Non-attendance at diabetes outpatient appointments: a systematic review

**Short title:** Non-attendance at diabetes out-patient appointments

**Authors:**

Sarah Brewster1,

Jazz Bartholomew2,

Richard IG Holt3,

Hermione Price1

**Institutions:**

1Research and Development Tom Rudd Unit, Moorgreen Hospital, Southern Health NHS Foundation Trust, Southampton, UK

2CRN Wessex, NIHR Clinical Research Network (CRN), University Hospital Southampton NHS Foundation Trust, Southampton, UK

3Human Development and Health, Faculty of Medicine, University of Southampton, Southampton, UK

**Corresponding author:** Sarah Brewster [Sarah.brewster@southernhealth.nhs.uk](mailto:Sarah.brewster@southernhealth.nhs.uk)

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* Diabetes is a chronic disease associated with significant risk of complications. Its management is complex and healthcare appointments provide an opportunity to support individuals with their self-management.
* Missed diabetes appointments are associated with worse outcomes. The main contributors to non-attendance include balancing the costs and benefits to attending by the individual, an individual’s coping strategies and relationships with healthcare professionals.
* Interventions designed to improve attendance have delivered modest effects but have progressed from simple appointment reminders to service improvement projects, patient navigators and virtual clinics.
* Further work is required to improve non-attendance rates at diabetes healthcare appointments.

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# Abstract

**Background:** Non-attendance at diabetes outpatient appointments is a sizeable problem worldwide and has been associated with sub-optimal health outcomes. We aimed to describe the characteristics, health outcomes and reasons given for non-attendance at doctor or nurse-led diabetes appointments, and interventions to improve attendance.

**Methods:** PubMed, EMBASE, CINAHL and PsychInfo were searched from database inception to February 2019. Included articles were peer-reviewed, published in English, relate to adults or young persons with type 1 or type 2 diabetes, and addressed one of the above aspects of non-attendance. Studies were excluded if reporting on other types of diabetes or reviewing attendance at structured education, retinal screening, paediatric, antenatal, podiatry or dietetic clinics.

**Results:** 34 studies of varied designs were identified (15 observational, 1 randomised control trial, 9 qualitative, 5 surveys, 4 service improvements). The definition of non-attendance varied. Younger adults, smokers and those with financial pressures were less likely to attend. Non-attendance was associated with higher glycated haemoglobin; other outcomes were varied but typically worse in non-attenders. Reasons for non-attendance in qualitative studies fell into three categories: balancing the costs and benefits of attendance, coping strategies and the relationships between the person with diabetes and healthcare professionals. Interventions included appointment management strategies, service improvements, patient navigators and WebCam appointments.

**Conclusions:** Non-attendance is only partially explained by logistical issues. Qualitative studies suggest complex psychosocial factors are involved. Interventions have progressed from simple appointment reminders in an attempt to address some of the psycho-social determinants, but more work is needed to improve attendance.

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Key words: Diabetes, non-attendance

# Introduction

Non-attendance at healthcare appointments is a significant problem across the world. According to NHS England’s quarterly review ending March 2019, the overall non-attendance rate for general follow-up hospital outpatient appointments was 8% [1], with non-attendance rates appearing similar for people with diabetes compared to other chronic health conditions [2]. Non-attendance is associated with sub-optimal outcomes for the patient, and is a poor use of healthcare resources [3, 4].

Diabetes is a long-term condition associated with a number of complications, the incidence of which increases if the diabetes is not managed optimally [5, 6]. Despite significant advances, there remains a sizeable gap between advised and actual clinical outcomes achieved by people with type 1 and type 2 diabetes

Healthcare appointments are an opportunity for healthcare professionals (HCPs) to support individuals with diabetes with their self-management. Understanding the reasons why people do not attend outpatient appointments can help reveal barriers or personal determinants that also affect their ability to manage their condition.

It is unclear from observational studies whether poor appointment keeping is causally related to sub-optimal outcomes as non-attendance may stem, at least in part, from ill-health [7]. Regardless, non-attendance behaviour can serve as a marker for identifying those at risk of poor outcomes, and who should be targeted with alternative care models or outreach services [7]. Steps taken to help people with diabetes attend more regularly could translate into better outcomes for the individual.

In 1998, a review by Griffin reported that there were relatively few qualitative studies exploring the beliefs and attitudes of people with diabetes towards clinic attendance. Contradicting the wider literature on non-attendance behaviour at the time, certain features such as socio-demographic characteristics were not associated with non-attendance at diabetes appointments. Griffin identified that interventions to address non-attendance at diabetes clinics were primarily aimed at providing reminders, with few organisational or patient-professional relationship interventions [8].

In a more recent review, Hynes et al reported how the experience young people with type 1 diabetes have during transition into adult care influences subsequent clinic attendance. Building strong patient-professional relationships to improve the perception of the value of attending appointments was important [9].

Over two decades since Griffin’s review, there have been substantial changes to healthcare systems and diabetes care that may affect clinic attendance. It is therefore timely to re-consider the contributors, consequences, and potential solutions for non-attendance at healthcare appointments among adults and young people with diabetes.

# Review Aim

This review summarises the literature on non-attendance at diabetes healthcare appointments. The objectives were three-fold:

1. To establish the features of missed diabetes healthcare appointments, the characteristics associated with those not attending and the impact on health outcomes.
2. To explore factors that influence attendance or non-attendance at diabetes appointments.
3. To describe interventions to improve attendance at diabetes appointments.

# Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist was followed (Appendix A) [10].

## Search Strategy

An initial scoping review was conducted using Google Scholar. This was followed by an online search of four databases, MEDLINE, CINAHL, Embase and PsychInfo using the EBSCO and OVID platforms to include articles from database inception to February 2019. The grey literature was not searched. Details of the review were registered with PROSPERO: Reference CRD42019128305. The development of the search terms and the final search strategy used is described in Appendix B.

## Study selection: Inclusion/exclusion criteria:

Peer-reviewed papers conducted in all countries and of all designs were included if published in the English language and addressed one of the research questions. Non-attendance was defined as unexplained missed appointments and did not include cancelled or re-booked appointments. Articles had to be specific to outpatient diabetes appointments with a diabetes specialist doctor, general practitioner (GP) or nurse. Studies referring to people with diabetes other than type 1 or type 2 diabetes were excluded. Studies reviewing attendance at structured education, retinal screening, antenatal clinics, dietetic or podiatry appointments were excluded as attendance at these diabetes contacts is influenced by different factors, such as dislike of group sessions, differences in perceptions about healthcare vs. education and the response to an active diabetes-related complication.

The focus of this review was adults and young people with diabetes. Papers on transitional and young person clinics were included, as many of these studies incorporated adults, and the pattern of later attendance at clinics is often developed during early adulthood. Papers that solely included people aged <18 years were excluded.

One researcher (SB) ran the search with the assistance of a librarian. Two researchers (SB, JB) screened the study titles and abstracts identified from the search. Results were compared and discussed until a consensus was reached. All included studies were discussed by all authors. Figure 1 shows the PRISMA flow diagram of the article selection process [10]. One researcher (SB) cross-checked the references of included studies, which did not identify any additional articles.

## Quality Assessment and Data Synthesis

Quality assessment and data synthesis was performed by one researcher (SB). The papers were assessed using the nine‐item checklist developed by Hawker et al for appraising disparate studies- Appendix C [11]. This tool was chosen to accommodate the diversity of study types assessed in one checklist, facilitating inter-study comparison. No studies were excluded based on quality. Data were extracted, summarised and tabulated by SB and discussed by all authors (table 1). Findings were grouped according to the review aims and a narrative synthesis was undertaken. Due to the methodological, statistical and conceptual heterogeneity between studies, a meta-analysis was not performed.

# Results

## Types of studies identified and reported rates of non-attendance

34 studies of varying designs were identified (15 observational, 1 randomised control trial, 9 qualitative, 5 surveys, 4 service improvements). Sixteen were studies from the United Kingdom [12-26], four from Europe [9, 27-29], six from North America [7, 30-34] and eight from the rest of the world [35-42]. Six studies specifically focused on young adults in transition from paediatric to adult services, all of which had a mean participant age of >18 years (age range 15-30 years) [17, 18, 29, 35, 40, 43].

Reported baseline non-attendance rates at diabetes appointments were mostly between 10% and 30% [7, 12, 14, 15, 17, 19, 24, 29, 31, 38, 39, 44], but the extreme ranges were 8.3% [25] and 76% [18]. The means of quantifying non-attendance varied; some studies calculated the number of missed appointments as a percentage of total booked appointments [7, 14, 17, 19]. Non-attendance was also determined as the number of people missing more than one appointment in a defined period [15, 18, 20, 21, 28-32, 35, 37, 39, 44, 45] or when there was no record of HbA1c measurement in primary or secondary care in the previous 12-15 months [24, 25]. Re-referred ‘lapsers’ made up 19% of the ‘new patient’ clinic load at one UK diabetes service [12] and appointment cancellations were only defined as a separate entity in one study where they occurred more frequently than non-attendance (18% vs 12%) [31].

The number of studies addressing each of the research questions is displayed in table 2 with some studies addressing more than one aim.

## Features associated with missed appointments, the characteristics of non-attenders and the impact on health outcomes

Articles reporting on the features of missed appointments, the characteristics of non-attenders and the impact on health outcomes associated with missed appointments were predominantly observational in design. Longer gaps between appointments was a predictor for non-attendance [39] but there was no seasonal variation in attendance rates [22]. A machine learning algorithm helped predict missed diabetes appointments at a Japanese hospital and found that ‘how and when’ an appointment was booked contributed more to attendance than the individual’s clinical condition [41]. Factors with the strongest predictive accuracy of a missed appointment included making appointments on a Sunday, scheduling appointments for a Friday, a history of diabetic ketoacidosis in those with type 2 diabetes and a recent prescription of Rilmazafone (a water soluble benzodiazepine). Factors associated with reduced likelihood of a missed appointment included a history of treated Graves' disease, a previously kept appointment on Friday or booked on Monday.

Attendance may be influenced by the role of the referring HCP and the skill set of the receiving HCP [34]. Adults with type 2 diabetes referred by doctors across three healthcare centres in Chile were less likely to attend appointments than those referred by dietitians or nurses. Appointments with doctors, however, were better attended than with other HCPs. Some people preferred to see a doctor over a dietitian or nurse, but the majority expressed no preference.

### Characteristics of non-attenders:

Table 3 summarises and compares findings across studies on the characteristics of people who are less likely to attend clinic appointments.

#### Age, gender and duration of diabetes.

Non-attendance was more likely in young adults [7, 21, 24, 25, 27, 39, 44] and older (age>70 years) individuals with diabetes [24], but this was not seen in all studies [7, 12, 20, 28]. The association of age persisted if transition clinic studies were excluded. Shorter duration of diabetes was associated with non-attendance [21], but age of diabetes onset [21] and duration were not predictive of attendance behaviours in other studies [12, 27]. Some [15, 25, 39, 44], but not all, studies [12, 18, 20, 21, 24, 27] found that men were less likely to attend.

#### Employment, socio-economic pressures and parenthood

A number of demographic factors including unemployment [28], financial pressures [7, 25], smoking [21, 27, 28, 44], increased alcohol intake [28] and parenthood, particularly being a single parent [21], were associated with non-attendance. In contrast, social deprivation was only mildly associated with non-attendance in one Scottish study [24].

#### Ethnicity and culture

Ethnicity was only reported in one study which identified people of Malay, Indian and other ethnic minorities as more likely to miss diabetes hospital appointments in Singapore [39]. Geographical location did not have a notable association with non-attendance despite different healthcare systems.

#### Illness perceptions and attitudes

A study in Thailand found no association between illness perception and diabetes clinic attendance [36]. A postal questionnaire of attachment styles found that in those without depression (88%), dismissive behaviour was most closely related to non-attendance at primary care reviews and people with fearful attachment styles were more likely to attend same day appointments [33].

#### Other associations

Other less well reported characteristics included the presence of other co-morbidities, attendance at diabetes education and insulin treatment in the context of type 2 diabetes. Apart from hypothyroidism, which was associated with lower non-attendance rates, the presence of other co-morbidities was not associated with missed appointments [27]. Non-attendance was associated with a lower co-morbidity score at a diabetes service in North California [7], although people with clinical levels of anxiety and/or depression were less likely to attend appointments [25]. Lack of therapeutic diabetes education and insulin therapy in the context of type 2 diabetes both increased the likelihood of non-attendance in Spain [27].

## Health outcomes associated with non-attendance

Nine studies reported an inverse relationship between glycaemic control and clinic attendance [7, 12, 20, 21, 25, 27, 29, 34, 44], but this association was not seen in a retrospective review of diabetes services in Limerick, Ireland [28]. Associations with other biomedical outcomes were less well established. In studies that reported body mass index (BMI), higher BMI was associated with non-attendance in two studies [20, 44] but not others [12, 15, 27]. Higher blood pressure [15, 20, 27] and adverse lipid profile [15, 27] were more common in non-attenders when reported.

A study from Indiana, USA, reported that people with diabetes who did not attend primary care appointments were no more susceptible to subsequent hospital attendances over a 6 month period unless the person with diabetes was recently discharged from hospital and then missed their follow-up in primary care when re-attendance was more likely [45]. By contrast, another study, also from Indiana observed that emergency department attendances were more frequent in those who missed, or who had cancelled but re-scheduled an appointment [31].

The prevalence of diabetes related microvascular [12, 27] and macrovascular complications [12] was increased in non-attenders in the two studies that reported complications. Greater morbidity from diabetes related complications was also identified in white non-attenders aged >64 years at a hospital diabetes service in Wolverhampton, England [20]. Analysis of data from the Health Improvement Network (THIN) database, a UK longitudinal database with more than eight million patient records, found that non-attenders with type 1 diabetes had greater all-cause mortality after adjustment for demographic variables and other risk factors [44].

## Reasons for non-attendance at diabetes appointments

Of the nine studies examining reasons for non-attendance, three were surveys [12, 15, 20] and six used interviews and/or focus groups [9, 13, 17, 26, 37, 42] .

### Reasons derived from surveys

The main reasons given for not attending clinic according to patient surveys included: overcrowded clinics, prolonged waiting, lack of continuity, not seeing the consultant frequently enough, being too ill or too well to attend, non-specific personal reasons, and neglecting the diabetes [12, 15, 20]. When people with diabetes were asked to offer suggestions on how to improve services to facilitate attendance, these typically focused around clinic logistics [15].

### Reasons for non-attendance derived from interviews and focus groups

The diabetes clinic is regarded as a valuable resource by young people with diabetes, healthcare providers [43] and ethnic minorities [13]. The importance attached to attendance was also evident in South Africa where people with diabetes claimed that attending assisted better self-management [37]. Rarely was non-attendance due to lack of motivation, perceived seriousness of the disease or perceived risk [13].

Snow et al proposed that three groups of people with diabetes exist: those who balance the costs, particularly the immediate obstacles to attending against the benefits, those who do not, and those who move from one group to another with time [17]. For the minority who do not consider the costs and benefits, attenders typically reported doing so out of routine, something instilled in them during childhood, whereas those with a period of non-attendance attributed it to a time of denial.

Three main themes emerged from the qualitative studies exploring the factors influencing attendance at diabetes healthcare appointments.

#### Illness perception, distress and coping strategies

Illness perception, diabetes distress and coping strategies all influence attendance patterns both positively [13, 43, 46] and negatively [42, 43, 46], in contrast to the earlier study from Thailand which found no association between illness perception scores and attendance patterns [36].

A sense of denial was described by young people missing appointments at a diabetes clinic in London, England, particularly when they felt their diabetes had become unmanageable [17]. According to young people in Ireland, distress-related diabetes negatively influenced self-management, which then either served as a motivator or a significant barrier to subsequent clinic attendance [43]. Denial was also a factor identified in adults with diabetes in Iran [42], and even when people with diabetes in South Africa were optimistic about their current health status, three-quarters expressed a belief that they were likely to develop health complications as a result of diabetes [37].

Focus groups and interviews with ethnic minorities from a diabetes clinic in London illustrated that handing over the responsibility of their health to someone else, notably family members, was a way of coping and managing their condition [13]. This coping strategy was most apparent for those who did not speak English, who relied on others for their attendance.

A Welsh study analysing interviews of non-attending adults with type 1 diabetes identified three groups based on their cognitive, emotional and coping strategies according to the health behaviour model [26]. The ‘high fear’ group use coping strategies to minimise anxiety rather than reduce health threat. The ‘patient as the expert’ group have strong internal control and are less likely to invite or accept advice from others. The ‘low motivation’ group, who despite appearing calm, perceive a health threat as externally visible and underestimate their risk.

#### Logistics and characteristics of the appointment/diabetes service

Appointment logistics were reported in all six qualitative studies. Bureaucratic problems and communication failures contributed to non-attendance [17] as did forgetfulness [37]. When asked, people with diabetes felt that appointment reminders would help boost attendance, with a telephone call being the preferred method of communication [37].

Barriers described by people with diabetes included lack of clinic flexibility [13], long waiting times [43, 46], meeting unfamiliar service providers [43], geographical location [13, 37], hassle associated with travel to the appointment [13, 37, 42], parking problems [13], conflicting commitments such as work or other appointments [13, 17, 37, 42, 46], misunderstanding of appointment requirements [37], physical disability [42], financial difficulties [13, 37, 42] and a dislike for hospitals and/or doctors [46].

Semi-structured interviews in Iran recognised that some women described prejudice of their husbands, tradition and local customs as interfering with their acceptance of modern medicine and ability to attend appointments [42]. Issues with language and literacy was also a barrier for some in London, England [13]. Facilitators to attendance were less frequently reported but included timely test results, a reliable system of reminders, and practical information [17].

#### Relationships with the healthcare team:

The importance of positive relationships was well described [13, 17, 42, 43]. Semi-structured interviews with people not attending a young person’s type 1 diabetes clinic in Ireland identified the relationship between the person with diabetes and HCPs as the predominant theme contributing to this behaviour [43]. Confidence and trust in HCPs was important to adults with diabetes in London [13], and young persons were most negatively affected by criticisms, particularly in relation to their HbA1c and self-management [17]. The value of friendly, positive staff was appreciated by all as was emotional support and reassurance [17]. Short, impersonal appointments with unfamiliar HCPs negatively impacted relationships and thus attendance [43]. Outside of the UK, Heydarabadi et al also identified poor ‘patient-doctor’ relations as a barrier to attendance in Iran [42]. In Ireland, young adults with diabetes felt that collaborative relationships between them and HCPs helped foster engagement and also attendance [43].

A difference in opinion appeared to exist between those with type 1 and type 2 diabetes in London, England, regarding specialist care [13]. Those with type 1 diabetes perceived specialist care to be superior, whereas those with type 2 diabetes had less understanding of the different roles of GPs and specialists [13]. Campbell-Richards proposed that these varying opinions may influence attendance for some.

## Interventions aimed at improving attendance or identifying those at risk of defaulting from clinic

Seven of the eight studies examining interventions to improve attendance were observational [14, 16, 19, 30, 32, 38, 40] and one was a randomised controlled trial (RCT) [35]. The types of interventions varied and included patient navigators [30, 32, 35, 40], web-based consultations [14], and strategies to improve appointment management, service structure and patient information [16, 19, 38].

### Patient Navigators

Patient navigators provide personal guidance to patients, helping them negotiate their way through healthcare systems. Two of the four studies reporting patient navigators were from North America focusing on adults with diabetes [30, 32]. The other two from Australia [35] and Israel [40] were specific to people with type 1 diabetes transitioning to adult care. The role and skills of the patient navigator(s) varied across studies, but all reported improved attendance and clinical outcomes.

Weaver et al examined the effect of weekly phone calls by a navigator on new patient attendance at a diabetes clinic in Alabama [30]. The clinic was specifically for un-insured people discharged from hospital with a diagnosis of diabetes but without on-going care. The patient navigator was a registered dietitian and certified diabetes educator. The intervention significantly reduced non-attendance rates over a 6-month period. Attendance following a navigation call was associated with an average 22 mmol/mol (2%) decrease in HbA1c from the time of hospital referral to first clinic appointment. Both patients and patient navigator reported the main barriers to clinic attendance were being resident in a shelter, difficulty in contacting the person with diabetes, non-English speakers, transport difficulties and hospitalisation at the time of the appointment.

In the study from Boston, US, Horny et al enrolled people with an elevated HbA1c (>69mmol/mol, 8.5%) and a record of at least one non-attendance at a diabetes specialist clinic in a “safety-net”, not-for-profit urban hospital [32]. The two patient navigators were non-clinical with no previous diabetes experience, but were selected for their communication skills. They received basic diabetes training and attended a course on patient navigation. There was a modest reduction in HbA1c (-0.6 %, -6 mmol/mol intervention group vs. +0.5%, +5 mmol/mol control group) and non-attendance rates, but no reduction in hospital admissions or emergency department attendances.

An RCT assessed the effect of an appointment manager for those with type 1 diabetes transitioning from a tertiary paediatric clinic to adult diabetes services in Melbourne, Australia [35]. The patient manager acted as the point of contact between the two services and provided pre-appointment text messages and telephone calls. Missed appointments were automatically re-booked. Disengagement from services was defined as not attending a single adult appointment over 12 months. No improvement was seen in attendance or engagement at 12 months post transition, but an independent positive association was apparent at 12-24 months post transition (disengagement: 6% intervention arm, 49% control arm; number of clinics attended: 2.5 in the intervention, 1.4 in the control ). Pre-transition attendance predicted post-transition attendance to a small degree, but both pre-transition attendance and the intervention did not have independent effects on HbA1c after transition. In Israel, an improvement in mean HbA1c (67mmol/mol, 8.3% to 57mmol/mol, 7.4% ) and clinic attendance was demonstrated amongst people with type 1 diabetes one year after the introduction of patient navigators into a specialist transition clinic [40]. 80% of planned transition participants attended three or more appointments in the year post transition compared to 60% pre-transition, and 47% of those re-referred to the transition clinic after being lost to follow-up attended three or more appointments the year following transition.

### Patient Information and service -restructuring

Keeping people with diabetes informed and improving clinic efficiency improves attendance rates [16, 19, 38]. Issuing an information pack on what to expect at an upcoming diabetes outpatient appointment in Merseyside, UK, reduced overall non-attendance rates from 15% to 4.6% [19]. This association was most pronounced for those who received a supplementary telephone call one week before their appointment (non-attendance 1.4% vs. 7.3% for those without the supplementary telephone call).

Wilson and Greenhalgh took measures to re-engage individuals lost to a young persons’ service [16]. Letters of invitation put blame for non-attendance on the service, not the person with diabetes. The letter was followed by a supportive telephone call. The running of the clinic was radically changed. Staff were encouraged to be positive and non-judgemental, and a clinic nurse sat in the waiting room to put attendees at ease. Health promotion flyers/posters were made available, and diabetes nurse specialists were employed to offer flexible appointments. Non-attenders were phoned to check how they were, and another appointment re-booked. The intervention was not formally quantified, but patient satisfaction improved and there was positive feedback from those who had missed appointments for a number of years.

Ho undertook an extensive work-flow analysis to improve the efficiency of a tertiary diabetes centre in Singapore, which informed subsequent changes [38]. When asked, people with diabetes said that an acceptable appointment waiting time was 30-60min and so each doctor had their consultations timed and appointments scheduled to accommodate this. New patient communication sheets helped facilitate flow from one part of the clinic to another. Telephone reminders were made one week before an appointment, and clinic information sheets sent to individuals detailing the running of the clinic and any tests required beforehand. The changes improved patient satisfaction and attendance rates (non-attendance decreased from 30% to 21%). Turnaround time did not significantly improve.

### Web-Cams

Vijayaraghavan et al assessed whether offering clinic appointments via Skype using a Webcam to all people attending a specialist diabetes clinic in Newham, London would be acceptable to people with diabetes and address non-attendance [14]. The quality improvement project successfully reduced non-attendance from 25% to 13% and was regarded by people with diabetes as being accessible and user-friendly. Interviews, focus groups and questionnaires highlighted that the intervention improved accessibility and flexibility, saved time and cost, whilst improving the clinician-patient relationship. Participants felt more 'in control' of the consultation process, and described more attention being paid to them by the physician.

# Discussion

Research exploring non-attendance at diabetes clinics is diverse. How non-attendance is defined and computed differs across studies, a finding not unique to this review [47]. Studies on characteristics of non-attenders provide conflicting information, but in most instances, non-attendance was more likely in young adults, those from a lower socio-economic background and those who smoke. The first two of these associations are in keeping with the current broader literature on non-attendance across medical specialities [47]. The day of the appointment and experience of the provider can also have an impact as seen in other specialities [47].

In accordance with Griffin’s review, non-attenders typically have higher HbA1c and a greater vulnerability to adverse health outcomes. Nonetheless, as described by Griffin, this association cannot imply causation. As demonstrated in qualitative work by Snow et al, sub-optimal measures including HbA1c can instil fear of being judged by HCPs, consequently leading to non-attendance [17].

The reasons for non-attendance are manifold and differ both between individuals and for any one individual. The influencing factors may also vary from one missed appointment to the next. Contributors given in surveys are more logistical in nature but interviews and focus groups have provided richer data on the self-determinants and complex interplay between the behavioural, emotional and cognitive issues that may be involved and should be considered when attempting to address non-attendance. Although qualitative work is limited, it has highlighted the importance of HCP-patient relationships and an individual’s coping mechanism. Periods of denial may even be part of coming to terms with a chronic health condition, not unique to diabetes. Other barriers (personal, organisational, environmental, economic, social or service related) are well reported, all of which can have a more profound influence on attendance than the perceived benefit of appointments. Some of these are more amenable to change (e.g. clinic structure) than others (e.g. language barriers).

Despite the breadth of different countries represented by the studies in this review, the characteristics and outcomes associated with non-attendance and the underlying reasons for this behaviour show no particular geographical patterns. Perhaps this is a reflection of the few studies from low- and middle-income countries. Financial difficulties influencing attendance existed both in private and government funded healthcare systems, although details of the financial difficulties were not described. Cultural and language barriers were not widely reported but do exist. When assessing illness perception in Thailand, a majority of participants were Buddhist and were more likely to believe that their diabetes was a result of internal factors [36]. In Iran, local customs meant that women felt unable to attend appointments on their own [42]. In England, language barriers meant that people handed over responsibility of their condition to their family members [13].

Regardless of the underlying reason for non-attendance, with missed appointments being associated with poorer outcomes, the behaviour can serve as a way of identifying those most at need who may benefit from additional or alternative models of healthcare delivery. Various interventions have been tried across a breadth of long-term conditions to improve clinic attendance, many focusing on different ways to remind people about their appointments [48]. Those who simply forget an appointment are likely only a small proportion of all non-attenders, however, and unlikely to be exposed to the same health implications as those who do not attend for other reasons. Perhaps this explains the modest effect simple appointment reminders have had on attendance when delivered by post, telephone call or text message [48]. By contrast, informing people what to expect at appointments can be more effective, perhaps by reducing some of the perceived barriers to attending, fear of the unknown and also by helping people to feel more empowered. Diabetes services have started to use novel techniques to deliver this information, including online videos [49].

In keeping with Griffin’s recommendations, over time there has been a gradual move away from blaming non-attenders, towards the design of interventions that are more supportive, informative and patient empowering. In addition to greater access to information, examples of this have included providing patients with points of contact (e.g. patient navigators), offering an alternative appointment medium (e.g. virtual clinics) and attempting to improve the running and logistics of services.

# Study Limitations

Due to the low number of RCTs and the high number of observational and qualitative studies, a statistical analysis was not undertaken and a summary of findings was produced. The majority of studies used basic designs, retrospective methods and convenience samples. The participants were typically attending single hospital based clinics, potentially limiting the generalisability of findings. Transferability can be achieved with a rich description of the study context, but this was lacking in several instances. A number of studies used univariate analyses which fails to address possible confounding factors. These limitations make it hard to determine the ‘active ingredients’ associated with any effects or outcomes seen.

The inclusion criteria in this review relied on non-attendance at diabetes appointments being a primary or secondary outcome. These criteria may have excluded studies reporting non-attendance when this was not a clear endpoint. Repeated appointment cancellation has been associated with more frequent emergency department attendances [31] but was not explored in this review and often overlooked in papers reporting on non-attendance.

Although the review focussed on adults with diabetes, we included studies that reported attendance at transition or young persons’ diabetes clinics. We acknowledge that the reasons for non-attendance by teenagers living at home with parental support are likely different from older adults with diabetes. Nevertheless we believe that it was important to include these studies to avoid missing important findings that span all age groups. The mean age of participants in all the transition papers was over 18 years. Even in the study by McCarlie et al which included people as young as 12 years of age, most of the participants were older than 30 years of age, and the study also provided important information on people older than 70 years [24]. An association has been observed between attendance at transition clinics and attendance patterns in later life, providing relevant evidence about long-term non-attendance.

Some of the reported variation in non-attendance rates across studies reflects how they were quantified. When defined as a percentage of total scheduled appointments, this fails to identify those missing multiple appointments who may be most at risk of unmet health needs. The same problem is true when a single missed appointment is classed as non-attendance. Furthermore, in some instances, non-attendance may have been artificially elevated due to administration error.

Qualitative studies that performed interviews rarely discussed potential biases and reflexivity of the interviewer(s). Along with the surveys, they also did not share the reasons why some individuals declined to participate. These individuals are an important group as they are arguably most vulnerable to the potential consequences of missed appointments.

# Conclusion

Non-attendance at diabetes appointments is a complex behaviour that is likely influenced by the person with diabetes, HCP and service factors. Qualitative work suggests that perceived barriers to attending, relationships and coping mechanisms are important contributory factors. The health outcomes for those who frequently miss appointments is worse compared to people who attend regularly. Interventions to improve attendance are limited but these have started to move away from appointment reminders to clinic restructuring, better supporting people with diabetes in the transition to adult services, patient navigators and alternative appointment formats including virtual clinics.

Future work addressing the gaps in our understanding of non-attendance, looking deeper into the issues and personal determinants that influence this behaviour, is pertinent in view of the poor quality of the currently available evidence. Much uncertainty remains in spite of the conclusions reached. Interventions designed to address the problem are complex and should be informed by the local context, communication with relevant stakeholders and collection of relevant primary and empirical data. The Medical Research Council’s framework for complex interventions provides an iterative structure to consult when designing and evaluating a complex intervention [50]. Using this in the process can allow for clearer identification of ‘active ingredients’ contributing to an effect and facilitate generalisability of an intervention across healthcare settings.

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# Tables

## Table 1: Table of included studies

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Author, Year, Citation Number | Study aim(s) relevant to this analysis | Participants | Number of participants/records studied and mean age of participants | Study design/Method | Location of study |
| Archibald et al (1992) [12] | To explore the demographics of non-attenders and the underlying reasons for defaulting. | All patients re-referred during one calendar year who had lapsed from follow-up for at least 12 months. | 74 (37 non-attenders, 37 attenders).  Mean age of non-attenders (SD):  49.9 ± 16.4 years  Mean age of regular attenders (SD): 53.0 (12.4) years | Observational-Retrospective cohort.  Questionnaire included. | Liverpool, England |
| [Akhter et al (2012)](https://doi.org/10.1002/pdi.1670)  [15] | To investigate the reasons for non-attendance, characteristics of non-attenders and possible service improvement strategies from the point of view of the person with diabetes. | People with type 1 diabetes who had not attended at least 1 appointment in the diabetes service over the preceding year, and who were aged >25yrs. | 126 non-attenders  Mean age (SD): 43.9 (12.7) years | Telephone survey | Cambridge, England |
| Alvarez et al (2018)  [34] | To determine whether a relationship exists between HbA1c and the frequency of attendance at scheduled appointments, having been referred from or to a particular speciality. | **Adults** (20-95 yrs) with type 2 diabetesfrom one of 3 family healthcare centres. | 2290 patient records  Mean age: 62.9 years (range 20-95). | Observational-retrospective cohort (descriptive and analytical study of patient records) | Chile, S. America |
| Campbell-Richards (2016)  [13] | To understand why there are high rates of non-attendance at the Newham diabetes service in ethnic minorities in order to identify any unmet needs and inform non-attendance strategies. | People with diabetes and of African, Bengali, Pakistani or White ethnicity. | Focus groups: focus group for type 1 diabetes (n=3), type 2 diabetes focus group (n=2). Interviews: regular attendees (n=5) and non-attendees (n=5).  Mean age not specified | Qualitative- Focus group and semi-structured interviews. | Newham, England |
| Casey et al (2012)  [29] | To determine attendance rates at a dedicated young adult clinics and whether poor attendance is a predictor of adverse outcomes. | People with type 1 diabetes aged 18-25 years attending the Galway University Hospital diabetes service. | 137 records  Mean age (SD): 22.9 (1.96) years | Observational-Retrospective cohort | Galway, Ireland |
| Ciechanowski et al (2006)  [33] | To determine behavioural and clinical characteristics of diabetes associated with depression and non-attendance at primary care reviews in a representative primary care population. | People with diabetes from 9 primary care clinics. | 3923 patients  Mean age (SD) of secure, dismissing, fearful and pre-occupied attachment styles respectively :  62.7 (12.8) years  64.3 (9.8) years  59.8 ( 14.6) years  63.8 (14.4 ) years | Observational: Retrospective cohort and a postal questionnaire | Washington, USA |
| Currie et al (2013)  [44] | To determine if a diagnostic record of poor medication taking or appointment non-attendance was associated with all-cause mortality in people with type 1 diabetes. | Type 1 diabetes (all ages) | 2946 records  Mean age (SD) of adherent:  27.9 (19.2) years  Mean age (SD) of non-attenders:  29.1 ( 17.4) years | Observational- Retrospective cohort (data extracted from the Health Improvement Network (THIN) database) | Across the UK |
| Dyer et al (1998)  [21] | To examine factors associated withnon-attendance at a diabetic clinic. | People with type 1 diabetes attending one of four major diabetes outpatient clinics or young persons’ clinics , age >16 years at a hospital in Birmingham | 259 records  Mean age (SD) of attenders:  29 (9)years  Mean age (SD) of Non-attenders :  27 (7) years | Observational-Retrospective cohort.  Questionnaire sent to a subset of 83 patients. | Birmingham, England |
| Elders et al (2014)  [25] | To establish the characteristics of adults with type 1 diabetes who disengaged entirely from diabetes care provision. | Adults with Type 1 diabetes. Those who were classified as disengaged had no recorded HbA1c value in either primary or secondary care during the preceding 15 months compared to those who had. | 2772 records  Mean age (SD) of engaged:  44.8 (15.8) years  Mean age (SD) of disengaged:  37.2 (13.2) years | Observational-cross-sectional | Grampian, Scotland |
| Garcia Diaz et al (2017)  [27] | To measure the impact of glycaemic control on adherence to hypoglycaemic agents and to medical visits, and to explore factors that predict adherence. | Notes of historical cohorts of people with type 2 diabetes age >18yrs attending a hospital clinic in Lanzarote 2011-2016 | 639 records  Mean age (SD): 62 (11.5) years | Observational-retrospective cohort | Lanzarote, Spain |
| Gill and Owens (1998)  [22] | To establish the degree of non-attendance at the diabetes centre at the Walton Hospital, Liverpool. This included attendance rates at the 4 routine diabetes clinics and the 'special' diabetes clinics (new referrals, young persons, foot problems and antenatal). | Patients with appointments at the diabetes centre. | 7015 appointments assessed  Mean age not specified | Observational-prospective audit | Liverpool, England |
| Hammersley et al. (1985) [20] | To establish why people with diabetes did not attend, assess their medical supervision and compare their glycaemic control and prevalence of diabetes complications to people who attended hospital clinics regularly | White European people with diabetes aged >64yrs who did not attend their appointment between 1971-1981. | 148 (74 non-attenders, 74 matched controls)  Mean age of non-insulin dependent attenders: 56.7 years  Mean age of non-insulin dependent non-attenders: 55.7 years  Mean age of insulin users who attended: 47.7 years  Mean age of insulin users who attended: 47.0 years | Observational-retrospective cohort.  Questionnaire included. | Wolverhampton, England |
| Hardy et al (2001)  [19] | To establish whether an information pack sent to people with diabetes 2 weeks prior to their appointment and a telephone call 1 week before reduced non-attendance rates of new referrals to the diabetes clinic. | New referrals to the diabetes centre compared to historical new patient controls | 325 new patients following introduction of the intervention.  Mean age not specified | Single centre, prospective, non-randomised controlled study. | Merseyside, England |
| Heydarabadi et al (2017) [42] | To identify and explain factors influencing non-attendance of people with type 2 diabetes to rural health centres. | East Health Centre people with Type 2 diabetes, family members of people with type 2 diabetes, healthcare professionals of people with Type 2 diabetes. All aged >27 years. | 26 (14 people with diabetes, 6 health workers, 3 doctors and 3 members of the person with diabetes’ families).  Age range 27-60 years | Qualitative-phenomenological method. Semi-structured interviews. | Iran |
| Ho (2014)  [38] | An intervention to improve patient turn-around time (duration of time the patient spends at the diabetes centre for an appointment) | N/A | N/A | Quality Improvement project. | Singapore |
| Horny et al (2017)  [32] | To improve self-management, glycaemic control and improve efficiency of care with the introduction of patient navigators. | People with diabetes enrolled in the clinic with an HbA1c >8.5% (69 mmol/mol) who had at least one non-attendance in the past year or if their health care professional requested the service. | 656: 234 (intervention), 422 (reference) 196 in each group matched on propensity scores.  Mean age (SD) intervention group : 56.3 (13.6) years  Mean age (SD) reference group:  55.7 (13.6) years  Mean age (SD) intervention match sample: 56 (14) years  Mean age (SD) reference matched sample: 56 (13.7) years | Observational-Retrospective cohort study. | Boston, USA |
| Hynes et al (2015)  [43] | To develop a theory explaining attendance at a hospital-based diabetes clinic. | Young adults with type 1 diabetes (18-25yrs) and service providers from one hospital-based diabetes clinic were interviewed | 29 (21 young adults with type 1 diabetes and 8 service providers)  Mean age: 22.4 years (range 16-28 years) | Qualitative-Grounded theory methodology. Data were collected through semi-structured interviews. | Galway, Ireland |
| Karter et al (2004)  [7] | The relationship between missed appointments and glycaemic control. | People on the Kaiser Permanente N.Californiadiabetes register who had at least 1 outpatient appointment during the year 2000, maintained continuous membership and medical plan drug benefits and who had an HbA1c during the study period. | 84,040 records  Mean age (SD): 60.8 (13.5) years | Observational-Cross-sectional | N. California, USA |
| Kellett (1988)  [28] | To follow patients at a newly formed diabetes clinic from 1982 to 1985 and establish non-attendance rates. Outcomes were compared between non-attenders and those who attended. | Diabetes clinic attendees | 127 records  Mean age (SD) of attenders:  35 (12.5) years  Mean age (SD) of non-attenders:  34 (9.1) years | Observational-retrospective cohort | Limerick, Ireland |
| Kurasawa et al (2016)  [41] | To predict a missed clinical appointment using a machine based learning algorithm | Records of people with diabetes attending a hospital diabetes clinic in Japan. | 879 records | Observational: Development and validation of a machine learning algorithm. | Tokyo, Japan |
| Lawson et al (2005)  [26] | To understand the reasons behind the decision not to attend a type 1 diabetes hospital clinic. | People with type 1 diabetes who had not attended their hospital apt for 18 months. Age >25 years. | 12 participants  Mean age not specified | Qualitative study. Interpretative phenomenological analysis of semi-structured interviews | Cardiff, Wales |
| Levy-Shraga et al (2016) [40] | To determine whether a dedicated transition clinic for emerging adults with type 1 diabetes can improve glycaemic control and visit attendance. | People with type 1 diabetes attending the transition clinic. Age 22.1 yrs±2.7 | 53 records  Mean age (SD): 22.1 (2.7) years | Observational-retrospective cohort | Israel |
| Low et al (2016)  [39] | To assess the magnitude and risk factors of missed appointments in the diabetes centre in a Singapore hospital. | People with diabetes attending the clinic June 2010-May 2012. | 1610 records  Mean age (SD): 56.7 (14) years | Observational-retrospective cohort | Singapore |
| Masding et al. (2010)  [18] | To determine non-attendance rates at a transitional diabetes clinic and the characteristics of non-attenders. | People attending the Poole Hospital diabetes transition clinic (age 15-21yrs) | 114 records: 53 records (Jan-Dec 2004); 61 records (Sept 2007-2008)  Mean age 2004 cohort:  17 years (range 14-21)  Mean age 2007-8 cohort:  18 years ( range 15-20) | Observational-comparative retrospective audit from Jan-Dec 2004 and Sept 2007-Sept2008. | Dorset, England |
| McCarlie et al (2002)  [24] | To consider the factors which may influence the uptake of routine diabetes care. | Patients on the Ayshire and Arran diabetes register with no record of HbA1c or fundoscopy in the previous year aged >12 yrs. | 9,026 records  Mean age not specified. | Observational study-audit | Scotland |
| McComb et al (2017)  [31] | To determine the prevalence and impact of appointment cancellation | Adults with diabetes age >18 yrs | 7586 patient appointments  Mean age not specified. | Observational-audit | Indiana, USA |
| Ngwenya et al (2009)  [37] | To determine the factors influencing non-attendance with clinic appointments in people with diabetes at a Gauteng Hospital in 2007/2008 | Consecutive non-attending people with diabetes (all >18 yrs. mean age 51.2 years) | 76 people with diabetes  Mean age: 51 years (range 18-85) | Qualitative-Face to face and telephone interviews of a convenience sample of consecutive non-attending people with diabetes prospectively recruited for the study. Interviews lasted approximately 7 min. | Pretoria, S. Africa |
| Nuti et al (2012)  [45] | To assess whether no-shows to primary care are associated with increased risk of emergency department visits or hospital admissions among people with diabetes. | Diabetes age >18yrs attending outpatient clinics associated with an academic medical centre in Indiana. | 8787 records  Mean age not specified. | Observational-Prospective cohort. | Indiana, USA |
| Snow and Fulop (2012)  [17] | To study the reasons for attendance behaviour from the patient point of view. | Type 1 diabetes aged 18-25yrs | 102 patient records, 17 patient interviews  Mean age not specified. | Qualitative-Semi-structured interviews/case studies of 17 purposively chosen patients (9 men, 8 women) based on attendance behaviours-7 as regularly attending, 5 with a record of intermittent attendance, 3 who had never attended within the survey period, 2 who were new to the clinic but had an extensive history of non-attendance. Interviews were 20-30min. | London, England |
| Thongsai (2014)  [36] | To identify predictors of non-attendance and to investigate the influence of illness perceptions on attendance at diabetes outpatient clinics. | Thai people with type 2 diabetes age >18yrs. | 442 participants  Mean age: 60 years | Qualitative-Descriptive study. Illness Perception Questionnaire (IPQ) tool used for measuring patient perception of illness (but amended to be in Thai). | Phitsanulok, Thailand |
| Vijayaraghavan et al (2015) [14] | Hypothesised that web-based consultations would reduce cost per contact by reducing non-attendance rate, demonstrate improved health outcomes over time and reduce cost for the patient by reducing travel. | Patients attending a hospital diabetes clinic in Newham. | 96 participants  Mean age not specified. | Intervention with a qualitative study component. All people attending follow-up appointments with one of the consultants or one of the nurses were offered the online appointments. Intervention was followed by 28 online Questionnaires, 34 interviews (19 in depth and 15 face to face) and 5 focus groups. | Newham, England |
| Weaver et al (2019)  [30] | To determine if providing patient navigation affects first appointment no-show rates and HbA1c in uninsured patients with diabetes at a free clinic. | Uninsured people with diabetes aged >19yrs. | 192 (96 in each cohort)  Mean age: 42.6 years (range 19.1-79.7) | Quality Improvement Project. | Alabama, N. America |
| White et al (2017)  [35] | To assess the effect of an appointment management intervention on clinic attendance and disengagement after transition. | Type 1 diabetes. Aged 17-19 yrs. Recruited from a tertiary paediatric clinic and scheduled for transition to adult services at one of eight centres in Melbourne. | 120 patients  Mean age (SD) over all :  18.8 (0.6) years | Randomised control trial. Patients randomly assigned (1:1) to usual care or the appointment assignment intervention using sequentially sealed opaque envelopes. | Melbourne, Australia |
| Wilson and Greenhalgh (1999)  [16] | To follow-up all non-attenders to a young person's diabetes clinic (age 16-25 years) | People with diabetes attending the young persons’ clinic. | Not specified. | Quality Improvement | Manchester, England |

Footnote: Where type of diabetes has not been specified in column 3, this indicates participants with either type 1 or type 2 diabetes

Abbreviations: SD- Standard Deviations; HbA1c – Glycated haemoglobin

Table 2: The number of identified articles addressing each of the research questions of the review.

|  |  |
| --- | --- |
| **Research question addressed** | **Number of studies identified** |
| Characteristics of non-attenders or missed appointments and/or health outcomes associated with non-attendance | 18 |
| Reasons for non-attendance | 9 |
| Evaluation of an intervention | 8 |

Table 3: Characteristics and outcomes associated with non-attendance at outpatient clinics and their respective supporting studies.

|  |  |  |  |
| --- | --- | --- | --- |
| |  | | --- | | **Factors associated with non-attendance** | | **Supporting studies** | **Conflicting or neutral studies** |
| Age (young adulthood) | [18, 21, 24, 25, 27, 39, 44] | [7, 12, 20, 28] |
| Male sex | [15, 25, 39, 44] | [12, 18, 20, 21, 24, 27] |
| Smoker | [21, 27, 28, 44] |  |
| Low socio-economic status or unemployed | [7, 25, 28] | [24] |
| Ethnicity (Ethnic minorities) | [39] |  |
| Shorter duration of diabetes | [21] | [12, 20] |
| Having children | [21] |  |
| On insulin in the context of T2DM | [27] | [20] |
| Having not attended diabetes education | [27] |  |
| Increased Body Mass Index (BMI) | [20, 44] | [12, 15] |
| Higher glycated haemoglobin (HbA1c) | [7, 12, 18, 20, 25, 27, 34, 44] | [28] |
| Higher blood pressure | [15, 20, 27] |  |
| Worse lipid profile | [15, 27] |  |
| Increased micro- or macrovascular risk | [12, 27] |  |

# Figures

Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram showing the article selection process [10].

# Electronic Appendix