ensure that databases are maintained to a high standard. The type of predictors examined by this study are limited to those available in patient records. Unfortunately the data did not include several factors which have consistently been found to be important in previous studies, for example, socio economic status (SES)²⁷⁻³⁰, self-management, and history of glycaemic control¹⁷, psycho-social factors (e.g. attitudes, beliefs and knowledge about DRS^{6,17,21-23} and recommendations from a health care professional^{17,21,22,25}).

Recommendations for future research

Given the limited nature of the data a consideration for future research could be to replicate this study using more extensive audit data. Data is routinely collected from practices participating

in diabetes care initiatives across Ireland, for example, the Midlands Diabetes Structured Care Programme which reported on RetinaScreen uptake in the most recent audit³. Determining how to enhance the uptake of DRS is recognised as an important implementation challenge for health systems, as evidenced by dedicated research programmes in the UK^{14,21}, Canada^{8,31}, and Australia³². Qualitative work with Irish people with diabetes and health care professionals has been conducted to explore barriers and enablers of DRS uptake and to inform the development an intervention to be delivered in general practice³³. The feasibility trial of this intervention is currently underway³⁴.

Conclusion

We found over one third of people eligible to participate in the free national retinal screening programme, Diabetic RetinaScreen, had not done so. The results suggest DRS attendance could be supported by raising awareness of screening and supporting professionals to register and encourage their patients with diabetes to attend. Type 2 diabetes, which accounts for about 90% of all cases of diabetes³⁵, is largely managed in primary care, making this a suitable setting in which to introduce strategies to support DRS uptake. Further research is needed to better understand barriers and enablers of DRS uptake in the Irish context, and to determine strategies would effectively target these factors. In Ireland, the population eligible for screening is increasing each year³⁶, therefore implementing effective strategies to maximise uptake of DRS must be a priority from the outset.

Data availability

Permission was not sought from participating practices or the Clinical Research Ethics Committee to share the data outside of the research team. De-identified data from the current study are available for further (collaborative) research purposes on reasonable request. Available datasets include the audit data. To access the data, please contact the corresponding author (fiona.riordan@ucc.ie) or the Principal Investigator (patricia. Kearney@ucc.ie). Researchers must provide a written proposal on how the data will be used in research before access is granted.

Ethics

The research was approved in Ireland by the Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC.

Acknowledgements

We would like to acknowledge the contribution of the two primary care practices in which data collection was conducted.

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Irene M. Stratton 

Gloucestershire Retinal Research Group, Cheltenham General Hospital, Cheltenham, UK

Thank you for your careful responses to my questions and the changes you have made to the paper.

My main concern here is with the prominence given to the "8.2%" with diabetic retinopathy. Self-report is notoriously poor in the area of ophthalmology. I sit in a screening programme office for at least half a day a week and have done so for the past decade. Many of those attending for screening have no idea why they are having their eyes photographed and don't understand the report letters and so would not know if they had DR or not - especially if it was microaneurysms alone.

I am happy with the rest of the paper but this number should be relegated to the discussion and more reliable estimates of the prevalence of diabetic retinopathy provided.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Diabetic retinopathy, screening, ophthalmology, statistics.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 10 Dec 2019

Fiona Riordan, University College Cork, Cork, Ireland

Thank you for your review. We have revised the introduction to place the emphasis on objective prevalence estimates. We have moved the self-report estimate to the discussion as suggested.

Competing Interests: No competing interests were disclosed.

Version 1

Reviewer Report 14 October 2019

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**Irene M. Stratton**

Gloucestershire Retinal Research Group, Cheltenham General Hospital, Cheltenham, UK

"Diabetic retinopathy (DR) affects 8.2% of the Irish population with type 2 diabetes over 50 years and is one of the leading causes of blindness among working-age adults". Diabetic retinopathy affects about 30% of people in England with diabetes and similar in Scotland so it's unlikely to be 8.2% in Ireland. That's any DR (one microaneurysm or more). If the authors mean sight threatening DR then this should be stated.

"Screening uptake has also been identified as a challenge in countries such as the UK; with attendance rates ranging from 56–90%⁷". This is in Wales - is this range between GP surgeries or areas of Wales?

Are the appointments fixed time appointments? Are the patients able to change the time or place of the screening? Are the appointments weekdays and working day only?

Maybe those who were recorded as already having attended screening thought that the service they had been using was as good (maybe more convenient) than the DRS?

Barriers to consent would seem to me to be a bigger problem than attendance.

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Diabetic retinopathy, screening, ophthalmology, statistics.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 08 Nov 2019

Fiona Riordan, University College Cork, Cork, Ireland

Thank you for your feedback. We have detailed our response to each comment below.

"Diabetic retinopathy (DR) affects 8.2% of the Irish population with type 2 diabetes over 50 years and is one of the leading causes of blindness among working-age adults". Diabetic retinopathy affects about 30% of people in England with diabetes and similar in Scotland so it's unlikely to be 8.2% in Ireland. That's any DR (one microaneurysm or more). If the authors mean sight threatening DR then this should be stated.

8.2% is the prevalence based on self-report among a cohort aged 50 and over with type 2 only who participated in The Irish Longitudinal Study of Ageing (TILDA). Were the whole population to be taken into account including <50 years and people with type 1 this figure would be closer to 30%. In TILDA retinopathy was confirmed using the question 'Has a doctor ever told you that you have any of the following conditions related to your diabetes?'. One of the listed conditions was 'damage to the back of your eye (diabetic retinopathy)'. In the Irish prevalence study, it was clarified that the prevalence of retinopathy was much lower than that reported by a previous study, The Cost of Diabetes in Ireland Study (CODEIRE) (retinopathy: 15% vs. 8.2%), outlining that this may be explained by differences in data collection methods (medical records vs. self-report). A regional study involving primary care patients (type 1 and type 2, and based on objective data), found a higher prevalence of 24.8%, similar to an estimate in a comparable cohort in a different region (25.6%).

We have amended the background section as follows (page 3, line 53):

Diabetic retinopathy (DR) is the most common microvascular complication of diabetes. DR affects 8.2% of the Irish population over 50 years with type 2 diabetes (1), and is the leading causes of blindness among adults of working age (2). This estimate is based on self-report; studies among regional cohorts of primary care patients with type 1 and 2, based on objective data, have reported higher estimates (25-26%) (3, 4).

"Screening uptake has also been identified as a challenge in countries such as the UK; with attendance rates ranging from 56–90%⁷". This is in Wales - is this range between GP surgeries or areas of Wales?

There should have been an additional reference here (Lawrenson *et al.*) citing range in the uptake rates across England. We have revised this line (61) to include reference to studies which illustrate the variation in uptake rates internationally. The Welsh paper by Thomas *et al.* reports the uptake of the Diabetic Retinopathy Screening Service for Wales (DRSSW) as 80%. This figure is included in the range now provided (page 3 line 64):

Screening uptake has also been identified as a challenge internationally, with attendance rates ranging from 28-92% (8-14).

Are the appointments fixed time appointments? Are the patients able to change the time or place of the screening? Are the appointments weekdays and working day only?

People can contact RetinaScreen to change the time of the appointments. They cannot change the location; the appointment is offered for their local screening centre. Appointments are weekdays and during working day only. As part of a process to develop an intervention to improve the uptake of retinopathy screening (now cited in the 'Recommendations for future research' section on page 11) we conducted interviews and consensus meetings with people with diabetes. They reported difficulties arranging appointments during the day. We have clarified this point about rescheduling appointments in the methods section (page 4, line 87):

Once consented they receive an appointment for a fixed time in their local screening centre. They can contact RetinaScreen to change the time and date of their appointment.

We have also reflected on this in the discussion section (page 9, 216 -226):

An Irish study conducted in 2015 which surveyed people with diabetes attending general practices and diabetes outpatient clinics about screening behaviours, reported 91% had never previously heard of RetinaScreen (30). However, since then the programme has introduced further advertising and may be more familiar to people with diabetes. Conversely, those attending another screening service may find it is more convenient. RetinaScreen appointments are offered on weekdays and during the working day. It is possible that people may find it difficult to attend appointments at these times. Our follow-up qualitative work with patients indicated competing demands, including work and family commitments were barrier to attendance. Similarly, a 2016 systematic review identified several individual, social, cultural and environmental barriers DRS attendance, including work commitments (e.g. finding it hard to take time off work) (25).

Maybe those who were recorded as already having attended screening thought that the service they had been using was as good (maybe more convenient) than the DRS?

Yes, this could be the case. People who we interviewed as part of our follow-up qualitative work were influenced by the familiarity or locality of an existing service. There was also confusion with regard to the service being offered by the national programme, RetinaScreen, and other providers. For example, some people were attending an optician and thought this was equivalent to attending the screening programme. RetinaScreen is quality assured and facilitates patients to access the appropriate treatment pathway should they require further treatment. Therefore, it is important patients participate in the programme. We have included a line to clarify that people may find existing service more convenient (page 9, 216 -226) which links in with the point above in relation to appointment times:

Conversely, those attending another screening service may find it is more convenient. RetinaScreen appointments are offered on weekdays and during the working day. It is possible that people may find it difficult to attend appointments at these times. Our follow-up qualitative work with patients indicated competing demands, including work and family commitments were barrier to attendance.

Barriers to consent would seem to me to be a bigger problem than attendance.

We agree. Providing consent is the first point at which people are required to interact with the programme. Therefore, as we would expect the main barriers occur this point, when people decide whether to participate in the programme. We have included a line to clarify this in the discussion and abstract:

Discussion (page 8, line 208)

Over one third of people eligible to participate in RetinaScreen had not consented, suggesting barriers may occur at this stage. Encouragingly, once consented, most people (96%, n = 365/382) attended their screening appointment.

Abstract (page 2, line 45):

Implementing strategies to improve DRS uptake, in particular barriers to consent, should be a priority.

Competing Interests: No competing interests were disclosed.

Reviewer Report 08 October 2019

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Amelia J. Lake 

¹ School of Psychology, Deakin University, Geelong, Vic, Australia

² The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, Australia

The study described in this paper is rigorously designed and conducted and an appropriate early step to optimise uptake of RetinaScreen, a nationally-coordinated retinal screening programme in Ireland.

The paper describes an audit of RetinaScreen registration, consent and uptake for adults living with diabetes from two primary care clinics. The audit was conducted during initial implementation (Nov 2013 – Aug 2015).

Of the audit population (N=722), 582 had been registered with RetinaScreen. Of those, 382 consented to be part of the RetinaScreen programme with 365 attending a retinal screening appointment. With such high uptake for those who consented, the aim of the study was to identifying factors associated with non-consent to participate in RetinaScreen.

The authors reported that the only variable significantly associated with non-consent was whether people had previously attended another retinal screening service. This is a useful finding which highlights the importance of promoting ease and benefits of RetinaScreen to both customers and operators of existing private optometry practices.

I enjoyed reading the paper and the study is scientifically sound. I note the following points for consideration by the authors:

Is the work clearly and accurately presented and does it cite the current literature?

The work is clearly and accurately presented. However, many of the references cited are specific to the Irish context and/or reflect the time preceding and during the study period (i.e. <2016). The subject matter is relevant internationally and I suggest that the authors consider several reviews and studies (noted below) when discussing both known barriers and directions for future research.

Are the conclusions drawn adequately supported by the results?

Although the authors discussed the limited nature of the source data, I suggest that they more strongly emphasise this point. Existing research has consistently demonstrated that demographic (e.g. socioeconomic status, ethnicity), clinical (e.g. sub-optimal glycaemic management) and psycho-social (e.g. attitudes, beliefs, knowledge, healthcare professional recommendation, confusion between routine eye care and retinal screening) factors also strongly influence uptake and engagement with retinal screening programmes. Unfortunately, none of these factors could be considered in the current study.

Other points:

As noted by the authors, this work was conducted during an initial implementation phase and service innovation has evolved since the audit data was collected. As such, the paper would benefit from inclusion of a 'Recommendations for future research' section. Suggestions include: replication of this study (with a greater breadth of audit data) to revisit factors associated with non-consent; exploration of individual-level and practice-level barriers to RetinaScreen registration and consent to participate. If possible, the authors may like to comment on any work currently being undertaken in this area.

Minor citation, grammatical and formatting errors:

- I commend the authors' use of person-centered language, which is in accordance with international practice (see diabetes language position statements published by Diabetes Australia, Diabetes UK and the American Diabetes Association). I suggest that the authors replace 'patient' with appropriate terminology throughout the paper.
- Please rectify typo in paragraph 1 of Methods ('add' repeated in the one sentence).
- Please amend disparity between the number of people with diabetes registered with RetinaScreen reported in-text (Methods para.1, n=141) and in Fig.3 (n=140).
- Please include RetinaScreen (2019) citation and URL in references (see 'single step registration and consent' in Discussion) and include URL where appropriate (e.g. reference number 14, 16, 26).

In conclusion, the article is scientifically valid in its current form and I approve it for indexing. The issues that I have raised pertain to restrictions on the conclusions that can be drawn, given the limited data on which the analyses are based. Nonetheless, the findings are very interesting and will assist retinal screening programme implementers in determining where to direct promotional messaging and strategies, both nationally and internationally.

References

1. Diabetic Retinopathy Screening: A Systematic Review on Patients' Non-Attendance. *International Journal of Environmental Research and Public Health*. 2018; **15** (1). [Publisher Full Text](#)

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Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Diabetes, diabetic retinopathy screening and behavioural medicine.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 08 Nov 2019

Fiona Riordan, University College Cork, Cork, Ireland

Thank you for your comments and feedback and for the suggested references. We have referenced these studies in the discussion:

(page 9, line 217 - 228)

A lack of awareness of DR and the risk has previously been reported as a barrier to attendance in the international literature (6, 18, 24-27).

(page 9, line 238 - 242)

In several international studies, a recommendation to attend screening from a primary care professional has been found to motivate DRS attendance (24-26, 29). A recent systematic review of barriers and enablers to DRS across different income groups cited poor patient-physician communication as a key barrier to DRS attendance.(27)

Are the conclusions drawn adequately supported by the results?

Although the authors discussed the limited nature of the source data, I suggest that they more strongly emphasise this point. Existing research has consistently demonstrated that demographic (e.g. socioeconomic status, ethnicity), clinical (e.g. sub-optimal glycaemic management) and psycho-social (e.g. attitudes, beliefs, knowledge, healthcare professional recommendation, confusion between routine eye care and retinal screening) factors also strongly influence uptake and engagement with retinal screening programmes. Unfortunately, none of these factors could be considered in the current study.

We have revised the limitations section to emphasise these other factors (page 10, line 258 – 262): *Unfortunately the data did not include several important factors which have consistently been found to be important in previous studies, for example, socio economic status (SES) (30-33), self-management, and history of glycaemic control (24), and psycho-social factors (e.g. attitudes, beliefs and knowledge about DRS (6, 18, 24-27) and recommendations from a health care professional (24-26, 29)).*

Other points:

As noted by the authors, this work was conducted during an initial implementation phase and service innovation has evolved since the audit data was collected. As such, the paper would benefit from inclusion of a 'Recommendations for future research' section. Suggestions include: replication of this study (with a greater breadth of audit data) to revisit factors associated with non-consent; exploration of individual-level and practice-level barriers to RetinaScreen registration and consent to participate. If possible, the authors may like to comment on any work currently being undertaken in this area.

We have included the following section (page 11, line 264 -273) on future research with reference to studies in the UK, Canada and Australia:

Recommendations for future research

Given the limited nature of the data a consideration for future research could be to replicate this study using more extensive audit data. Data is routinely collected from practices participating in diabetes care initiatives across Ireland, for example, the Midlands Diabetes Structured Care Programme which reported on RetinaScreen uptake in the most recent audit (22). Determining how to enhance the uptake of DRS is recognised as an important implementation challenge for health systems, as evidenced by dedicated research programmes in the UK (13, 25), Canada (34, 35), and Australia (36). Qualitative work with Irish people with diabetes and health care professionals has been conducted to explore barriers and enablers of DRS uptake and to inform the development an intervention to be delivered in general practice (37). The feasibility trial of this intervention is currently underway (38).

Minor citation, grammatical and formatting errors:

I commend the authors' use of person-centered language, which is in accordance with international practice (see diabetes language position statements published by Diabetes Australia, Diabetes UK and the American Diabetes Association). I suggest that the authors replace 'patient' with appropriate terminology throughout the paper.

We have amended this throughout.

Please rectify typo in paragraph 1 of Methods ('add' repeated in the one sentence).

Amended.

Please amend disparity between the number of people with diabetes registered with RetinaScreen reported in-text (Methods para.1, n=141) and in Fig.3 (n=140).

Amended; 140 is correct.

Please include RetinaScreen (2019) citation and URL in references (see 'single step registration and consent' in Discussion) and include URL where appropriate (e.g. reference number 14, 16, 26).

These references have been added in appropriate location (line 57, 78, 84, 242)

Competing Interests: No competing interests were disclosed.
