Barriers to and enablers of diabetic retinopathy screening attendance: a systematic review of published and grey literature


Published in:
Diabetic Medicine

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
Link to publication record in Queen's University Belfast Research Portal

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Download date: 23. Aug. 2019
Barriers and enablers to diabetic retinopathy screening attendance: A systematic review of published and grey literature

[Running title: Barriers and enablers to diabetic retinopathy screening attendance: Review]

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Word Count: 4997
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**Funding sources:** National Institute for Health Research Health Technology Assessment Programme (NIHR-HTA) (Project Reference Number 13/137/05).

**Conflicts of interest:** none
Abstract

Aims

Attendance for screening to detect sight-threatening diabetic retinopathy is suboptimal. Identifying the theoretical determinants (barriers and enablers) of attendance behaviour can inform interventions to improve attendance. We aimed to identify and synthesise studies reporting modifiable barriers/enablers associated with retinopathy screening attendance, and identify those most likely to influence attendance.

Methods

We searched MEDLINE, EMBASE, PsycINFO, Cochrane Library and sources of grey literature to February 2017. Data (i.e. participant quotations, interpretive summaries, survey results) reporting barriers/enablers were extracted and deductively coded into domains from the Theoretical Domains Framework; with domains representing categories of theoretical barriers/enablers proposed to mediate behaviour change. Inductive thematic analysis was conducted within domains to describe the role each domain plays in facilitating or hindering screening attendance. Domains that were more frequently coded and for which more themes were generated were judged more likely to influence attendance.

Results

Sixty-nine primary studies were included. We identified six theoretical domains (‘environmental context and resources’, ‘social influences’, ‘knowledge’, ‘memory, attention, decision processes’, ‘beliefs about consequences’ and ‘emotions’) as key mediators of diabetic retinopathy screening attendance behaviour. Specific barriers/enablers populating these domains were identified at multiple levels. For example, some patients confused screening with routine eye care; recommendations by a healthcare professional facilitated screening attendance; at the system level, inaccurate registers were reported; and community-level media coverage was an enabler.
Conclusions

Across a variety of contexts, we found common barriers and enablers to retinopathy screening that are important to target by interventions aiming to increase screening attendance.

Keywords: Diabetic retinopathy, Screening attendance, Barriers, Enablers, Facilitators, Theoretical Domains Framework.
Introduction

Diabetic retinopathy is a leading cause of severe sight loss in people of working age\textsuperscript{1,2}. Although effective treatments are available\textsuperscript{3}, their success is dependent on early detection and timely referral. Diabetic retinopathy screening (DRS) effectively reduces risk of sight loss; however, screening attendance is consistently below recommended levels\textsuperscript{4-6}.

Interventions that target DRS behaviour are more likely to be effective if they target the determinants (barriers and enablers) of attendance for screening. The Theoretical Domains Framework (TDF) of behaviour proposes 14 ‘theoretical domains’ for identifying and categorising barriers/enablers (e.g. ‘knowledge,’ ‘beliefs about consequences,’ ‘social influences’). Each domain represents a set of related constructs that may mediate behaviour change. For example, the ‘social influences’ domain includes the constructs ‘social support,’ ‘group norms’ and ‘social comparison’\textsuperscript{7}.’ The TDF thus provides a theory-driven basis for investigating the potentially wide-ranging barriers/enablers of behaviour change.

The TDF has been applied in numerous studies to systematically identify and characterise barriers/enablers to implementation across various clinical contexts, primarily through interview and survey studies. More recently the TDF has been applied in systematic reviews of barriers/enablers, as a coding framework for data synthesis\textsuperscript{8}. Identifying barriers/enablers in the literature, framing these in terms of theoretical domains, and identifying their likely importance for screening attendance, are steps that might explain why some interventions are more effective than others. This would enable intervention designers to optimise interventions by ensuring that they target the likely determinants of screening attendance.
We aimed to gain an understanding of DRS attendance behaviour by identifying the theoretical determinants of DRS attendance.

The specific objectives were to:

- Identify the published and grey literature reporting perceived barriers and enablers associated with DRS attendance
- Extract reported barriers/enablers and categorise these according to TDF domains
- Apply pre-specified criteria to identify the likely importance of TDF domains in influencing DRS attendance.
Methods

A detailed protocol for this review has been published and registered in PROSPERO (CRD42016032990). In brief, we included studies reporting primary data relating to modifiable factors that might hinder or facilitate DRS attendance. We included studies reported in English, conducted between January 1990 and February 2017, basing the lower date limiter on the publication of the St Vincent Declaration (“Diabetes care and research in Europe: the Saint Vincent declaration,” 1990), which set a target to reduce new blindness in Europe by one third or more, as this is arguably the catalyst for the development of DRS programmes worldwide. Six bibliographic databases were searched to identify the published literature [MEDLINE, EMBASE, PsycINFO, Web-of-Science, CENTRAL in the Cochrane Library, Proquest]. An example search strategy for MEDLINE is provided in supplementary Appendix A. Grey literature databases were also searched, e.g. OpenGrey, and PsycEXTRA, alongside a Google search engine search using the terms: “diabetic retinopathy” AND screening AND [barrier* OR “facilitat* OR enable]. We limited the Google search to the first 15 pages. Reference lists of included studies were screened for additional studies. Following de-duplication, one member of the research team (EGR) screened all identified titles and abstracts against the inclusion/exclusion criteria. A second review author (FL) screened approximately 10% of the titles and abstracts to check reliability. Full-text copies of potentially eligible studies were obtained and a final decision was made on inclusion.

Data extraction and analysis

We followed analysis methods used in previous studies applying the TDF to interview transcripts from semi-structured interviews. These methods follow a combined content and framework analysis approach (Figure 1) involving four steps: 1) data extraction; 2) deductive analysis (TDF coding); 3) inductive analysis (thematic synthesis); and 4) identifying
important domains.

FIGURE 1 HERE

Step 1: Data extraction.
One review author (EGR) identified and extracted data reporting participants’ (e.g. people with diabetes and/or healthcare professionals (HCPs)) perceptions of modifiable barriers/enablers to DRS attendance. Extracted data included participant quotations from qualitative studies, quantitative findings from questionnaire and survey studies and authors’ interpretive descriptions and summaries of results. Predictors of and associations with attendance/non-attendance reported in quantitative studies were also extracted.

Step 2a. Pilot coding exercise
In order to practise coding extracted data into TDF domains, three pilot transcripts were collaboratively coded using the TDF. Any discrepancies were discussed until agreement was reached (supplementary Appendix B presents the TDF codebook).

Step 2b. TDF coding
One review author (EGR) coded the data extracted from all remaining studies. Extracted data was coded according to which TDF domain they were judged to represent, guided by the TDF codebook.

Step 3: Thematic synthesis
In line with a framework analysis approach, step 3 focussed on sifting and sorting the data within each domain to thematically synthesise and identify emerging content themes. One review author (EGR) grouped together similar data relating to perceived barriers/enablers to DRS attendance, for each of the 14 domains. Theme labels and, where appropriate, sub-theme labels were then generated for each cluster of similar data to express these shared
views. These initial grouping and theme labels were reviewed by two additional review authors (FL, JF) to assess their agreement with: 1) grouping of extracted data; 2) assigned theme labels; and 3) whether the theme was appropriately allocated to the given domain. Disagreements were discussed until consensus was reached and theme groups/labels/allocation of domains were revised accordingly.

Additionally, EGR assigned the data within the themes as either representing barriers or enablers to DRS attendance. This was usually clear from the original papers as it was either reported in a table titled ‘barriers to DRS’ or ‘enablers to DRS’ attendance or interpreted as one or the other by the study author. Each theme/sub-theme was then classified as: 1) a barrier theme if the data within it related to barriers only (e.g. receiving insufficient notice of appointments); 2) an enabler theme if the data within it related to enablers only (e.g. support from local community groups/networks) and 3) both a barrier and an enabler theme if it related to both (e.g. [In]flexibility of choice of times/dates of appointments).

Step 4: Identifying important domains
Each domain identified in step 2 was reviewed against an established set of three ‘importance criteria’\textsuperscript{11} to determine which domains were likely to be important for influencing screening attendance: (1) \textit{frequency} (number of studies that identified each domain; (2) \textit{elaboration} (number of themes and sub-themes) within each domain; and (3) ‘\textit{expressed importance}’ (either a statement from the authors’ interpretation or direct quotes from study participants expressing importance).
Quality assessment

One review author (EGR) rated included studies using items from the Critical Appraisal Skills Programme Qualitative Checklist (CASP) (http://www.casp-uk.net/casp-tools-checklists) and the Mixed Methods Appraisal Tool (MMAT) (https://www.mcgill.ca/familymed/research/projects/mmat). Mixed-methods studies were appraised using both quantitative and qualitative appraisal tools. A second review author (JL) assessed a random sample of studies (20%) and differences of opinion regarding quality were resolved by discussion.
Results

Study Characteristics

After removing duplicates we screened 3,194 studies and reviewed 234 full text articles. We excluded 165 studies with reasons and included 69 studies that met our inclusion criteria (see Figure 2 for the PRISMA flow diagram). Table 1 presents an overview of the characteristics of included studies. Full details are provided in supplementary Appendix C.

FIGURE 2 HERE
TABLE 1 HERE

Quality of included studies

Overall, studies were judged to be at low, medium or unclear risk of bias (supplementary Appendix D).

Deductive analysis

In total, 737 units of data were extracted: 468 qualitative (167 quotations from study participants and 301 from authors’ conclusions) and 269 quantitative (e.g., percentages of participants agreeing with a questionnaire item, or odds ratios).

Reported barriers were identified in all but one of the TDF domains (‘skills’). Enablers were identified in all but two domains (‘beliefs about capabilities’ and ‘skills’). Overall there were almost twice as many themes/sub-themes identified as barriers only than as enablers only (61 vs 34). Twenty-one themes/subthemes represented both barriers/enablers. Table 2 reports the frequencies of barriers/enablers identified within each TDF domain.

TABLE 2 HERE
Inductive analysis

Supplementary Appendix E presents all themes and sub-themes identified within each domain, alongside frequencies, relevant studies and sample quotes. A narrative description of the themes, within domains, is presented below, for the domains that were identified as high in importance.

Importance of TDF domains

Domain frequency

The data units were coded most frequently into the following domains: 1) environmental context and resources (52 studies); 2) social influences (35 studies); (3) knowledge (35 studies); 4) memory, attention and decision processes (34 studies); 5) beliefs about consequences (26 studies); and 6) emotions (23 studies).

Level of elaboration

Approximately 82% of themes/sub-themes relating to barriers and 69% relating to enablers were captured in the same six theoretical domains (Table 2, columns 2 & 3). Table 3 (columns 3 & 4) lists the numbers of themes and sub-themes identified within each domain.

Rank order of domain importance

In Table 3, the fourteen TDF domains are presented in rank order. In general, there was good convergence between frequency (number of studies in which the domain was evident) and elaboration (number of themes and sub-themes based on the inductive analysis).

TABLE 3 HERE
**Expressed importance**

Study authors’ interpretations of the study findings (e.g., in Discussion sections) articulating specific beliefs as important influences, also provided evidence of the importance of barriers/enablers. Quotations expressing importance are presented in supplementary Appendix G alongside the domain they were judged to represent. For example, the following quotes from included studies represent expressed importance for the domain: 1) ‘environmental context and resources’ (“Getting to and from screening appointment was important pragmatically for many patients, who had to overcome a range of issues”) and 2) ‘beliefs about consequences’ (“The main reason for refusal was the retinal photos taken might worsen sight”). The number of studies that identified each domain through expressed importance was counted: the higher the count, the higher the expressed importance. On this basis, important domains were: environmental context and resources (21 studies); knowledge (19 studies); memory attention and decision processes (12 studies); social influences (10 studies); beliefs about consequences (6 studies); and emotions (5 studies). This list corresponds well with the list of six domains of high importance identified by the importance criteria ‘frequency’ and ‘elaboration’ (Table 3).

**TABLE 3 HERE**

In summary, there was good convergence between all three criteria for identifying the importance of six theoretical domains, suggesting these domains are likely to be key mediators of screening attendance behaviour.
Thematic synthesis for domains identified as having high importance

The content themes in the domains that were identified as potentially important factors influencing screening attendance are described in further detail in the sections below, with example references.

Environmental context and resources (52 studies)

Theme: Accessibility to the screening clinic (31 studies)

This theme was identified by both patients and HCPs. “Accessibility” included issues with transportation (e.g. lack/cost/poor quality) and distance to the DRS clinic. In one correlational study, in an urban area, attendance was associated with living within an eight-mile radius of the screening facility and with access to public transportation\(^\text{12}\). In several studies, distance from home to DRS services was thought to improve attendance\(^\text{13,14}\). In two studies, mobile screening units were associated with higher attendance, compared to screening appointments at high street optometrists\(^\text{15,16}\).

Theme: Time (competing demands) (29 studies)

Patients often cited ‘time constraints’ as a barrier to attendance. Competing demands on their time were due to: work commitments (e.g. finding it hard to take time off work); family responsibilities (e.g., childcare); and clashes with other immoveable life events (e.g., holidays, religious/cultural activities. One HCP commented that: “People go away...to the Caribbean, Africa, Asia, Pakistan, India... and because they’re away they’re not going to get their screening done”\(^\text{17}\).
Themes: Financial concerns (27 studies) and consequences of private insurance (5 studies)

Financial concerns, such as the cost of the eye exam/care and the cost or lack of insurance were common, especially in the US studies\textsuperscript{18,19} but attendance was sometimes not influenced by insurance\textsuperscript{20}. Self-employed or casual employees reported costs owing to lost income when they took time off work to attend screening appointments\textsuperscript{21,22}.

Theme: Scheduling appointment issues (19 studies)

Problems with scheduling appointments, including a long wait to receive an appointment and inability to get an appointment, were barriers to attendance. Three UK studies mentioned that patients had not received an invitation or had been given insufficient notice\textsuperscript{22-24}. Patients expressed a preference for appointment flexibility but, in one study, older patients preferred fixed appointments\textsuperscript{25}. Centrally-allocated appointments were perceived by some HCPs to be problematic\textsuperscript{14}, as they undermined their own attempts to bring patients to the clinic\textsuperscript{17}.

Theme: Time (service issues) (9 studies)

Long wait times on the day of the appointment and lengthy appointments were barriers to attendance. For multiple appointments patients reported ‘waiting around’ all day\textsuperscript{26}, while long appointments could be especially problematic for people with diabetes, due to lengthy food abstinence\textsuperscript{27}.

Theme: Referral issues (8 studies)

The absence of a referral was a substantial problem for some. In one UK study, a patient who normally attends her screening appointments had attempted to access screening through her GP practice but was refused as she was in temporary accommodation waiting to be
rehoused\textsuperscript{27}. In some countries, patients were not referred because there was no available eye doctor\textsuperscript{13}. Inaccurate or incomplete registers could also result in lack of referral\textsuperscript{14,17}.

*Theme: Specialist diabetes services and staff (6 studies)*

The integration of specialist diabetes services or ‘one-stop-shops’ was viewed as beneficial: “\textit{if the eye appointment was on the same day as the DM [Diabetes Mellitus] appointment I would definitely attend}”\textsuperscript{13}. However, inflexible or incompatible administration systems were a problem\textsuperscript{17}. Having a specialist practice nurse was associated with increased attendance in two studies\textsuperscript{15,28}.

*Social influences (Total = 35 studies)*

*Theme: Doctor-patient communication (25 studies)*

Doctor-patient communication was discussed in many studies. A recommendation by the HCP to attend screening was an enabler\textsuperscript{29,30} and having received a recommendation from a healthcare provider to attend screening was associated with attendance\textsuperscript{31-33}. The absence of a HCP recommendation was a barrier in other studies\textsuperscript{34-37}. Some patients reported lack of information provision from their healthcare providers\textsuperscript{26,29,38}, especially at the point of diagnosis.

Language and/or communication style, especially for patients whose first language was not the same as the HCP’s, was a barrier. In some studies patients reported language difficulties as the primary reason for not attending screening appointments\textsuperscript{23}. In one study a patient “\textit{didn’t understand her physician and was too intimidated to ask him to slow down when conversing}” and was unaware of the recommendation to attend\textsuperscript{21}. In some studies, participants felt that systems were in place to overcome this barrier (e.g., provision of
interpreters and accompanying family members)\textsuperscript{14,27,39}. However, HCPs noted that accompanying relatives might not have the language skills needed to interpret correctly\textsuperscript{14}.


text

**Theme: Trust in doctors (5 studies)**

Advice and recommendations from doctors were perceived to be an enabler in several studies and some patients were content to rely on their doctor’s advice regarding screening\textsuperscript{29}. However, in one study it was reported that a small number of patients did not trust doctors\textsuperscript{30} and another reported that low confidence in doctors was more common in non-attenders than attenders\textsuperscript{33}. Perceived discrimination in the healthcare system was associated with longer time periods between screening visits\textsuperscript{40}. Conversely, a study of Aboriginal patients in Canada reported that a culturally sensitive community-based clinic overcame such barriers\textsuperscript{21}.

**Theme: Presence or absence of support from family members (N =11)**

Family support, both practical (e.g. providing transport to the clinic) and emotional (e.g. encouragement, offering gentle reminders), was an enabler\textsuperscript{29,30}, and its absence was a barrier\textsuperscript{41,42}. Family support was especially important to patients in communities that traditionally rely on their family members to look after them\textsuperscript{39} or when the patient had a physical disability\textsuperscript{37}.

**Theme: Encouragement/support from local community groups/networks (3 studies) plus media attention and coverage (4 studies)**

Community-based programmes fostered trust and support\textsuperscript{21} and provided information\textsuperscript{39,43}. Furthermore, local media (TV, newspapers, radio channels) had potential to raise awareness and promote attendance at screening, whereas lack of media attention could contribute to low attendance\textsuperscript{27}.
Theme: Stigma (3 studies)

Some patients spoke of social stigma or shame being attached to a diabetes diagnosis\textsuperscript{39,43}. HCPs also spoke about the difficulties of being confronted by a patient’s perceptions of stigma\textsuperscript{44}.

Knowledge (Total = 35 studies)

Theme: (Lack of) Awareness of illness (19 studies)

Several studies reported that patients’ lack of knowledge about diabetes, diabetic retinopathy and the link between the two was a barrier to attendance. Understanding of how diabetes can affect vision was an essential and motivating factor associated with attendance: “If I had realised the possibility that I would suddenly go (blind), that I wouldn’t realise that it was coming on, I think I would have taken more care.”\textsuperscript{45}. There was a significant association between believing diabetes could affect vision and attendance\textsuperscript{42}. HCPs argued that some patients lack understanding of the link between diabetes and vision\textsuperscript{22,46}. However, HCPs were not always happy to make the link clear, being careful not to alarm their patient: “I would never say to someone that there is a possibility that you could go blind from diabetes”\textsuperscript{45}.

Theme: (Lack of) Awareness of screening (17 studies) and confusion between screening and routine eye tests (8 studies)

Lack of awareness of the need to screen (including recommended frequency) was a barrier to attendance, and awareness was an enabler: “On the one hand a group of over-65s had very little knowledge about why they attend for DRS. They know it is important that they go, and so they keep the appointments but they did not know ... that screening helped to prevent blindness”\textsuperscript{14}. In one study, patients who were not able to explain why diabetic retinopathy screening is needed reported more barriers than those who could\textsuperscript{47}. Some patients were not
aware of the difference between DRS and routine eye tests; hence, some patients believed they had attended screening when they had not\textsuperscript{23,27,32}.

	extit{Theme: Education and training} (8 studies)

Receiving diabetes self-management or blindness prevention classes significantly increased attendance\textsuperscript{19,48,49}, whilst patients who had not received education on diabetes care were screened significantly less often than those who had\textsuperscript{50}.

	extit{Memory, attention and decision processes} (Total 34 studies)

	extit{Theme: Symptoms} (24 studies)

The absence of symptoms often resulted in patients deciding not to screen\textsuperscript{14,22,37,43,51}. This barrier was evident across different countries and screening contexts (e.g. UK, USA, Africa, Asia, and Australia) and may be especially relevant for men\textsuperscript{13}. However, even when symptoms were experienced some patients did not always link these to diabetic retinopathy but to an inevitable consequence of getting older\textsuperscript{37}.

	extit{Theme: Competing health problems} (13 studies)

Many patients experience competing health problems that can overshadow concerns with their eyes. For some patients, missing a screening appointment might be due to a temporary illness or health problem\textsuperscript{23,24,27} but for others it was a consequence of comorbidities\textsuperscript{25,42,52} or the burden of diabetes\textsuperscript{17,29,39}.

	extit{Theme: Forgetting} (10 studies)

For some patients, failure to attend screening was attributed to: forgetting to make an appointment\textsuperscript{25}; forgetting to attend\textsuperscript{24,26,53}; or forgetting whether they had previously
attended. Several studies alluded to HCPs’ attempts to prompt or remind patients in advance of their upcoming appointment and some reported that reminders prompted them to maintain regular attendance.

**Theme: Patients’ perception that they have been checked elsewhere (5 studies)**

Sometimes patients believed they had been or were going to be checked elsewhere because they were transferring their eye care to another specialist, or their eyes had already been examined by a family physician or as part of routine eye test by an optician.

**Theme: Knowing it’s a routine test (3 studies)**

An enabler was expecting screening to be part of their routine care.

**Beliefs about consequences (Total = 26 studies)**

**Theme: Perceived necessity of screening (13 studies) and screening provides valuable information on the health status of your eyes (7 studies)**

Some patients do not attend as they believe it is unnecessary. ‘I was told that my eyes are fine at my last screening’, ‘my diabetes is under control’ and ‘screening is not useful at my age’. However, other patients reported that screening will identify problems early and this was motivating. Others reported that screening can provide reassurance that all is well. Some patients explained that they attended screening as family members had experienced problems with diabetes or retinopathy in the past.


Themes: Short-term effects of screening (11 studies) and concerns about the harmful effect of the screening procedure (4 studies)

Some patients reported that screening has negative short-term effects, for example, some patients dislike mydriatic eye drops (given to temporarily dilate the pupils)\textsuperscript{31,54,58}, which were often uncomfortable or, in some cases, painful\textsuperscript{27,29,37}. In one case a woman had developed a phobia of these eye drops\textsuperscript{24}.

Mydriatic drops were also inconvenient due to their temporary effects on vision. Hence, patients were prohibited from driving until the effects of the drops had worn off or it was difficult to navigate public transport\textsuperscript{27,31}. Some patients reported that screening could have long-term negative effects on vision, either from the drops or from the retinal photographs\textsuperscript{23,59}.

Emotions (Total = 23 studies)

Theme: Fear or anxiety (20 studies)

For some patients, the fear of losing their vision was a strong incentive to attend screening\textsuperscript{14,26,31}. However for some, fear of a diagnosis of diabetic retinopathy was a barrier\textsuperscript{45,57,60}. Patients were also fearful of the screening procedure\textsuperscript{24,29,47} or of a medical intervention if they were confronted with a diagnosis\textsuperscript{29,41,61}. In one study, non-adherent patients expressed less concern about losing their vision than adherent participants\textsuperscript{62}.

Theme: Defensive responses

Defensive responses were sometimes noted. In one study young adults who participated in their study reported that they wanted to attend screening, but actively engaged in avoidance strategies\textsuperscript{56}. In other studies patients simply refused to attend, without explanation\textsuperscript{13,24,46}. 

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“[the patient] is refusing to even discuss his condition, so all you can do is keep sending invites”24.

Theme: Emotional burden of diabetes

For some patients, attending screening appointments could exacerbate negative emotions relating to lack of control of their diabetes, including feelings of failure, guilt, fear and anger14,26,45.

Details of the domains and the corresponding barriers/enablers that were considered less important are provided in supplementary Appendix F.
Discussion

We employed a systematic, theory-informed and replicable approach to identifying barriers and enablers associated with DRS attendance. The combined content and framework analysis identified six TDF domains as the most influential factors in screening attendance: 1) ‘environmental context and resources’, 2) ‘social influences’, 3) ‘knowledge’, 4) ‘memory, attention and decision processes’ 5), ‘beliefs about consequences’ and 6) ‘emotions’. Interventions that target these domains may be more likely to increase screening attendance. In contrast, three TDF domains seemed to have the least influence on screening: 1) ‘optimism’, 2) ‘reinforcement’ and 3) ‘skills’. Hence, we propose that interventions targeting these three domains are less likely to increase screening attendance (Tables 2 and 3).

Implications for practice

Thematic synthesis within domains resulted in specific content themes that may help to identify potential targets for future QI interventions. The content themes were identified at multiple levels, including: the patient (e.g. confusion between screening and routine eye care); the HCP (e.g. recommendation to screen, or lack of such recommendation, by HCP); the healthcare system (e.g. inaccurate registers) and the wider community (e.g. lack of media coverage) (supplementary Appendix F).

Four key recommendations based on the findings from the thematic synthesis are: (i) reduce inconvenience to patients; (ii) increase awareness among patients of the importance of screening; (iii) increase patients’ sense of comfort and support; and (iv) improve message content.
i). Reduce inconvenience to patients

Many of the barriers/enablers identified relate to perceptions of convenience. Difficulties with transportation, distance to the screening clinic, competing health and time demands, lack of instrumental/pragmatic support and scheduling appointment issues were reported to be important factors that may hinder attendance, whereas attempts to reduce inconvenience by improving accessibility, flexible appointments and integrating services were reported to facilitate attendance. Therefore, providing local screening facilities, ‘one-stop shops’ (integrating screening with other DM appointments), offering flexible appointment systems to patients and childcare facilities, and providing transportation may be advantageous.

ii). Increase awareness of the importance of screening

Both patients and HCPs reported that a lack of awareness or understanding of diabetic retinopathy, DM and the link between the two was a barrier to attendance. Similarly, a lack of awareness of the importance of screening, the recommended frequency or a lack of targeted patient education were also reported to be patient barriers, whereas providing blindness prevention programs or general diabetes self-management education was reported to be an enabler. The perceived absence of a HCP recommendation to attend screening and/or a lack of information provision from the HCP were also perceived patient barriers and therefore facilitating HCPs to provide such recommendations could potentially address this barrier. Similarly, using the local media and local community networks to improve awareness and promote attendance was reported as a potential but often untapped resource.

iii). Increase patients’ sense of comfort and support

Some patients reported barriers relating to difficulties with: communicating with HCPs, a lack of trust in doctors, a lack of emotional support, and negative emotions (e.g. fear, worry). Although there were limited reports of potential enablers to overcome such barriers, there was some mention that: community-based clinics; social/cultural compatibility between the
patient and HCPs; and compassion from the HCP were enablers which might encourage patients’ feelings of comfort, support and trust. There is some evidence for additional benefits of using culturally competent interventions that are tailored to the needs of people from ethnic minority groups for improving diabetes-related outcomes.\textsuperscript{63}

\textit{iv). Improve message content}

The absence of symptoms was a commonly-mentioned barrier to attendance. Furthermore, some patients perceived that DRS was not necessary, especially if they felt their diabetes was under control, they were not old, or if their previous test result was clear. Therefore, it would seem desirable to provide messages that highlight the asymptomatic nature of diabetic retinopathy and make salient the potential consequences if left unchecked. Likewise providing messages that emphasise and highlight the benefits of early detection, the safety of the procedure and the reassurance a positive result can provide would be recommended and help in part overcome barriers around emotional fears and concerns. In addition, a barrier related to the confusion between attendance at diabetic retinopathy screening and routine eye tests. Messages highlighting the difference between the two and emphasising the importance of continuing to attend despite attendance at other eye tests could be helpful. Furthermore, messages that emphasise that DRS is a routine part of diabetes care are also recommended as this belief was identified as an enabler. The offer of a reminder to attend DR screening was also regarded as an enabler addressing this domain.

\textbf{Recommendations for future research}

Identifying disparities in adherence to screening was not an objective of the current review and therefore it is not possible to recommend which sub-groups/populations require the greatest attention. However, a recent review has summarised the literature from the US and highlighted disparities in a number of sub-groups including: males; youth-vs. adult-onset
diabetes; specific minority populations; low socioeconomic status. Future research could
endeavour to identify which theoretical domains are most important for people within these
sub-groups. For example, we identified only two studies that explored factors impacting
young adults. This patient group is not only under-researched but also at high risk of
vision loss/blindness from diabetic retinopathy. In one of these studies, Lake et al. compared the barriers and enablers of young adults with type 2 diabetes (18-39 year) with a
group of older adults with type 2 (40+ years) and found that younger adults had a higher
number of barriers compared to older adults as well as factors that appeared to be highly
relevant to younger adults such as ‘social comparison with others’, ‘concerns for the impact
on the family unit’, ‘unrealistic optimism’ and ‘perceived invulnerability’. Such knowledge
will allow for future interventions to be tailored to those most at risk.

**Strengths, limitations and challenges**

The combination of deductive coding (informed by a theoretical framework to guide barrier
identification) and inductive analysis (to allow more granular content themes, unanticipated
findings and patient insights to emerge) is a strength of this review. Furthermore, the review
identified potential influence of patient, HCP, organisational and contextual factors on
screening attendance. We were able to code all extracted data from the 69 studies into the
TDF domains, thus demonstrating that the TDF framework provides a comprehensive
coverage of barriers and enablers.

Another strength was its inclusiveness. We included published and grey literature; qualitative
and quantitative methodologies; patients’ and HCPs’ perspectives; and any context and/or
screening model. Although not all barriers and enablers will be relevant to all settings, this
review gives a comprehensive overview of potential factors that may influence screening attendance.

The studies in this review predominantly identified barriers and enablers from the perspective of the patient rather than the perspective of the organisation or HCP. Even the data we had from the HCPs mostly focused on their views regarding patient barriers.

A number of the studies were poorly described. This hampered our ability to differentiate between HCPs’ and patients’ perspectives or to distinguish between different patient subgroups. Furthermore, the data extracted and analysed in the present review was that which was reported, analysed and interpreted by the study authors. It is possible that our data set may have been biased, in that authors may have selectively reported findings on perceived barriers/enablers that were more prevalent, interesting, or had a better fit with the stated research question. A further limitation is that the theoretical framework used is limited in so much as it does not specify relationships between domains and hence the likely strength of direct impact of barriers on behaviour is not known.

Concluding remarks

Six theoretical domains were identified as the factors most likely to be key mediators of DRS attendance behaviour. Interventions to increase DRS attendance are more likely to be effective if they target these domains. Thematic synthesis identified key content themes that offer further insight into which specific issues need to be addressed (notably, accessibility of screening clinic, time (competing demands), financial concerns, and scheduling appointment issues). Future research is needed to identify which domains are most important for subgroups of patients that have been identified as most at risk.
## TABLE 1. Characteristics of included studies

<table>
<thead>
<tr>
<th>Study characteristics</th>
<th>Frequencies (TOTAL N=69 studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study Methods</strong></td>
<td>45 (65%) quantitative (e.g. questionnaires, surveys)</td>
</tr>
<tr>
<td></td>
<td>18 (26%) qualitative (e.g. interviews/focus groups)</td>
</tr>
<tr>
<td></td>
<td>6 (9%) mixed methods</td>
</tr>
<tr>
<td><strong>Study Location</strong></td>
<td>30 (43%) USA.</td>
</tr>
<tr>
<td></td>
<td>13 (19%) UK</td>
</tr>
<tr>
<td></td>
<td>10 (14%) Asia</td>
</tr>
<tr>
<td></td>
<td>6 (9%) Africa</td>
</tr>
<tr>
<td></td>
<td>4 (6%) Australia</td>
</tr>
<tr>
<td></td>
<td>3 (4%) Canada</td>
</tr>
<tr>
<td></td>
<td>2 (3%) Europe 2</td>
</tr>
<tr>
<td></td>
<td>1 (1.5%) South America</td>
</tr>
<tr>
<td><strong>Publication Type</strong></td>
<td>56 (81%) full-text in peer-reviewed journals</td>
</tr>
<tr>
<td></td>
<td>5 (7%) full-text in unpublished reports/dissertations</td>
</tr>
<tr>
<td></td>
<td>8 (12%) abstracts/posters.</td>
</tr>
<tr>
<td><strong>Perspective of Reported Barrier/Enabler</strong></td>
<td>53 (77%) patient perspective</td>
</tr>
<tr>
<td></td>
<td>15 (22%) both patient and HCP perspectives</td>
</tr>
<tr>
<td></td>
<td>- n=11 specific ethnic groups (e.g. African Americans; American Indians; Aboriginal Canadians; people with South Asian or Hispanic origin)</td>
</tr>
<tr>
<td></td>
<td>- n=5 people who were classified as either non- or late- attenders</td>
</tr>
<tr>
<td></td>
<td>- n=3 adults (e.g. 40+)</td>
</tr>
<tr>
<td></td>
<td>- n=2 younger adults</td>
</tr>
<tr>
<td></td>
<td>- n=2 (7%) women only</td>
</tr>
<tr>
<td></td>
<td>- n= 2 people who had been diagnosed with DR</td>
</tr>
<tr>
<td></td>
<td>- n=1 patients receiving treatment</td>
</tr>
<tr>
<td></td>
<td>- n=1 participants in a blindness prevention programme</td>
</tr>
<tr>
<td></td>
<td>- n=1 Medicare population</td>
</tr>
<tr>
<td></td>
<td>- n=1 patients who were also hospital staff.</td>
</tr>
</tbody>
</table>
TABLE 2. Frequencies (number of papers reporting each theme/sub-theme) of barriers and enablers coded to each of the 14 domains of the Theoretical Domains Framework.

**Inductive analysis**

<table>
<thead>
<tr>
<th>TDF Domain</th>
<th>Barriers Only</th>
<th>Enablers Only</th>
<th>Both barriers and enablers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental context &amp; resources</td>
<td>17</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Social influences</td>
<td>6</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Knowledge</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Memory attention &amp; decision processes</td>
<td>9</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Beliefs about consequences</td>
<td>9</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Emotions</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Social professional role &amp; identity</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Goals</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Beliefs about capabilities</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Behavioural regulation</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Intention</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Optimism</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Reinforcement</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Skills</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
TABLE 3. Frequency and elaboration within each of the 14 Theoretical Domains Framework domains, presented in rank order from most important to least important.

<table>
<thead>
<tr>
<th>TDF Domain (rank order)</th>
<th>Frequency</th>
<th>Level of elaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of studies identified</td>
<td>No. themes</td>
</tr>
<tr>
<td>1. Environmental context &amp; resources</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>2. Social influences</td>
<td>35</td>
<td>11</td>
</tr>
<tr>
<td>3. Knowledge</td>
<td>35</td>
<td>6</td>
</tr>
<tr>
<td>4. Memory attention &amp; decision processes</td>
<td>34</td>
<td>6</td>
</tr>
<tr>
<td>5. Beliefs about consequences</td>
<td>26</td>
<td>9</td>
</tr>
<tr>
<td>6. Emotions</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td>7. Goals</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>8. Social professional role &amp; identity</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>9. Intention</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>10. Beliefs about capabilities</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>11. Behavioural regulation</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>12. Optimism</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>13. Reinforcement</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>14. Skills</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
FIGURE 1: Flow diagram of steps in the analysis.

1. **Extract data**
2. **Step 2(a) Conduct pilot coding exercise**
   - Code extracted data into TDF domains
   - **Step 2(b)** Sift and sort data to thematically synthesis and generate theme labels
3. **Step 3 Identify ‘important’ domains**
4. **Step 4**
Eligibility

165 full-text articles excluded
- Not linked to attendance = 57
- No barriers/enablers = 31
- Non-modifiable factors only = 19
- Not reported in English = 15
- Reviews/overviews = 14
- Duplicate results = 11
- Mixed with other patient groups = 5
- No results = 4
- Results mixed with other screening = 3
- Results mixed with other diabetes care = 3
- No access = 2
- Authors perspective only = 1

Included

69 studies included in systematic review

FIGURE 2: PRISMA flow diagram.
References


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59. Hossen AZ, M; Chakrabarti, R; Kawasaki, R; Critchley C; Shaw, J; Finger, R; Islam, F. Prevalence of diabetic retinopathy and the barrier in screening in a rural district in Bangladesh (abstract of unpublished work) [18/07/17]. URL: https://researchbank.swinburne.edu.au/items/fee628f8-972f-499a-8e0a-843377e8fb96/1/ (accessed 8.1.18).


**Acknowledgements:** We wish to acknowledge the 'What Works to Increase Attendance for Diabetic Retinopathy Screening? An Evidence Synthesis (WIDR-EyeS)' Project Stakeholder Advisory Group for their input to the development of the protocol for this review.

We thank Iris Gordon, Information Specialist for Cochrane Eyes and Vision Group for developing the electronic search strategy for the review.