Insights into optimising education for patients living with diabetes mellitus: A model for the post-pandemic era, informed by survey data

Petra Hanson\textsuperscript{1,2,3} | Dilan Parmar\textsuperscript{1,2} | Pranay Deo\textsuperscript{4} | Daniella Whyteoshodi\textsuperscript{1,2,3} | Charlotte Gotts\textsuperscript{1,2} | Paul J. O’Hare\textsuperscript{1,2,3} | Harpal Randeva\textsuperscript{1,2,3,5} | Thomas M. Barber\textsuperscript{1,2,3}

1Division of Biomedical Sciences, Warwick Medical School, University of Warwick, Coventry, UK
2Warwickshire Institute for the Study of Diabetes, Endocrinology and Metabolism, University Hospitals Coventry and Warwickshire, Coventry, UK
3NIHR CRF Human Metabolism Research Unit, University Hospitals Coventry and Warwickshire, Coventry, UK
4Department of Health Psychology, University of the West of England, Bristol, UK
5Aston Medical School, Aston University, Birmingham, UK

Abstract

\textbf{Background:} Patient education represents the key element in the management of diabetes mellitus (DM) and has changed dramatically during the last 3 years. Uptake of structured education is poor, and patient perception of received education varies greatly. The purpose of this study was to assess patients’ perception of adequacy of delivered education, barriers to attending structured courses and preferences for ongoing DM-related education.

\textbf{Methods:} Patients living with Type 2 DM attending diabetes clinics were invited to complete a questionnaire about their understanding of DM, adequacy of offered education and desired features of future courses, following their clinic appointment at University Hospitals Coventry and Warwickshire (UHCW). Those interested (n = 146) completed this questionnaire.

\textbf{Results:} Participants’ mean age was 58.2 years (standard deviation [SD] 13.6, median 59, interquartile range [IQR] 50–66), mean body mass index 34.5 Kgm$^{-2}$ (SD 9.1, median 33.7 Kgm$^{-2}$, IQR 29.8–41.7) and duration of T2DM was 13 years (SD 10, median 10 years, IQR 3–19). Thirty-one per cent of participants received no education at the time of their diagnosis with 51% of participants reporting no ongoing DM-related education. Thirty-seven per cent of participants did not understand the meaning of HbA1c. Preference for face-to-face versus remote delivery of DM-related education was roughly split, with 51% preferring the former. Attention to self-compassion and mental health needs were identified as key elements currently missing from DM-related education.


1 | INTRODUCTION

Living with diabetes mellitus (DM), perhaps more than any other 21st Century chronic disease, requires focus, diligence, drive and poise. Even with extensive input from healthcare professionals and specialist diabetes teams, DM remains quintessentially a self-managed condition. Despite variable support for patients from healthcare professionals, family, friends, employers and wider society, ultimately clinical outcomes and maintenance of wellbeing in patients with DM are utterly dependent upon patients’ management of themselves. This self-management is itself influenced by knowledge, attitudes, emotions and behaviours.

There are many ways to influence behaviour. Knowledge and understanding are key. However, effective behaviour change also requires us to focus on emotional regulation, given the central role of emotions in influencing our cognitions and behaviour. DM-related distress (characterised by stress, guilt and frustration) is common throughout a patient’s life-journey, and exemplified by the three-fold greater prevalence of depression amongst patients living with DM compared with the general population. Although there are many contributors to distress, lack of self-control (and importantly perceptions of self-control) predominates. DM-related distress commonly results in a vicious cycle of DM-resentment, cognitive bias and poor behavioural choices. A key to breaking or even preventing this cycle is to provide a comprehensive and ongoing educational programme for patients living with DM, including opportunities to interact with DM educators and perhaps, also other patients living with DM.

 Provision of education to patients living with DM has been a perennial problem within the National Health System (NHS) in the UK for decades. There are numerous challenges and hurdles. Pre-pandemic, many patients with DM had their educational needs addressed through standard group-based courses such as Dose Adjustment For Normal Eating (DAFNE) and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND), for patients living with Type 1 DM (T1DM) and Type 2 DM (T2DM) respectively. Mindful self-compassion programmes represent an alternate group-based educational programme for DM. This alternate educational programme results in clinically significant reductions in depression, DM-related distress and glycaemic control. However, the low uptake onto educational programmes generally for patients living with DM undermines any potential for meaningful clinical benefit, with only a small minority (15%-30%) of newly diagnosed patients with DM attending a structured educational programme, despite high rates of referral. Most common reasons for non-attendance of structured educational courses are work and time commitments, as courses normally take place during work hours, as well as financial and logistical reasons of travelling to venues.

During COVID-19 pandemic, the educational landscape changed dramatically. Face-to-face contacts were stopped or limited, and thus traditionally delivered structured educational courses could not take place. This was similar across the whole of Europe as the majority of centres reported extreme or quite severe disruption to educational provision for patients living with diabetes. New digitally enabled platforms were created, with some tested among people living with diabetes in a community setting (rather than in secondary care setting). A pilot of an online open course for people with type 2 diabetes found improvement in self-reported health knowledge and self-management ability in 6 months following the completion of the 2-day course. Whilst this represented a great initiative among restrictions imposed during pandemic, it is clear that such a self-directed digital platform cannot replace more formally delivered health care professional directed delivery.

There are two essential questions regarding the provision of structured effective education for patients living with DM. The first relates to the type and quality of education provided. The second relates to the accessibility of educational provision. It is important to gain insights into both of these key elements of educational provision to understand why patients with DM appear resistant to engagement with the traditionally offered educational programmes, and how we can address this through novel approaches in the future.

To explore some of these issues, our aim was to evaluate pre-pandemic knowledge, understanding, emotionality and DM-related educational status amongst patients with DM attending diabetes
1. Age: …………years Gender: M/F/other/prefer not to say
2. When were you diagnosed with diabetes? Year:
3. What medication are you currently taking for your diabetes? Tick all relevant options.
   - Metformin
   - Gliclazide
   - Glitn (sitagliptin, linagliptin, alogliptin, saxagliptin, vildagliptin)
   - Dapagliflozin/Empagliflozin/Canagliflozin
   - GLP1 analogues (bydureon, victoza, trulicity, exenatide, lixisenatide)
   - Insulin (which one) ……………
   - Others:
4. Do you monitor your own blood sugars? If not, please go to question number 4 d.
   a. How many times a day do you monitor?
   b. What has been the range of readings over the last 2 months?
   c. Do you ever get low readings (BM<4)?
      - Yes-once a week
      - Yes-once a month
      - Yes-other frequency ……………
      - No readings <4
   d. Are you interested in your HbA1c?
      - Yes-it was discussed at my last appointment
      - Yes-but not discussed at my last appointment
      - No- I am not sure what this means
   e. Do you have hypoglycaemia (low blood sugar) awareness? (Do you recognise symptoms when BMs are low?)
      - Yes
      - No
5. Have you encountered any problems with your current or previous diabetes medication to control blood sugar?
   a. Weight gain
      - Yes-how much: ……………
      - No
   b. Low blood sugar readings (reading <4)
      - Yes- how often: ……..
      - No
   c. Other side effects: ………………………………………………………………………

**FIGURE 1** Patient survey

outpatient clinics within a hospital-based secondary care setting. A further aim was to gain opinions from our patients with DM regarding the provision of DM-related education, including barriers, accessibility, format and suggested changes. These insights were used to develop an outline for a future post-pandemic hybrid model of DM-related education, to optimize its provision, format and accessibility for not just a minority, but for all patients who live with DM.

## METHODS

### 2.1 Patient recruitment and setting

Adult patients (age > 18 years) were recruited from Diabetes outpatient clinics at the Warwickshire Institute for the Study of Diabetes, Endocrinology and Metabolism (WISDEM Centre), University Hospitals Coventry and Warwickshire (UHCW), UK. Inclusion criteria included all patients who had decisional capacity, an established diagnosis of T2DM and undergoing glycaemic management at the time of recruitment. There were no exclusion criteria. The study was conducted between January and December 2019. Our study was approved by a local Research Ethics Committee and by the UHCW Research and Development Department.

### 2.2 Research design

This was a cross sectional study, using a bespoke questionnaire. Power calculation was not done; however we aimed to get a minimum of 100 responses. Following informed consent, we requested
6. What changes to your therapies have occurred over the last year?
   - No change
   - Addition of a new medication (which one): ……………………
   - Current medication ……………… (State name of drug) dose was changed from ……… to ………

7. Did you receive any education about the management of your condition when you were first diagnosed?
   - Yes-education delivered by a doctor
   - Yes-education delivered by a Diabetic Specialist Nurse
   - Yes-education delivered by other Healthcare professional (please state) …………
   - No education delivered when first diagnosed

8. Are you receiving any ongoing education about management of your condition? (Including driving advice)
   - Yes-online education
   - Yes-education by healthcare professionals
   - Yes-social forums/ patient groups/Friends/Family
   - Yes-formal education course (Desmond, Carbohydrate counting etc)
   - No ongoing education received
   - Other (state what) …………

9. Are you happy with the level of education you received so far? (Please circle)

10. Are there any deficiencies in your education in relation to diabetes? If so, what are they?

11. How can we improve diabetes-related patient education in future?

12. How do you prefer education delivered to you? (What form)

13. Are there any barriers to your educational needs? (Please state what these are)

14. What is your current weight and height?
   - Weight: ………………
   - Height: ……………

15. Has your weight changed in the last 6 months?
   - Yes-increased by ………
   - Yes-decreased by ………
   - No-stayed the same

16. Have you received any advice on weight management? Circle all relevant options
   - GP
   - Dietitian
   - World
   - Other health care professionals
   - Weight management courses (e.g., Slimming World)
   - No advice
   - other source of advice:

17. Is there anything else our service can do to help you with weight management?

FIGURE 1 Continued

Each recruited participant to self-complete a standard questionnaire (shown in Figure 1). The questionnaire design enabled exploration of demographic details, current knowledge and understanding of DM, adequacy of DM-related educational provision and barriers limiting accessibility of educational programmes and resources. The questionnaire also probed individual preferences for delivery methods of existing educational resources and suggested recommendations for improvements of educational provision.

2.3 Statistical analysis

IBM SPSS 26 was used for all statistical testing. All available data were used for individual analysis. Data were displayed using excel. Data on satisfaction with received education were non-parametric. Therefore, we used the Mann–Whitney U test for comparisons between data. The chi-squared test was used to analyse preference of future mode of education delivery based on patients’ age. We report descriptive
data as mean, median, interquartile range (IQR) and standard deviation (SD). A p value < 0.05 was considered significant. Some participants did not complete all the questions in the questionnaire and as a result the total number of responses can differ between individual questions. Percentages were rounded to the nearest percentage.

2.4 | Research objectives

To identify the number of patients attending secondary care diabetes service who have not had any formal diabetes education and to explore preferred methods of delivery for future diabetes self-management courses.

3 | RESULTS

3.1 | Participant cohort demographics

We report on data generated from self-completion of a standard questionnaire by participants (n = 146) attending our DM outpatient clinics at WISDEM centre, UHCW, during 2019. Age ranged between 29 and 86 years (mean 58.2 years; SD 13.6, median 59, IQR 50–66). Sex distribution was roughly equal with 57 males, 58 females and 31 participants not responding to gender question. Body mass index (BMI) ranged between 20.5 and 65.5 Kgm⁻² (mean 34.5 Kgm⁻²; SD 9.1, median 33.7 Kgm⁻², IQR 29.8–41.7). T2DM duration at the point of recruitment ranged between 1 and 41 years (mean 13 years; SD 10, median 10 years, IQR 3–19). Year of diagnosis ranged from 1979 to 2019 (mean year of diagnosis: 2006; SD 10, median 2009, IQR 200–2016).

3.2 | Adequacy of DM-related education provision

One hundred thirty-seven participants completed information about education received when first diagnosed with DM. Around the time of their diagnosis of T2DM, a third (31%) of the cohort had not received any form of DM-related education. For those patients who had received DM-related education around the time of diagnosis, this was delivered by a diabetes specialist nurse in 28% of the cohort, by a doctor in 20% of the cohort, by another healthcare professional in 6% of the cohort and by a combination of various health care professionals in 15% of the cohort (data shown in Figure 2). One hundred thirty-nine participants completed information about ongoing education. During the entire duration of their patient journey with DM, a half of the cohort (n = 71; 51%) reported receiving no ongoing DM-related education. Only a small minority of the cohort (n = 7; 5%) reported receiving ongoing formal DM-related education via a course. There was provision of DM-related education from a healthcare profession in 40% of the cohort (data shown in Figure 3). One hundred thirty-one patients completed information about understanding of HbA1c. As a reflector of adequacy of DM-related education, 37% of the cohort (n = 48) did not understand the meaning of ‘HbA1c’ (data shown in Figure 4).

Despite the clear deficiencies in DM-related educational provision outlined, overall happiness with DM-related education was relatively good (mean average score 3.9, based on a Likert scale 1–5 of how happy participants were with the level of education received with 5 being most happy). Mann–Whitney U test indicated a significant association between overall happiness with DM-related education and the provision of ongoing DM-related education (p < 0.001), with the mean level of happiness with education of 4.3 for those receiving ongoing education and 3.6 for those receiving no ongoing education, respectively. A substantial minority of the cohort (n = 38, 26%) reported deficiencies in their DM-related education. Of those reporting educational deficiencies, 16 (42%) desired the provision of greater general DM-related information and 6 (16%) wanted more dietary information and 5 (13%) reported more than one deficiency, such as dietary education, general diabetes education and timeliness combined (data shown in Figure 5).

3.3 | Preference for accessibility and format of DM-related education

A majority of the cohort (n = 109) specified a preferred method of ongoing DM-related education. Overall, the cohort was roughly split regarding preference for a face-to-face versus remote delivery of DM-related education, with 51% expressing a preference for the former.
For the remainder, 33% preferred remote delivery, and 16% preferred a combined approach of face-to-face and remote delivery. One variable chi-squared ($X^2$) analysis (with a cut off $X^2$ value of 5.99 for 2 degrees of freedom and alpha of 0.05), demonstrated that face-to-face delivery of DM-related education was preferred overall ($X^2(2) = 18.8, p < 0.005$), in the 51–64 years ($X^2(2) = 17.1, p < 0.005$) and ≥65 years age groups ($X^2(2) = 6.7, p = 0.05$). However, there was no difference in the preferred educational delivery method in the younger ≤50 years age group, ($X^2(2) = 2.4, p = 0.76$), although most wanted remote options (14, 45% remote; 7, 23% hybrid) (data shown in Figure 6).

### 3.4 | Participant feedback

There was expression of interest in options for skype contact, more accessible courses and support with eating behaviours and impulses. The main barriers to attending courses were mobility issues, language problems and learning difficulties. Patients would like healthcare professionals to ‘help with mental health issues’, create ‘smaller modules allowing disabled patients to attend’ and ‘apps/short articles/interactive’. Patients also wanted help with increasing their self-compassion and return to normality: ‘Don’t make the patient feel like a failure: We need to know how a normal life can be achieved’.
The data outlined from our audit reveal serious deficiencies in the adequacy of existing DM-related educational provision for our patients. This represents an important unmet need, and one that is well overdue. Unfortunately, the insights gained from our local audit are reflected nationally: the inadequacy of DM-related patient education is a national problem. It follows that tackling this problem requires a national solution. It is important to highlight here that the problems with DM-related educational provision are not necessarily related to the adequacy of the educational programmes on offer. Indeed, the existing DAFNE and DESMOND courses appear in many cases excellent. Rather, the main issue (as identified from our survey) is that although such traditional courses exist and are offered to patients, the courses themselves are poorly attended, with only a small minority of patients offered the course who attend it. Therefore, reformation of DM education needs to properly address its accessibility and other barriers to its successful implementation. Although patients from our survey expressing a preference wanted face to face education as an option, as many wanted remote or hybrid, so all three should be included in future programmes to maximise accessibility.

Our study had several limitations. It was done in one diabetes centre only and assessed people living with T2D accessing secondary care. Whilst we collected data on >100 patients, we would need to repeat the survey on larger numbers of patients, in different settings and localities to get a broader insight into the problem. Additionally, the
survey relied entirely on patient self-recall, and therefore there was potential for lack of accuracy from reduced memory of educational provision that may have occurred at diagnosis for example (especially as some of them were diagnosed in 1979: it is entirely feasible that not all patients can remember what happened that far back). Also, there may be potential for recall bias. It is known that one’s memory of the past is influenced by one’s current emotional status. If a patient is feeling distressed currently, then their outlook on the past (and future) will tend to be more negative, and their recollection of the utility of educational provision may be influenced in that way as well. We used HcA1c as a proxy measure of diabetes understanding, but of course to properly assess this would have required far greater questioning into many aspects of DM, which would not have been feasible within our study. It is possible that some patients may have a generally good grasp of DM without fully understanding HbA1c, or some may have simply forgot meaning of HbA1c when questioned. Building on the insights gained from our survey, we outline the current landscape for patient DM-related education in the UK. We then discuss the merits of digitally enabled and mindfulness-based educational programmes and finally describe a vision of a new era in DM-related education.

5 | DIABETES EDUCATION: A HYBRID MODEL POST-PANDEMIC

5.1 | Pre-pandemic landscape for patient DM-related education in the UK

Traditionally, there were three levels of DM-related educational delivery: (i) one-to-one advice; (ii) informal ongoing learning; (iii) structured health care professional directed education that meets nationally-agreed criteria, as defined by the National Institute for Health and Care Excellence. These criteria state that any educational course requires a foundational evidence-based with specific aims and objectives, driven by theory, resource effective, delivery by trained educators and regular auditing. However, the criteria do not specify what content is required.

The Department of Health and Diabetes UK provides guidance on the specific content of such DM-related courses, with information about day-to-day management of DM, the nature of DM, living with DM and sick day rules. The American Association of Diabetes Educators also created a framework for any patient centred DM-education, which allows the evaluation and creation of new courses and programmes. The framework has seven key behaviours, including healthy eating, physical activity, DM monitoring, taking medication, reducing the risk of DM-related complications, problem solving and healthy coping. These criteria provide a focus on overall healthier lifestyle, including metabolic health parameters, such as weight, blood pressure, lipids and mental health.

All level three educational programmes in the UK have to be Quality Institute for Self-Management Education and Training approved. Examples of some of the level three courses are DAFNE, X-PERT Diabetes Programme and DESMOND.

5.2 | Digitally enabled structured patient education

One of the first technology-enabled DM-related structured educational courses took place at Stanford University in California in 2010. Following this 6-week web-based programme, patients had improved self-efficacy, confidence in managing their condition and glycaemic control.

By 2017, there were at least 25 high quality studies that reported assessment of digitally enabled DM-related structured education. Review of these studies identified four key elements of a successful remote educational course: (i) two-way communication; (ii) patient-generated health data; (iii) tailored education and (iv) individualised feedback. Accordingly, all of these factors should be integrated into the design of any self-management education and support courses for patients with DM. Interestingly, healthy coping strategies (including stress management and peer support, which often have direct implications on other self-management behaviours such as healthy eating behaviours and physical activity) were under-represented in digitally enabled DM-related structured education. However, previous qualitative study found that patients felt digital health interventions could help address some of the unmet needs, such as placing an emphasis on emotional management, having up-to-date evidence-based guidance for patients and providing access to peer-generated and professional advice.

In the current pandemic, the way we deliver clinical care and associated patient educational courses has changed. With increasing prominence of remote delivery of outpatient interactions since March 2020, traditional face-to-face courses and educational activities have also become increasingly remote in their delivery. Courses such as with BERTIE (a course for patients with T1DM) and DESMOND for patients with T2DM have online versions. Additionally, in the second half of 2020, many novel DM-related educational courses switched their delivery via the Zoom or Teams platforms. The most recent change has been NHS commissioning ‘Changing health’ online platform to deliver Type 2 Diabetes Education, a programme called Healthy Living for People with Type 2 Diabetes. This online self-management support programme is designed as alternative means of accessing support alongside more traditional group-based structured educational programmes. This programme consists of videos, written information and quizzes. The field of digital-platforms delivering online education is rapidly expanding, and more research is required to ascertain the impacts of such approaches, especially as compared to health care professional delivered education. Both face-to-face and online structured self-management educational courses for patients with DM should provide skills for emotional regulation, attentional control, motivation and self-compassion, rather than only knowledge about diabetes.

5.3 | Mindfulness and DM-related education

Mindfulness is a state of moment-to-moment, non-judgmental, non-reactive attending and awareness and has historical origins.
Mindfulness has become more widely recognised in the Western world following the introduction of mindfulness-based stress reduction in 1979 and now is an increasingly popular concept, applicable to any discipline and everyday life.

Our understanding of the underlying mechanisms of action of mindfulness is slowly emerging with the fast-moving field of neuroscience and cognitive research. The key principles for the beneficial effects of mindfulness are believed to be improved self-awareness, improved emotional regulation and attentional control, all of which lead to better self-regulation.22

A narrative review of studies assessing the effect of mindfulness based interventions (MBI) in patients with DM showed that MBIs reduce HbA1c, cortisol, body weight, blood pressure and albuminuria, improve emotional regulation and result in improved rates of depression and DM-distress syndrome.23 A systematic review by Noordali et al.24 showed that MBIs result in psychological benefits of reduced depression, anxiety and distress symptoms. More recent studies showed that mindfulness-based stress reduction reduced HbA1c25 and insulin resistance.26

Current DM educational courses (DESMOND, DAFNE) deliver dietary information to patients without reference to mindfulness-based strategies and coping mechanisms. Multiple dietetic interventional studies showed that MBIs reduced emotional eating,27 reduced intake of energy and fat dense food28,29 and reduced HbA1c.30 Moreover, a systematic review of dietetic outcomes associated with mindfulness-based eating by Harmadiillah et al.31 revealed improvements in physiological markers and overall eating behaviours.

Unhealthy eating choices are often preceded by psychological stress32 and vice versa. As DM is associated with increased prevalence of mental health disorders,1 it follows that empowering patients to make daily, improved dietary choices via mindfulness-based dietetic education may act to reverse DM-related distress and increase the sustainability of resultant physiological improvements.

In short, mindfulness-based educational courses can teach patients healthy coping strategies and particularly improve their emotional regulation, self-awareness and attentional control, all of which are missing from the traditional DM-related educational courses.

### 5.4 A new era in DM-related education

A key feature of any future DM-related patient education is its accessibility to not just a small minority but to all patients. For this ideal to be realised, it is likely that future DM educational programmes are implemented via hybrid mode, through multiple formats and platforms, which includes for example remote access via Teams or Zoom, as well as online learning platforms and face-to-face learning.

Timing of courses is key, and offer of both in and out of working hours courses is crucial to reduce barriers such as childcare responsibilities and work commitments. Newly diagnosed patients may benefit from a health care professional delivered structured course (either remotely or in-person), which will also enable more interaction with other people living with T2D. Evidence shows that substantive educational value can be delivered in group consultations for diabetes, both in person and virtually.33 Furthermore, educational programmes should also be designed in a way that is malleable and can be moulded and tailored to individual groups of patients (to include, for example, multiple options for languages and culturally specific advice on dietary needs). Patients in primary care will have different needs to those attending secondary care. Involving patients in shaping education about their condition empowers as well as engages them and facilitates the attainment of healthcare’s quintuple aim: better-quality education as well as care for the same or lower cost, enjoyable for patients, students and teaching staff.34

Ongoing education can be provided by a platform enabling a mixture of online learning and self-monitoring that includes the option for two-way communication between the patient and a health care professional. There should also be an option for individualised feedback and for patients to gain insights from their own health data (such as levels of physical activity levels, food intake and blood sugar monitoring). The tailored educational components should include advice skills to improve self-regulation to enable patients to truly self-manage their condition. Finally, we believe that future DM-related educational programmes should incorporate evidence-based mindfulness strategies in a truly patient centred holistic manner. Through such a renewed approach to DM education, there will likely be increased interest and uptake amongst patients, and ultimately better self-management, healthier lifestyles, reduced distress and improved overall wellbeing.

### ACKNOWLEDGEMENTS

The authors would like to acknowledge research staff from HMRU that helped with collection of surveys, as well as patients that took part in this survey.

### CONFLICT OF INTEREST

The authors do not have any conflict of interest.

### FUNDING INFORMATION

The authors received no specific funding for this work.

### DATA AVAILABILITY STATEMENT

The datasets generated during the current study are available from the corresponding author upon reasonable request.

### REFERENCES


How to cite this article: Hanson P, Parmar D, Deo P, et al. Insights into optimising education for patients living with diabetes mellitus: A model for the post-pandemic era, informed by survey data. Lifestyle Med. 2022;3:e64. https://doi.org/10.1002/lmt2.64