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## Review Article

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

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## **What's new?**

- Diabetic retinopathy screening is effective but uptake is sub-optimal.
- Theoretical determinants (barriers and enablers) of screening attendance were identified that operate at the level of the person with diabetes (e.g. confusion between retinopathy screening and routine eye care), the healthcare professionals (e.g. lack of recommendation to screen), the healthcare system (e.g. inaccurate registers), and the wider community (e.g. lack of media coverage).
- Findings from this study will help to inform which theoretical determinants to target in interventions that seek to improve attendance at diabetic retinopathy screening.

## **Abstract**

**Aims** To identify and synthesize studies reporting modifiable barriers/enablers associated with retinopathy screening attendance in people with Type 1 or Type 2 diabetes, and to identify those most likely to influence attendance.

**Methods** We searched MEDLINE, EMBASE, PsycINFO, Cochrane Library and the 'grey literature' for quantitative and qualitative studies 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' (75% of included studies), 'social influences' (51%), 'knowledge' (50%), 'memory, attention, decision processes' (50%), 'beliefs about consequences' (38%) and 'emotions' (33%)] as the key mediators of diabetic retinopathy screening attendance. Examples of barriers populating these domains included inaccurate diabetic registers and confusion between routine eye care and retinopathy screening. Recommendations by healthcare professionals and community-level media coverage acted as enablers.

**Conclusions** Across a variety of contexts, we found common barriers to and enablers of retinopathy screening that could be targeted in interventions aiming to increase screening attendance.

## **Introduction**

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

Interventions that target screening behaviour are more likely to be effective if they address the determinants (barriers and enablers) of screening attendance. The Theoretical Domains Framework of behaviour change [7] proposes 14 ‘theoretical domains’ for identifying and categorizing 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’ [8]. The framework thus provides a theory-driven basis for investigating the potentially wide-ranging barriers to/enablers of behaviour change.

The Theoretical Domains Framework has been applied in numerous studies to identify and characterize systematically barriers to/enablers of implementation across various clinical contexts, primarily through interview and survey studies. More recently the framework has been applied in systematic reviews of barriers/enablers, as a coding framework for data synthesis, for example, in a study of barriers to the optimal clinical management of stroke [9]. 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 optimize interventions by ensuring that they target the likely determinants of screening attendance.

We aimed to gain an understanding of diabetic retinopathy screening attendance behaviour by identifying the theoretical determinants of screening attendance.

The specific objectives were to: identify the published and 'grey' literature reporting perceived barriers and enablers associated with screening attendance; extract reported barriers/enablers and categorize these according to Theoretical Domains Framework domains; and apply pre-specified criteria to identify the likely importance of Theoretical Domains Framework domains in influencing screening attendance.

## **Methods**

A detailed protocol for this review has been published [10] and registered in PROSPERO (CRD42016032990). In brief, we included studies reporting primary data relating to modifiable factors that might hinder or facilitate retinopathy screening attendance. We included studies reported in English and 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 was arguably the catalyst for the development of diabetic retinopathy screening programmes worldwide. Studies were excluded if the reported barrier to screening was non-modifiable, for example, relating to age, gender, socio-economic status or duration of diabetes.

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 Appendix S1. 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. After removal of duplicates, one member of the research team (E.G.R.) screened all identified titles and abstracts against the inclusion/exclusion criteria. A second review author (F.L.) rescreened 300 (10%) of the titles and abstracts to check reliability. Since the inter-rater agreement was substantial (Cohens  $\kappa=0.82$ ) it was judged unlikely that double-checking further papers would have had a material impact on the level of agreement. Full-text copies of potentially eligible studies were obtained and a final decision was made on inclusion by consensus amongst the review team.

### **Data extraction and analysis**

We followed analysis methods used in previous studies applying the Theoretical Domains Framework to interview transcripts from semi-structured interviews [11]. These methods follow a combined content and framework analysis approach (Fig. 1) involving four steps: 1) data extraction; 2) deductive analysis (Theoretical Domains Framework coding); 3) inductive analysis (thematic synthesis); and 4) identifying important domains.

#### *Step 1: Data extraction*

One review author (E.G.R.) identified and extracted data reporting participants' [e.g. people with diabetes and/or healthcare professionals (HCPs)] perceptions of modifiable barriers/enablers associated with screening attendance. A second reviewer (J.G.L.) checked the accuracy of data extraction on a random 20% sample of included studies. 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 theoretical domains, three pilot transcripts were coded independently by two reviewers (E.G.R. and F.L.). Any discrepancies were discussed until agreement was reached. The pilot transcripts were used to develop a Theoretical Domains Framework codebook (the content of the codebook is provided in Appendix S2).

#### *Step 2b: Theoretical Domains Framework coding*

One review author (E.G.R.) coded the data extracted from all remaining studies. Extracted data were coded according to which domain they were judged to represent, guided by the codebook. Using a process that was arguably more robust than the 20% double-coding specified in the study protocol [10], three members of the review team (E.G.R., F.L., J.J.F.) met to verify and discuss every extracted data item to assess the domain-level coding, in the context of step 3 (described below).

#### *Step 3: Thematic synthesis*

In line with a framework analysis approach, step 3 focused on sifting and sorting the data within each domain to synthesize thematically and identify emerging content themes. One review author (E.G.R.) grouped together similar data relating to perceived barriers of/enablers to screening attendance, for each of the 14 domains. Theme labels (describing broad content themes) and, where appropriate, sub-theme labels (nested within the themes, describing more detailed content) were then generated for each cluster of similar data to express these shared views. Three members of the review team (E.G.R., F.L., J.J.F.) met to



verify and discuss every extracted data item to assess: 1) their agreement with grouping of extracted data; 2) their agreement with assigned theme and sub-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 and allocation of domains were revised accordingly.

Additionally, E.G.R. assigned the data within the themes as either representing barriers to or enablers of screening attendance. This was usually clear from the original papers as it was either reported in a table titled 'barriers to' or 'enablers of screening 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' [12] to determine which domains were likely to be important for influencing screening attendance: (1) *frequency* (number of studies that identified each domain; (2) *elaboration* (number of themes and sub-themes) within each domain; and (3) '*expressed importance*' (either a statement from the authors' interpretation or direct quotes from study participants expressing importance).

## **Quality assessment**

One review author (E.G.R.) rated included studies using items from the Critical Appraisal Skills Programme Qualitative Checklist (<http://www.casp-uk.net/casp-tools-checklists>) and the Mixed Methods Appraisal Tool (<https://www.mcgill.ca/familymed/research/projects/mmat>). Mixed-methods studies were appraised using both quantitative and qualitative appraisal tools. A second review author (J.L.) independently assessed a random sample of studies (20%). Agreement was not formally assessed, but only minor differences of opinion regarding study quality were identified and resolved by discussion.

## **Results**

### **Study characteristics**

After removing duplicates, we screened 3194 studies and reviewed 234 full-text articles. We excluded 165 studies with reasons and included 69 studies that met our inclusion criteria (Fig. 2). Table 1 presents an overview of the characteristics of included studies. Full details of the included studies are provided in Appendix S3 and a list of excluded studies can be found in Appendix S8.

### **Quality of included studies**

The studies were judged to be at low (46.7%), medium (8.3%) or unclear (45%) risk of bias (Appendix S4).

## **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 units (e.g. percentages of participants agreeing with a questionnaire item, or odds ratios).

Reported barriers were identified in all but one of the theoretical 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 (62 vs 35). Twenty-one themes/subthemes represented both barriers/enablers. Table 2 reports the frequencies of barriers/enablers identified within each domain.

## **Inductive analysis**

Appendix S5 presents all themes and sub-themes identified within each domain, alongside frequencies, relevant studies and sample quotations. A narrative description of the themes, within domains, is presented below, for the domains that were identified as high in importance.

### **Importance of Theoretical Domains Framework 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). Table 3 lists the numbers of themes and sub-themes identified within each domain.

### *Rank order of domain importance*

In Table 3, the 14 theoretical 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).

### *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 Appendix S7, alongside the domain they were judged to represent. For example, the following quotations 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 (six studies); and emotions (five studies). This list corresponds well with the

list of six domains of high importance identified by the importance criteria 'frequency' and 'elaboration' (Table 3).

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).* The theme of accessibility to the screening clinic was identified by both people with diabetes and HCPs. 'Accessibility' included issues with transport (e.g. lack/cost/poor quality) and distance to the screening 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 transport [13]. In several studies, distance from home to screening services was thought to improve attendance [14,15]. In two studies, mobile screening units were associated with higher attendance compared with screening appointments at high street optometrists [16,17].

*Theme: Time (competing demands; 29 studies).* People with diabetes often cited time constraints as a barrier to attendance. Competing demands on their time were attributable to: work commitments (e.g. finding it hard to take time off work); family responsibilities (e.g.

childcare); and clashes with other immovable 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*' [18].

*Themes: Financial concerns (27 studies) and consequences of private insurance (five studies).* Financial concerns, such as the cost of the eye examination/care and the cost or lack of insurance were common, especially in the studies from the USA [19,20], but attendance was sometimes not influenced by insurance [21]. Self-employed or casual employees reported costs owing to lost income when they took time off work to attend screening appointments [22,23].

*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 people with diabetes had not received an invitation or had been given insufficient notice [23–25]. Some expressed a preference for appointment flexibility but, in one study, older people with diabetes preferred fixed appointments [26]. Centrally allocated appointments were perceived by some HCPs to be problematic [15], as they undermined their own attempts to bring their patients to the clinic [18].

*Theme: Time (service issues; nine studies).* Long waiting times on the day of the appointment and lengthy appointments were barriers to attendance. For multiple appointments some reported 'waiting around all day' [27], while long appointments could be especially problematic for people with diabetes, because of lengthy food abstinence [28].

*Theme: Referral issues (eight studies).* The absence of a referral was a substantial problem for some. In one UK study, a person with diabetes who normally attended her screening appointments had attempted to access screening through her general practice but was refused as she was in temporary accommodation waiting to be rehoused [28]. In some countries, people with diabetes were not referred because there was no available eye doctor [14]. Inaccurate or incomplete registers could also result in lack of referral [15,18].

*Theme: Specialist diabetes services and staff (six studies).* The integration of specialist diabetes services or ‘one-stop-shops’ was viewed as beneficial: *'if the eye appointment was on the same day as the DM [diabetes mellitus] appointment I would definitely attend'* [14]; however, inflexible or incompatible administration systems were a problem [18]. Having a specialist practice nurse was associated with increased attendance in two studies [16,29].

#### *Social influences (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 [30,31], and having received a recommendation from a healthcare provider to attend screening was associated with attendance [32–34]. The absence of an HCP recommendation was a barrier in other studies [35–38]. Some people with diabetes reported lack of information provision from their healthcare providers [27,30,39], especially at the point of diagnosis.

Language and/or communication style, especially for people whose first language was not the same as the HCP’s, was a barrier. In some studies people with diabetes reported language

difficulties as the primary reason for not attending screening appointments [24]. In one study a participant '*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 [22]. In some studies, participants felt that systems were in place to overcome this barrier (e.g. provision of interpreters and accompanying family members) [15,28,40]; however, HCPs noted that accompanying relatives might not have the language skills needed to interpret correctly [15].

*Theme: Trust in doctors (five studies).* Advice and recommendations from doctors were perceived to be an enabler in several studies, and some people with diabetes were content to rely on their doctor's advice regarding screening [30]; however, in one study, it was reported that a small number did not trust doctors [31] and another reported that low confidence in doctors was more common in non-attenders than attenders [34]. Perceived discrimination in the healthcare system was associated with longer time periods between screening visits [41]. Conversely, a study in a Canadian Aboriginal population reported that a culturally sensitive community-based clinic overcame such barriers [22].

*Theme: Presence or absence of support from family members (11 studies).* Family support, both practical (e.g. providing transport to the clinic) and emotional (e.g. encouragement, offering gentle reminders), was an enabler [30,31], and its absence was a barrier [42,43]. Family support was especially important in communities that traditionally rely on their family members to look after them [40] or when the person had a physical disability [38].

*Theme: Encouragement/support from local community groups/networks (three studies) plus media attention and coverage (four studies).* Community-based programmes fostered trust and support [22] and provided information [40,44]. Furthermore, local media (television,



newspapers, radio channels) had potential to raise awareness and promote attendance at screening, whereas lack of media attention could contribute to low attendance [28].

*Theme: Stigma (three studies).* Some people with diabetes spoke of social stigma or shame being attached to a diabetes diagnosis [40,44]. HCPs also spoke about the difficulties of being confronted by a person's perceptions of stigma [45].

#### *Knowledge (35 studies)*

*Theme: (Lack of) awareness of illness (19 studies).* Several studies reported that a lack of knowledge about diabetes, diabetic retinopathy and the link between the two was a barrier to attendance. An 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.'* [46]. There was a significant association between believing diabetes could affect vision and attendance [43]. HCPs argued that some people with diabetes lack understanding of the link between diabetes and vision [23,47]; 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'* [46].

*Theme: (Lack of) awareness of screening (17 studies) and confusion between screening and routine eye tests (eight 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 screening. 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'* [15]. In one study, people with diabetes

who were not able to explain why diabetic retinopathy screening is needed reported more barriers than those who could [48]. Some were not aware of the difference between diabetic retinopathy screening and routine eye tests; hence, some believed they had attended screening when they had not [24,28,33].

*Theme: Education and training (eight studies).* Receiving diabetes self-management or blindness prevention classes significantly increased attendance [20,49,50], whilst those who had not received education on diabetes care were screened significantly less often than those who had [51].

*Memory, attention and decision processes (34 studies)*

*Theme: Symptoms (24 studies).* The absence of symptoms often resulted in people with diabetes deciding not to attend screening [15,23,38,44,52]. 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 [14]; however, even when symptoms were experienced some did not always link these to diabetic retinopathy but to an inevitable consequence of getting older [38].

*Theme: Competing health problems (13 studies).* Many people with diabetes experience competing health problems that can overshadow concerns with their eyes. For some, missing a screening appointment might be attributable to a temporary illness or health problem [24,25,28], but for others it was a consequence of comorbidities [26,43,53] or the burden of diabetes [18,30,40].

*Theme: Forgetting (10 studies).* For some people with diabetes, failure to attend screening was attributed to: forgetting to make an appointment [26], forgetting to attend [25,27,54] or forgetting whether they had previously attended [15]. Several studies alluded to HCPs' attempts to prompt or remind their patients in advance of their upcoming appointment [15,28] and some reported that reminders prompted them to maintain regular attendance [44].

*Theme: Perception of people with diabetes that they have been checked elsewhere (five studies).* Sometimes people believed they had been or were going to be checked elsewhere because they were transferring their eye care to another specialist [54], or their eyes had already been examined by a family physician or as part of routine eye test by an optician [28,37].

*Theme: Knowing it's a routine test (three studies).* An enabler was expecting screening to be part of their routine care [31,32,55].

#### *Beliefs about consequences (26 studies)*

*Theme: Perceived necessity of screening (13 studies) and perception that screening provides valuable information on the health status of your eyes (seven studies).* Some people with diabetes do not attend as they believe it is unnecessary [33,43,56]: 'I was told that my eyes are fine at my last screening' [15,26], 'my diabetes is under control' [14,38,47] and 'screening is not useful at my age' [30,34]; however, others reported that screening will identify problems early and this was motivating [28,55,57,58]. Some reported that screening can provide reassurance that all is well [23,28,57] or that they attended screening as family members had experienced problems with diabetes or retinopathy in the past [28,31].

*Themes: Short-term effects of screening (11 studies) and concerns about the harmful effect of the screening procedure (four studies).* Some people with diabetes reported that screening has negative short-term effects, for example, some dislike mydriatic eye drops (given to temporarily dilate the pupils) [32,55,59], which were often uncomfortable or, in some cases, painful [28,30,38]. In one case a woman had developed a phobia of these eye drops [25].

Mydriatic drops were also inconvenient because of their temporary effects on vision; the individual was prohibited from driving until the effects of the drops had worn off or it was difficult to navigate public transport [28,32]. Some reported that screening could have long-term negative effects on vision, either from the drops or from the retinal photographs [24,60].

#### *Emotions (23 studies)*

*Theme: Fear or anxiety (20 studies).* For some, the fear of losing their vision was a strong incentive to attend screening [15,27,32], but, for others, fear of a diagnosis of diabetic retinopathy was a barrier [46,58,61] or fear of the screening procedure itself [25,30,48] or of a medical intervention if they were confronted with a diagnosis [30,42,62]. In one study, non-adherent participants expressed less concern about losing their vision than adherent participants [63].

#### *Theme: Defensive responses*

Defensive responses were sometimes noted. In one study, young adults who participated reported that they wanted to attend screening, but actively engaged in avoidance strategies [57]. In other studies people with diabetes simply refused to attend, without explanation [14,25,47]: *'[the patient] is refusing to even discuss his condition, so all you can do is keep sending invites'* [25].

*Theme: Emotional burden of diabetes.* For some, attending screening appointments could exacerbate negative emotions relating to lack of control of their diabetes, including feelings of failure, guilt, fear and anger [15,27,46].

Details of the domains and the corresponding barriers/enablers that were considered less important are provided in Appendix S6.

## **Discussion**

We used a systematic, theory-informed and replicable approach to identifying barriers and enablers associated with screening attendance. The combined content and framework analysis identified six Theoretical Domains Framework 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 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 Quality Improvement interventions. The content themes were identified at multiple levels, including: the person with diabetes (e.g. confusion between screening and routine eye care); the HCP (e.g. recommendation to screen, or lack of such

recommendation, by the HCP); the healthcare system (e.g. inaccurate registers); and the wider community (e.g. lack of media coverage; Appendix S6).

Four key recommendations based on the findings from the thematic synthesis are: (1) to reduce inconvenience to people with diabetes; (2) to increase awareness of the importance of screening; (3) to increase a sense of comfort and support; and (4) to improve message content.

### **1) Reduce inconvenience to people with diabetes**

Many of the barriers/enablers identified related to perceptions of convenience. Difficulties with transport, 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. Providing local screening facilities, ‘one-stop shops’ (integrating screening with other diabetes appointments), offering flexible appointment systems and childcare facilities, and providing transportation may therefore be advantageous.

### **2) Increase awareness of the importance of screening**

Both people with diabetes and HCPs reported that a lack of awareness or understanding of diabetic retinopathy, diabetes 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 education were also reported to be barriers for people with diabetes, whereas providing blindness prevention programmes or general diabetes self-management education was reported to be an enabler. The perceived absence of an HCP recommendation

to attend screening and/or a lack of information provision from the HCP were also perceived 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.

### **3) Increase sense of comfort and support among people with diabetes**

Some 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 person with diabetes and HCPs, and compassion from the HCP were enablers which might encourage 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 [64].

### **4) Improve message content**

The absence of symptoms was a commonly mentioned barrier to attendance. Furthermore, some people with diabetes perceived that screening was not necessary, especially if they felt their diabetes was under control, they were not old, or if their previous test result was clear. It would seem desirable, therefore, to provide messages that highlight the asymptomatic nature of diabetic retinopathy and make salient the potential consequences if left unchecked. Likewise, providing messages that emphasize and highlight the benefits of early detection, the safety of the procedure and the reassurance a positive result can provide would be recommended and could help in part overcome barriers around emotional fears and concerns.

In addition, a barrier exists related to the confusion between attendance at diabetic retinopathy screening and routine eye tests. Messages highlighting the difference between the two and emphasizing the importance of continuing to attend despite attendance at other eye tests could be helpful. Furthermore, messages that emphasize that retinopathy screening 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 diabetic retinopathy screening was also regarded as an enabler addressing this domain.

### **Recommendations for future research**

Identifying disparities in adherence to screening was not an objective of the present review and therefore it is not possible to recommend which sub-groups/populations require the greatest attention; however, a recent review has summarized the literature from the USA and highlighted disparities in a number of sub-groups including: males; youth- vs adult-onset diabetes; specific minority populations; and low socio-economic status [65]. 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 [30,57]. This 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.* [30] compared the barriers and enablers among young adults with Type 2 diabetes (age 18–39 years) with those among a group of older adults with Type 2 diabetes (age  $\geq 40$  years) and found that younger adults had a higher number of barriers compared with 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 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 insights from people with diabetes to emerge) is a strength of this review. Furthermore, the review identified potential influence of people with diabetes, HCPs, organizational and contextual factors on screening attendance. We were able to code all extracted data from the 69 studies into theoretical domains, thus demonstrating that the framework provides a comprehensive coverage of barriers and enablers.

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

The studies in the present review predominantly identified barriers and enablers from the perspective of the person with diabetes rather than the perspective of the organization or HCP. Even the data we had from the HCPs mostly focused on their views regarding their patients' barriers.

A number of the studies were poorly described. This hampered our ability to differentiate between the perspectives of the HCP and person with diabetes or to distinguish between different sub-groups of people with diabetes. Furthermore, the data extracted and analysed in the present review were those that were 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 was restricted in that it did not specify relationships between domains and hence the likely strength of the direct impact of barriers on behaviour is not known.

Although the majority of the title/abstract screening and quality appraisal was carried out by a single reviewer, there was excellent agreement on random subsets of studies that were checked by a second reviewer. Consequently, we do not believe that this constitutes a major limitation.

### **Concluding remarks**

Six theoretical domains were identified as the factors most likely to be key mediators of retinopathy screening attendance behaviour. Interventions to increase screening 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 people with diabetes that have been identified as most at risk.

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## Competing interests

None declared.

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## **Supporting information**

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Search strategies for phase 2 systematic review.

**Appendix S2.** Theoretical Domains Framework: Definitions and Examples

**Appendix S3.** Characteristics of the 69 included studies.

**Appendix S4.** Quality assessment.

**Appendix S5.** Themes/sub themes within each of the 14 domains from the Theoretical Domains Frameworks.

**Appendix S6.** Details of domains (and corresponding themes) that were considered less important.

**Appendix S7.** Expressed importance.

**Appendix S8.** Excluded studies

**Appendix S9.** References.

**FIGURE 1** Flow diagram of steps in the analysis.

**FIGURE 2** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

**Table 1** Characteristics of included studies

Study characteristics	Frequencies (total: 69 studies)
Study methods	45 (65%), quantitative (e.g. questionnaires, surveys) 18 (26%), qualitative (e.g. interviews/focus groups) 6 (9%), mixed methods
Study location	30 (43%), USA 13 (19%), UK 10 (14%), Asia 6 (9%), Africa 4 (6%), Australia 3 (4%), Canada 2 (3%), Europe 1 (1.5%), South America
Publication type	56 (81%), full-text in peer-reviewed journals 5 (7%), full-text in unpublished reports/dissertations 8 (12%), abstracts/posters.
Perspective of reported barrier/enabler	53 (77%), perspective of people with diabetes 15 (22%), both people with diabetes and HCP perspectives <ul style="list-style-type: none"> <li>• <i>n</i>=11, specific ethnic groups (e.g. African American; American Indian; Aboriginal Canadian; people with South-Asian or Hispanic origin)</li> <li>• <i>n</i>=5, people who were classified as either non- or late-attenders</li> <li>• <i>n</i>=3, adults (e.g. age <math>\geq</math>40 years)</li> <li>• <i>n</i>=2, younger adults</li> <li>• <i>n</i>=2 (7%), women only</li> <li>• <i>n</i>= 2, people who had been diagnosed with diabetic retinopathy</li> <li>• <i>n</i>=1, participant receiving treatment</li> <li>• <i>n</i>=1, participants in a blindness prevention programme</li> </ul>

	<ul style="list-style-type: none"> <li>• <math>n=1</math>, Medicare population</li> <li>• <math>n=1</math>, people with diabetes who were also hospital staff.</li> </ul>
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HCP, healthcare professional.

**Table 2** Frequencies (number of themes/sub-themes) of barriers and enablers coded to each of the 14 domains of the Theoretical Domains Framework

Theoretical Domains Framework domain	Barriers only	Enablers only	Both barriers and enablers
Environmental context and resources	17	3	6
Social influences	6	5	5
Knowledge	4	5	6
Memory attention and decision processes	9	3	0
Beliefs about consequences	9	5	0
Emotions	6	3	1
Social professional role and identity	5	1	0
Goals	2	1	1
Beliefs about capabilities	2	0	0
Behavioural regulation	0	2	1
Intention	1	2	0
Optimism	1	2	0
Reinforcement	0	3	1
Skills	0	0	0

**Table 3** Frequency and elaboration within each of the 14 Theoretical Domains Framework domains, presented in rank order from most important to least important.

<b>Theoretical Domains Framework domain (rank order)</b>	<b>Frequency</b>	<b>Level of elaboration</b>	
	Number of studies identified	Number of themes	Number of sub-themes
<b>1. Environmental context and resources</b>	52	11	23
<b>2. Social influences</b>	35	11	8
<b>3. Knowledge</b>	35	6	12
<b>4. Memory attention and decision processes</b>	34	6	9
<b>5. Beliefs about consequences</b>	26	9	10
<b>6. Emotions</b>	23	6	6
<b>7. Goals</b>	13	2	3
<b>8. Social professional role and identity</b>	11	3	5
<b>9. Intention</b>	9	2	4
<b>10. Beliefs about capabilities</b>	9	1	2
<b>11. Behavioural regulation</b>	7	3	0
<b>12. Optimism</b>	5	3	0
<b>13. Reinforcement</b>	3	2	4
<b>14. Skills</b>	0	0	0



