

A perspective piece on Diabetes Self-Management Education and Support (DSMES) programmes for under-represented groups with T2DM in the UK

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Abstract

Self-management is critical for optimisation of diabetes care, and diabetes self-management education and support (DSMES) programmes are well recognised to improve biomedical, behavioural and psychological outcomes for people living with diabetes. The aim of this perspective piece is (1) to delineate the barriers experienced by under-represented groups with type 2 diabetes mellitus (T2DM) and (2) to evaluate the role of targeted interventions and digital health as potential solutions to address these barriers and bridge the gaps in diabetes care. Common barriers to accessing DSMES programmes include practical issues such as timing and location, as well as psychological barriers such as stigma. Available evidence shows that tailoring diabetes self-management programmes to fit with people's culture or specific needs increases effectiveness and acceptability of DSMES programmes in seldom heard groups. Digital-based self-management programmes have the opportunity to reach a vast number of individuals and offer an alternative source to empower people with T2DM. However, technology may also widen health inequalities and increase social isolation. Therefore, further research is required to establish bespoke and effective diabetes self-management programmes for under-represented individuals with T2DM.

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Introduction

It has been approximately 20 years since the UK's National Service Framework for diabetes declared self-management the cornerstone of effective diabetes care and recognised that self-management can be achieved through the provision of information and psychological support.¹ People with diabetes require knowledge, skills and motivation to assess health risks, understand lifestyle behaviours and adopt new health behaviours.¹ Considering that over 99% of diabetes care consists of self-management by the individual, diabetes self-management education and support (DSMES) programmes have been recognised as an essential 'tool' to support the people with diabetes to self-care and self-manage effectively.²

Evidence supports the effectiveness of DSMES programmes particularly in reducing HbA_{1c}³⁻⁵ and improving cardiovascular outcomes.⁶ Despite these positive outcomes, the number of people with diabetes attending DSMES programmes remains low. The UK's most reliable attendance figures are derived from figures from the National Diabetes Audit (NDA), and the most recent data from 2016–17 shows improvement in both the offering of and attendance to DSMES programmes.⁷ However, barriers to accessing DSMES remain for all people with diabetes, but are even more prevalent for those from under-represented groups, including (but not limited to) individuals from minority ethnic groups or those who have intellectual disability (ID) or severe mental illness (SMI).⁸

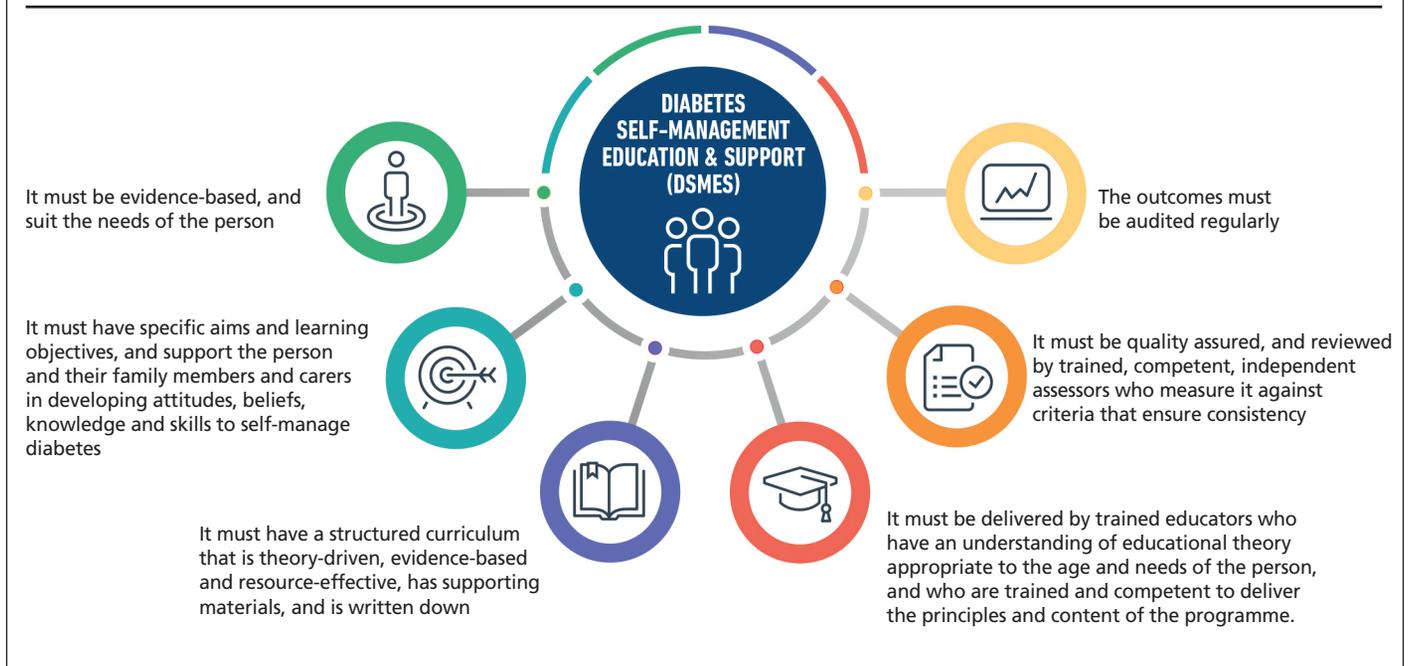
Aim

The aim of this perspective piece is firstly to discuss barriers to accessing DSMES programmes, focusing on under-represented groups including minority ethnic groups, people with ID and individuals with SMI. Secondly, we outline the evidence for targeted interventions in these groups and how technology could form a solution to address many of the barriers experienced by these under-represented groups.

Diabetes self-management education and support programmes (DSMES)

DSMES programmes are essential for all people with diabetes as they aim to promote diabetes knowledge, skills and understanding of how to self-care while also supporting long-lasting behaviour change.⁹ NICE recommends that all people with type

Figure 1. National standards for diabetes self-management and structured education programmes. A pictorial representation of the nationally agreed standards expected of all diabetes self-management and support programmes for people with type 2 diabetes in the UK.^{25,26}



2 diabetes mellitus (T2DM) are offered a structured education programme at the time of diagnosis.¹⁰

In the UK the recommended standards for all DSMES programmes are as follows: must be evidence-based and patient-focused; comprises a structured curriculum; have clear aims for the person with diabetes and their caregivers to support uptake of positive attitudes, knowledge, skills and health beliefs; must be delivered by trained educators, comprised of a multidisciplinary diabetes care team; must be care quality assured by independent reviewers; and the programme outcomes should be audited frequently to ensure quality of care delivery (Figure 1).^{10–13} Moreover, the UK Medical Research Council Framework recommends patient and public involvement in the curriculum development, design and implementation stage and the intervention should undergo multiple rounds of testing in feasibility studies to randomised controlled trials (RCTs).¹¹ The precise format of structured education programmes will vary according to the local population and resources available.

A number of UK face-to-face DSMES programmes meet NICE requirements and are accredited to be offered in the UK. The most well-established DSMES programmes are the X-PERT Diabetes Programme, DESMOND and the Diabetes Manual programme.^{14–16} Although these are the main accredited national programmes available, non-accredited programmes are also provided across local Clinical Commissioning Groups. Such programmes, however, fail to meet NICE requirements and, even though they vary in content and quality, they have not been validated to determine the impact on health behaviour and biomedical outcomes. These programmes differ in format

and content, incorporating one-to-one, group-based and telemedicine approaches, but which have not been directly compared in head-to-head analyses.¹¹

Effectiveness of DSMES programmes

The effectiveness of DSMES programmes has been well evidenced over the years in terms of biomedical, behavioural and psychological benefits. A number of high quality publications including a Cochrane review in 2005 demonstrated the effectiveness of group-based training for self-management on fasting blood glucose levels, HbA_{1c}, diabetes knowledge, systolic blood pressure levels and body weight.¹⁷

At an international level, DSMES programmes^{14,15,18} have been shown to significantly improve HbA_{1c}, body mass index, triglycerides, cholesterol, blood pressure and creatinine.¹⁹ However, the heterogeneity in study design, education programme structure and outcomes assessed render it difficult to compare and contrast studies, and to delineate the most effective components of education programmes that should be widely adopted.¹¹ Focusing on the UK programmes in particular (X-PERT, DESMOND and Diabetes Manual), they have all been shown in RCTs to improve psychosocial outcomes in the short term and the former two showed significant HbA_{1c} reduction also. The DESMOND programme further showed sustained improvements in psychosocial outcomes at three years.²⁰

Figure 2 summarises a number of common characteristics across DSMES programmes that were shown to be associated with positive outcomes. Common participant characteristics were also observed: those who showed a greater reduction in

Figure 2. Successful features of diabetes self-management education and support programmes. A pictorial representation of the features of diabetes self-management education and support programmes that are associated with greater improvements in HbA_{1c}.²⁶

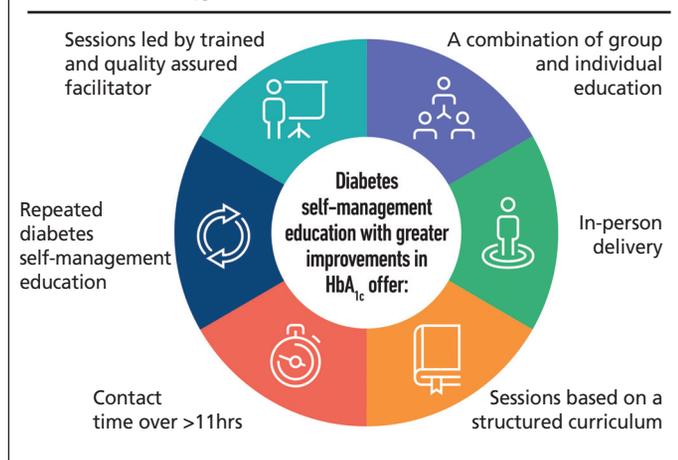
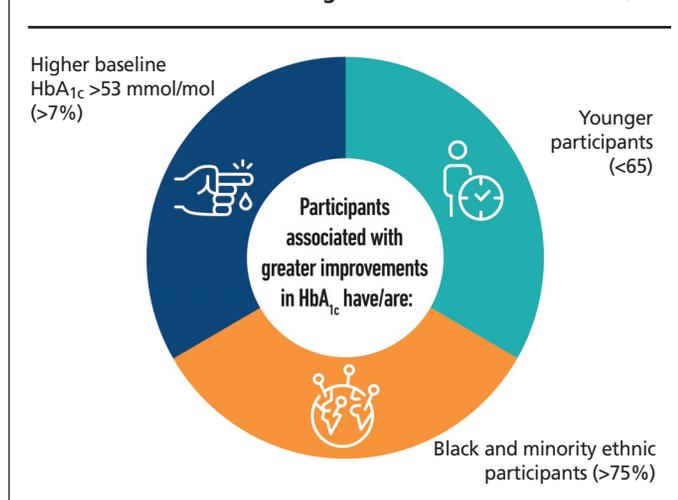


Figure 3. Who benefits the most from diabetes self-management education and support programmes? A pictorial representation of the characteristics of participants that are associated with greater reductions in HbA_{1c}.²⁶



HbA_{1c}; those with a higher baseline HbA_{1c}; those of a younger population (<65 years); and groups with higher proportions of people from minority ethnic groups (Figure 3).

Barriers to DSMES programmes

Despite the global availability of DSMES programmes, a number of barriers have been identified that may affect attendance at these programmes. In 2014 and 2017, two systematic reviews summarised a list of reasons for non-attendance. The most common reasons were: (1) issues with timing and/or length of courses; (2) access/transportation issues; (3) family and/or work

conflicts; (4) lack of information about the course; (5) lack of information on benefits of attending by healthcare professionals; (6) participants' beliefs that they already had sufficient information to self-manage their condition; and (7) contentment with the information received from their general practitioner or diabetes team.^{21,22}

In 2015 the All-Party Parliamentary Group for Diabetes, a non-partisan cross-party interest group in the UK, published a booklet entitled "Taking Control: Supporting People to Self-Manage their Diabetes". Based on a research study conducted in the region of Cheshire and Merseyside Strategic Clinical Networks, experts and people with type 1 and T2DM identified a number of potential barriers to programme uptake. The list of these barriers was similar to the aforementioned systematic review but also considered additional barriers including: (1) psychological burnout of managing a condition for so long; (2) issues with the use of the term structured 'education' and how it may put off people with diabetes; and (3) shame and stigma associated with the condition, particularly among minority ethnic groups.² The authors reported a large number of referral letters sent by GPs, which consisted of little information about the purpose or benefit of the DSMES programmes.² This lack of engagement by GPs may be a significant contributor to the disparity between recorded referrals and attendance by the National Diabetes Audit.⁷

Poor data collection was identified as an additional barrier to uptake, leading to minimum information about who attended and, more importantly, who did not attend. This limitation to service provision led to the introduction of an electronic referral system. In various South London boroughs electronic referral and booking systems have been introduced along with various other improvements to service which have increased attendance rates. Leading on from this is the development of a toolkit by the Health Innovation Network to optimise delivery and attendance to DSMES.²³ More recently, a NICE surveillance review 2019 identified the Embedding Diabetes Education RCT as having the potential to inform and change recommendations to improve attendance.²⁴ The Embedding Diabetes Education trial is one of the largest and complex trials and has developed an 'embedding toolkit' aiming to address the barriers and enablers to uptake at service user, healthcare professional and organisational level.²⁴

Barriers to DSMES in under-represented groups

Minority ethnic groups

The UK represents a richly diverse population with South Asian people (Indian, Pakistani and Bangladeshi) making up the majority of the largest minority.²⁵ This subgroup nevertheless has a 2–4 times higher risk of T2DM and develop diabetes on average 5–10 years earlier than their white European counterparts.^{26–28}

Additional barriers to accessing high quality diabetes care for minority ethnic groups include communication issues and language differences, migrant status, low socioeconomic status and relatively higher levels of deprivation.²⁹ Allory *et al* found that barriers for deprived people with diabetes included geographical restrictions, lack of promotion of the DSMES programmes, lack of relationships built with their healthcare professionals and lack of support to integrate with a new community within the DSMES programme.³⁰

The UK HEAL-D study evaluated barriers to diabetes education in Afro-Caribbean people with diabetes through focus groups and qualitative analysis. They reported that, although Afro-Caribbean individuals were motivated to manage their diabetes and prevent diabetes-related complications, they would benefit from tailored information around diet, physical activity and weight loss related to their lifestyles. Sociocultural barriers to diabetes management included acceptance within their culture of increased body size and rejection of body mass index, combined with lack of social opportunities to undertake physical activity. Therefore, culturally appropriate education interventions aimed at Afro-Caribbean groups with diabetes should consider these findings.³¹

For Bangladeshi people with diabetes in the UK, Greenhalgh *et al* similarly showed this community were motivated to manage their diabetes but semi-structured interviews revealed that barriers were structural, linguistic and cultural in nature. Importantly, they experienced knowledge gaps in diet, exercise and cause of diabetes,³² which could be addressed through culturally appropriate DSMES programmes.

The mainstream UK diabetes education programmes are designed for the majority, and therefore do not address the specific learning needs for members of minority ethnic groups. This has led to increased trials of culturally tailored education programmes incorporating community and church members.²⁹ Culturally appropriate health education for T2DM in minority ethnic groups including African Americans and South Asians may be a way to achieve improved outcomes, particularly in HbA_{1c}, total cholesterol and knowledge.³³

A meta-analysis by Pillay *et al*³ found that DSMES programmes led to greater reductions in HbA_{1c} in minority persons (subgroups with >75% non-white participants) compared with majority white groups; differences were also noted in baseline glycaemic control with minority subgroup HbA_{1c} level 13.1 mmol/mol (1.2%) higher than the white majority subgroup.³ Despite clear evidence illustrating the benefits of DSMES programmes, engagement with this population can be difficult, particularly if programmes fail to consider potential cultural, contextual and linguistic aspects.

A systematic review by Hawthorne *et al* compared RCTs with structured education targeted at minority ethnic groups and showed that, despite wide heterogeneity between studies, HbA_{1c} significantly improved at 3 and 6 months and diabetes knowledge scores improved at 6 months. Importantly, culturally appropriate diabetes education was superior to mainstream education.²⁹ Attridge *et al* performed a Cochrane review of RCTs (n=7,453) and a meta-analysis (n=28 trials) showing that HbA_{1c} significantly improved at 3 and 6 months in culturally appropriate structured education compared with usual education; HbA_{1c} improvement was sustained to a lesser extent up to 12 and 24 months following the intervention. Improvement in lipids was not sustained beyond 3 months and the diabetes knowledge score improved at 3 and 12 months.³³ Zeh *et al* further supported these findings, outlining that culturally appropriate DSMES programmes, which address cultural, language, religious and health literacy differences, led to improvements in a range of patient-reported outcome measures. However, the deemed cultural competency of these education programmes

varies widely, accounting for differences in the benefits observed.³⁴

For Muslim people with diabetes, Ramadan presents additional challenges to their diabetes management and care. The importance of structured education to help people with diabetes optimise management of their diabetes during Ramadan is recognised by the European Association for the Study of Diabetes (EASD) and American Diabetes Association (ADA) guidelines, and structured education which incorporates community awareness packages has been shown to be effective at reducing hypoglycaemia.³⁵

Given the degree of heterogeneity present between studies evaluating culturally competent diabetes education, delineating the most effective elements of these programmes has been challenging. However, Jain *et al* reported on the role of peer-educators in health education for minority ethnic groups, including the observed benefits and flexibility of this approach.³⁶ Similarly, Alzubaidi *et al* supported this finding for Arabic people with diabetes.³⁷ It is equally important to acknowledge that cultural adaptation of interventions should not be homogenous but rather individualised to each minority ethnic group and adapted to the given cultural context. Culturally adapted programmes in the UK include DESMOND BME³⁸ and DoSA (Diabetes for South Asians).³⁹

Diabetes and intellectual disability (ID)

According to data from the National Diabetes Audit 2016–17, the prevalence of ID is around 40% higher in people with diabetes compared with the general population, and 90% of people registered with ID and diabetes have T2DM.⁷ Self-management of T2DM can present significant challenges for this population due to socioeconomic inequalities,⁴⁰ limited support worker knowledge⁴¹ and poor living arrangements which contribute to a sedentary lifestyle.⁴² Health services further contribute to the situation by failing to make reasonable adjustments that take account of, and respond to, the cognitive and communication impairments experienced by many of this population.

A systematic review by MacRae *et al* explored self-management in people with ID and found that they wanted to learn more about their condition, and similarly that their caregivers lacked knowledge and did not feel able to provide diabetes management advice.⁴³ Furthermore, a qualitative study by Brown *et al*⁴⁴ identified from structured interviews that increasing access, improving communication and providing resources adapted to people with T2DM and ID were key to improving diabetes care. Maine *et al* performed semi-structured interviews in people with T2DM and ID, providing additional insight into how self-management education should be targeted; key themes that arose focused on enhancing diabetes knowledge, tailoring strategies for ID, ensuring autonomy, removing stigma, self-care and incorporating feedback from caregivers.⁴⁵ Trip *et al* also focused on the importance of educating caregivers to help further support service users.⁴⁶ Another systematic review by Maine *et al*, which included 23 RCTs, outlined that diabetes education for people with ID needed to align with their needs, be widely accessible, ensure appropriate resources were available and provide adequate social support in order to improve illness perception and self-efficacy.⁴⁷

Health literacy is an additional barrier to diabetes education. For

example, Osborne *et al* showed that limited health literacy was indirectly associated with suboptimal glycaemic control and reduced diabetes self-care behaviours, and this was attributed to inadequate social support for individuals with lower health literacy. This is an important finding because it demonstrates that health literacy does not need to be a barrier to optimising diabetes management.⁴⁸

The DESMOND ID programme⁴⁹ was the first study to adapt and pilot a national structured self-management programme for adults with ID and T2DM. In a pilot study, the DESMOND ID intervention was found to be both acceptable and feasible, and led to a small significant improvement in HbA_{1c} but with a wide confidence interval. Following this, the STOP education programme, which was specifically designed for individuals with T2DM and ID, also passed feasibility testing, demonstrated benefits for service users and care givers alike, and is currently undergoing a RCT.⁵⁰ Given the early stages of these education interventions for people with T2DM and ID, this reflects the need for further research to deliver more patient-centred and effective DSMES programmes for this at-risk group.

Diabetes and severe mental illness (SMI)

People with SMI (including schizophrenia, bipolar and major depressive disorder) experience poorer outcomes and are twice as likely to develop T2DM than those without SMI.⁵¹ Diabetes self-management is considered important in this population, as people with SMI often feel disempowered to self-manage their diabetes.

El-Mallakh *et al* interviewed people with T2DM and schizophrenia and found that psychotic symptoms were significant barriers to diabetes self-care behaviours and that self-management education needed to focus on helping individuals to manage their mental ill health, whilst accommodating for their diabetes as well.⁵² These findings were further supported by Blixen *et al* who showed that people with SMI were exposed to significant stress and stigma, lacked social support and experienced fragmentation of care; it was recommended that all three of these factors needed addressing, and interventions should focus on the diabetes and the mental ill health in combination to help support self-care behaviours.⁵³

The STEPWISE RCT targeted people with T2DM and schizophrenia, schizoaffective disorder or first-episode psychosis (n=414) and found that, although there was no improvement in biomedical or psychological outcomes and it was not cost-effective, participants valued the educational intervention and participant retention was good.⁵⁴ However, the study recognised that significantly greater resources and funding were required when delivering education programmes in this cohort. Another RCT evaluating a stigma-coping and empowerment intervention in people with schizophrenia or depression observed significant improvement in psychological outcomes, including quality of life, functioning and compliance, but did not significantly differ from the usual care arm.⁵⁵ A systematic review performed by Cimo *et al* in people with T2DM and schizophrenia highlighted the importance of diet and exercise advice, with a focus on cognition, motivation and discussion around weight management, particularly with antipsychotic therapies.⁵⁶ On the other hand, Fenton *et al* undertook an RCT evaluating a 12-week education prevention programme and found significant

improvements in weight, waist circumference, HbA_{1c} and blood pressure; however, this study also included people with pre-diabetes.⁵⁷ A 2016 Cochrane review evaluating the effects of DSMES interventions for people with SMI suggested that the evidence remains insufficient as to whether these types of interventions improve outcomes. In this review, small improvements in BMI and weight post intervention, and improved diabetes knowledge and self-efficacy were observed. Despite the positive outcomes, we must acknowledge the main limitation of this review – the inclusion of only one RCT with a small sample size. This limitation highlights the need for further research into the real impact of self-management programmes in those with existing mental health conditions.⁵¹

Role of digital online self-management programmes for T2DM

Health technology has evolved over the last two decades and sources such as digital self-management programmes are now used as supplementary and/or stand-alone sources for knowledge and emotional/social support in the management of chronic conditions.^{58–61} Indeed, an incline in the adoption of digital health education has been observed during the coronavirus pandemic and our group have previously reported on the value of digital health in diabetes care and self-management.⁶⁰

Despite the rise of digital DSMES programmes, evaluation of this form of support reveals equivocal results; some studies report improvements solely on biomedical outcomes, such as HbA_{1c},^{62,63} while other studies report improvements in psychological outcomes.⁶⁴ However, the evidence on psychological outcomes remains scarce, with recent systematic reviews presenting conflicting results and suggesting no significant difference in outcomes such as diabetes-related distress and depression. Woolley *et al* performed a review of reviews to evaluate online education in diabetes management and, although direct comparisons were challenging due to study heterogeneity, they showed varying degrees of improvement in biomedical, psychosocial and self-efficacy outcomes, with particular benefits observed in diabetes knowledge and social support following online diabetes education.⁶⁵

The first of several digital self-management programmes for people with T2DM in the UK was a multicentre RCT in primary care (HeLP-Diabetes), which showed significant but modest changes in HbA_{1c} but no difference in change in distress scores between the two randomised groups at 12 months. The intervention was widely accepted by participants and met the high recruitment targets. The findings from this trial support the role of digital programmes to increase overall access and uptake to diabetes self-management education.⁵⁸ Barriers associated with face-to-face DSMES programmes are often easier to address with digital programmes, as users have the opportunity to access and read material at their own time and pace.

Digital health interventions similarly need to address the barriers and be culturally appropriate for under-represented groups with T2DM. A review by Doshi *et al* summarised the evidence for telemedicine in various vulnerable groups with T2DM, but the interventions often combined in-person and telehealth strategies



Key messages

- DSMES programmes are proven to be an effective and cost-effective part of diabetes care. However, many complex barriers are faced in relation to attending these programmes, including practical issues such as transport and immobility as well as psychological barriers such as shame and stigma
- Digital self-management programmes could have the potential to increase overall access and uptake to DSMES programmes; however, attention is needed when developing digital self-management programmes to ensure that all sociodemographic groups are included, minimising the possibility of digital inequality and social isolation
- Culturally appropriate health education for T2DM in minority ethnic groups may be a way to achieve improved outcomes
- Currently, DSMES programmes are becoming available for under-represented groups including those with SMI, ID and for ethnic minority groups. Digital-based self-management programmes have the opportunity to reach a vast number of individuals and offer an alternative source to empower people with T2DM

rendering it difficult to ascertain what led to biomedical benefits.⁶⁶

Despite the promise of digital health as a long-term, cost-effective solution in diabetes education and care,⁶⁷ it is however important to acknowledge that people with diabetes who belong to a subgroup are still individuals and therefore preferences within subgroups may vary with other factors. For example, Woolley *et al* showed that age and educational attainment were the best predictors of diabetes education style preference, highlighting the importance of patient-centred diabetes education.⁶⁸ Digital health may also present additional barriers to minority groups such as individuals who do not own smart phones or have internet access. Furthermore, some may struggle to gain access or use the information provided due to low levels of health literacy.⁶⁹ Therefore, digital health should be considered as one of many solutions to diabetes education for minority and high-risk groups.

Summary and recommendations

We have outlined the importance and theory behind self-management education and support for people with T2DM. We have also outlined the landscape in the UK for the well-established diabetes education programmes. We have explored the fundamental barriers faced by all people with T2DM in accessing diabetes education, and this is important to address because we are not meeting NICE guideline standards for structured education uptake in the UK. However, of particular concern are the additional barriers to accessing diabetes education for minority groups – including minority ethnic groups, ID and SMI – all of whom are at greater risk of diabetes and have

poorer diabetes management compared with the general population. Barriers prevalent in these minority groups centre around culturally insensitive education programmes that inadvertently may widen diabetes knowledge gaps and are not sufficiently inclusive. Education programmes which specifically target the minority individual ethnic groups are beneficial, but can be resource-intensive and further evidence is warranted to identify the relative improvements in biomedical, psychosocial and behavioural outcomes in the short and longer term. The coronavirus pandemic has presented an opportunity to increase the accessibility of diabetes education, particularly through online education programmes; however, the same barriers for minority ethnic groups remain. The evidence to support culturally appropriate DSMES is already lagging behind mainstream DSMES, hence there is an opportunity to focus attention on culturally appropriate digital health from the outset. The best way to address these barriers is to integrate relevant patients and the public in the design stages of the education programme. Furthermore, further research is needed to elucidate the cultural differences and sensitive ways to address norms that do not align with optimisation of diabetes self-management.

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Author contributorship MH & LQ are joint lead authors. MH, LQ, FT and SS led the development of the manuscript. MH, LQ, FT, SS, KK and MJD revised the content and structure of the manuscript. All authors read and approved the final manuscript.

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