



Akhter, K., Bunn, C., Graffy, J., Donald, S., Ward, C. and Simmons, D. (2017) Empowerment-based education for established type 2 diabetes in rural England. *Practical Diabetes International*, 34(3), pp. 83-88. (doi:[10.1002/pdi.2088](https://doi.org/10.1002/pdi.2088))

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This is the peer-reviewed version of the following article: Akhter, K., Bunn, C., Graffy, J., Donald, S., Ward, C. and Simmons, D. (2017) Empowerment-based education for established type 2 diabetes in rural England. *Practical Diabetes International*, 34(3), pp. 83-88, which has been published in final form at [10.1002/pdi.2088](https://doi.org/10.1002/pdi.2088). This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#).

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Deposited on: 28 February 2017

Practical DIABETES

Empowerment-based education for established type 2 diabetes in rural England

Journal:	<i>Practical Diabetes</i>
Manuscript ID	PDINTL-17-003
Wiley - Manuscript type:	Original Article
Date Submitted by the Author:	23-Jan-2017
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Keywords:	education, type 2 diabetes, knowledge, ethnographic, rural

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Empowerment-based education for established type 2 diabetes in rural England

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Abstract

People with newly diagnosed type 2 diabetes are offered structured education, but there are few programmes for those with established diabetes. The empowerment based education approach from the United States has been advocated as one approach that supports self-management, but is not used in England. The aim of this study was to assess the acceptability of empowerment-based diabetes education for patients with established Type 2 diabetes.

One 3.5 hour workshop was offered to participants joining a trial of peer support in Rural Cambridgeshire, UK. Four main aspects of self-care (Carbohydrates and portion size; truths and myths about diabetes; know your numbers and medications; keeping active and foot care) were addressed, followed by a question and answer session. Change in diabetes knowledge and participant perspectives were evaluated using questionnaires. Qualitative evaluation was by ethnographic observation of sessions.

Patient expectations were met in 93.5% of participants. Aspects thought to be particularly useful related to diet and carbohydrates and also medications. Ethnography revealed 5 main themes: diet, group process, health service experience, within session peer support and educator clinical grounding. 60% of those participating increased their ability to answer diabetes knowledge based questions.

Adopting the 'Empowerment approach' is a valid method of diabetes education for those with established type 2 diabetes in England. Delivery by experienced educators is important to address queries that arise during the sessions.

Introduction

The prevalence of type 2 diabetes (T2DM) is increasing,¹ placing a growing burden on individuals, their families and healthcare systems.² The cornerstone of management includes appropriate lifestyle choices supported by regular medication and blood glucose self-monitoring, where necessary. As daily care of diabetes is carried out almost entirely by the patients, it is especially important that they develop adequate self-management skills and healthy behaviours in relation to their diabetes.³

Diabetes self-management education (DSME) is a fundamental component of diabetes care that helps patients acquire the required knowledge, information, self-care practices, coping skills, and attitudes.⁴ The overall objectives of DSME are to support informed decision-making, self-care behaviours, problem-solving and active collaboration with the health care team and to improve clinical outcomes, and quality of life.⁵ DSME interventions have a positive impact on diabetes-related health and psychosocial outcomes, specifically increasing knowledge and improving blood glucose monitoring, dietary and exercise habits, foot care, medication taking, coping, and improving glycaemic control systolic blood pressure and weight⁶⁻⁸.

In the UK, there are two national structured, evidence based education programmes for those with newly diagnosed Type 2 diabetes: DESMOND⁹ and X-Pert.¹⁰ However, there is less evidence for educational programmes for those with established T2DM in the UK.¹¹ In the United States, the 'empowerment' approach to diabetes education, where content follows the questions from participants, rather than in a structured format, has been shown to be beneficial in a randomised controlled trial.¹² This study tested whether the 'empowerment'

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2
3 approach to patient education is acceptable and effective in increasing diabetes knowledge
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5 among patients with pre-existing T2DM in the East of England.
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8 9 **Method**

10 **Participants & setting**

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13 Adults with type 2 diabetes were invited into RAPSID (RAnomised controlled trial of Peer
14 Support In type 2 Diabetes – ISRCTN 66963621)¹³ from across Cambridgeshire, and
15 adjacent areas in Essex and Hertfordshire, UK. Participants were recruited mainly through
16 general practice, with a minority responding to posters in the community as previously
17 described¹³. Those with terminal illness, psychosis or dementia were excluded. Following
18 consent, baseline measurements included HbA1c, lipids, anthropometric measurements,
19 blood pressure and measures of depression (PHQ8¹³), quality of life (EQ5D¹⁴) diabetes self
20 efficacy¹⁵, the Revised Diabetes Knowledge Scale (RDKS¹⁶) and diabetes distress.¹⁷
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22 Consenting participants were offered a single diabetes education session prior to
23 randomisation into the trial, which compared the impact of group and/or 1:1 peer support on
24 metabolic control.
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41 **Education Intervention**

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43 The education intervention was delivered in groups of up to 15 to build on group learning
44 processes and held at local community centres, general practice or hospital venues. The
45 format was based upon the ‘Empowerment approach’ of Funnell & Anderson¹⁸ and was
46 delivered using a variety of interactive tools (group discussion, quizzes, experiential learning
47 and identifying carbohydrates). The role of the facilitator (a diabetes specialist dietician or
48 nurse) was to engage the participants in group discussion, increase awareness about diabetes-
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3 related facts while maximising peer learning and activities that would enhance their
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5 understanding of self-care.
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10 The 3.5 hour workshop began with mutual introductions and covered four topics, followed by
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12 a question and answer session:
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- 14 1. Identifying carbohydrates and understanding portions
 - 15 2. Truths and myths about diabetes
 - 16 3. Know your numbers and medications
 - 17 4. Keeping active and looking after your feet
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25 **Evaluation**

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27 Knowledge about diabetes was assessed by participants being asked to complete the RDKS at
28
29 the beginning and end of the education sessions.¹⁶ The original instrument consists of 23
30
31 knowledge test items developed and validated by the Michigan Diabetes Research Training
32
33 Center.¹⁶ The first 14 items are a general test, with an additional 9 item sub-scale which is
34
35 only appropriate for people who use insulin. To tailor the questions to the aims of the
36
37 education programme, 10 items were selected, covering food (3 items), blood glucose,
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39 glucose testing, weight management, physical activity, HbA1c, foot care and the annual
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41 review.
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47 Statistical analyses were performed using SPSS Version 19. Characteristics were compared
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49 using analysis of variance (continuous variables) or chi squared (discrete variables) test. The
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51 effect of the group session on proportion of correct answers was tested by paired-sample *t*-
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53 tests. The characteristics of those who increased their scores by $\geq 10\%$ were investigated
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3 using stepwise logistic regression. Statistical significance was set at $p < 0.05$. All tests were 2
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5 tailed.
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10 At the end of the workshop, participants were also asked to complete an anonymous
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12 evaluation form which asked what they found most and least useful and whether their
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14 expectations were met.
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17 18 **Ethnographic observations**

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20 36 of the 128 education sessions were observed by a social scientist (CB) using ethnographic
21
22 methods.¹⁹ The researcher's presence and purpose were made known to the participants both
23
24 at the education sessions and in the study consent form. Notes were taken by hand,
25
26 transcribed and entered into NVivo 10 for analysis, using a grounded theory approach.²⁰ A
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28 subset of the transcriptions was read by another social scientist to check the interpretive
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30 processes through which the emergent themes were derived. Ethics approval was received
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32 from the Cambridgeshire REC2 Committee.
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38 39 **Results**

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41 Across the 63 participating practices, 21,961 were invited to join the RAPSID trial. 1,366
42
43 were recruited and of these, 797 (58.3%) attended the diabetes education sessions. Despite
44
45 contacting participants three times, it proved hard to arrange a convenient session for the
46
47 others. Of those attending, 578 completed the RDKS before and after the session and table 1
48
49 provides information on these. A further 38 completed the RDKS only before and 17 only
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51 after the session. Those completing the RDKS before and after the session were similar to
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53 others besides having a lower BMI (data not shown).
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3 Table 2 shows that more correct answers were given after the session, particularly in relation
4 to sugary drinks, the normal blood glucose range, the impact of excess weight on the action
5 of insulin and HbA1c. Overall, 60% increased their correct answers by at least one question.
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10 Those taking insulin increased the proportion of correct knowledge answers by 5 (95%
11 confidence interval 3-8) %, while others increased theirs by 10 (9-12) %. In a logistic
12 regression, those increasing their correct answers by $\geq 10\%$ had a lower proportion of correct
13 answers at baseline but no other variables showed significant associations.
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21 **Workshop evaluation**

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23 The post-session evaluation form was returned by 456 participants. 193 (42%) reported that
24 learning about diet and foods was most useful, 71 (16%) referred to learning about diabetes
25 and its management, 26 (6%) referred to the format of the sessions and discussing the
26 condition with others, 80 (18%) said it was “all useful” and 78 (17%) left this blank. Only 70
27 (15%) identified any aspect as “least useful”. Adverse comments on content related to:
28 medication (15), diet and foods (10), medical information about diabetes (8), alcohol (5),
29 exercise (3). Some found the quizzes and flipcharts unhelpful (6), were irritated by other
30 participants (6) or felt the session was too long or complicated (6). 93.5% said the session
31 met their expectations.
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45 **Ethnographic observations**

46 **Dissecting diet**

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48 The group interactions observed by CB suggested that participants found the material on diet
49 and food to be of most use, in line with the survey results. The allotted time for discussion of
50 dietary practices often over-ran and groups frequently spent much of their time asking
51 educators to comment on advice they had received in the past. Discussion was not limited to
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3 advice received from health professionals, but also extended to suggestions that patients had
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5 received from others with diabetes, as shown in Table 3. In the latter case, it seemed that the
6
7 educator was steering the group away from unhelpful and scientifically problematic advice
8
9 rather than allowing the dietary ‘myths’ to become a focus of conflict between the ‘expert’
10
11 health professional and the ‘naïve’ patient. The educator empowered participants by offering
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13 them an alternative understanding of how beans and root vegetables interact with blood
14
15 glucose levels.
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20 21 **Group consultations**

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23 The empowerment approach that informed the educators’ responses to dietary queries helped
24
25 establish a dynamic resembling that of a clinical consultation, but within the group setting.
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27 Patients often raised questions about their condition, how it is monitored and what actions
28
29 they should take in situations they find themselves in, such as hypos. A typical exchange is
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31 shown in Table 3, where the educator responds to PH6’s practice of eating pork pies to
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33 alleviate ‘feeling faint’ on the golf course by reasoning out the low carbohydrate content of
34
35 the food. However, the consultation dynamic often expanded beyond exchanges between
36
37 individual patients and professionals into something approaching a ‘group consultation’.
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43 **Experiencing health services**

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45 Participants swapped experiences of the health service, usually during the section on what
46
47 they should expect from annual review appointments. Because most sessions brought
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49 together patients from either the same GP practice or from neighbouring areas, much of the
50
51 discussion related to the minutia of local health care provision and identified disparities
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53 between the care received within the group. The example in Table 3 shows PBA9 receiving
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55 encouragement from a patient registered with the same GP practice, as well as from the
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3 educator. In such moments, the education session moved beyond didactic delivery of
4 information, and allowed participants to compare their experiences of the health service with
5 those of others.
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10 11 **Peer Support**

12 Participants often began to discuss the idea of helping one another as a key aspect of the
13 RAPSID trial. In some instances, this led participants to exchange ideas and experiences
14 relating to self-management as shown in Table 3. Through such exchanges, participants
15 began to share techniques for self-management and thereby to support their peers.
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25 **Clinical grounding**

26 The clinical experience of the educators allowed them to establish a trusting environment in
27 which they were able to facilitate participants to explore their diets, medications, conditions
28 and experiences of healthcare and to begin to support one another. The fact that the educators
29 who delivered these sessions were experienced dietitians and specialist nurses used to
30 delivering group education and working within a multi-disciplinary diabetes hospital clinic,
31 allowed them to speak with confidence about this host of topics. The importance of this
32 clinical grounding was also evident in the interaction in Table 4 where Ed.3 invokes a multi-
33 disciplinary 'we... in the clinic'. By offering a balanced and experientially-grounded account
34 of why some patients are asked to use test strips and others are not, Ed.3 was able to add to
35 the group's understanding of the 'NHS position' without disregarding or reinforcing PC3's
36 objections.
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Discussion –

Our study has shown that the ‘empowerment approach’ for ongoing education for those with type 2 diabetes is acceptable, increases knowledge and provides the opportunity to tailor education to patients in the group setting. The impact of such education programmes on metabolic control are notoriously difficult to evaluate, with a recent meta-analysis suggesting a minimum of 10 hour per annum is needed to reduce HbA1c among patients with T2DM²¹. Indeed, even with patients with newly diagnosed T2DM, education was associated with improved HbA1c in X-pert,¹⁰ but not DESMOND. Bearing this in mind, as the original evidence for adopting the ‘empowerment approach’ came from the US, following a randomised controlled trial, it was felt that its adaptation to a UK setting needed evaluation in terms of its acceptability and impact on knowledge, rather than in trial with clinical outcomes, i.e. equipoise had already been reached.

This programme had a different purpose to the original empowerment programme,¹⁸ which is a series of 6 sessions, and the X-pert and DESMOND programmes for those with newly diagnosed diabetes. The sessions were not designed to address skills acquisition (e.g. glucose monitoring or insulin self-treatment). Structured diabetes education was available across the study area for those who were newly diagnosed, so in principle, all that should have been needed was a ‘catch up’. However, the questionnaire revealed that only 54.8% had previously received structured education. Many would otherwise have had education from the practice nurse or perhaps a visiting dietician. Even so, the low level of knowledge was surprising and suggests that more diabetes education is needed. The demand for knowledge about food/diet was a consistent theme highlighting a potential gap in existing services.

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3 The ethnographic study also suggested that delivering this ongoing diabetes education
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5 requires a high level of experience and skill. This may be better delivered by those with past
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7 participation in multidisciplinary hospital clinic or relevant further training in diabetes care,
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9 so that a broader range of experiences can inform the answers given.
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14 One gap in patient diabetes education in the UK is it's provision to those who have already
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16 undertaken structured education.²² X-pert has developed a module, and DESMOND advise
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18 that theirs can be used in this way, however, neither has been validated and the cost would
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20 probably be more than this 3.5 hour session. It is suggested that the approach used here could
21
22 be offered on a regular basis, perhaps annually, organised locally to answer questions,
23
24 address new developments and fill any important gaps in knowledge. Those taking insulin
25
26 should receive a separate programme. One key feature would be to ensure a quality assurance
27
28 and training framework to mandate consistency and quality as included in the NICE
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30 recommendations¹¹ and consistent with current work on health professional competency
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32 frameworks.²³⁻²⁵ This would fit well with the current national X-pert programme²⁶.
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38 **Strengths and limitations**

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40 Repeating a questionnaire could reflect question familiarity (i.e. the participants were
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42 sensitised to the questions asked before the session) and the topics covered were limited
43
44 hence the improvement in response did not necessarily reflect a similar degree of learning.
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46 However, the ethnographic observations confirm a learning environment was created, and the
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48 anonymous post-workshop evaluation showed that the participants felt that they benefited
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50 from the session. Those treated with insulin had less benefit, possibly because they knew
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52 more beforehand from their prior education about insulin. Another limitation was the
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3 relatively low participation rate, which was largely a product of practical difficulties
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5 arranging sessions in spite of multiple contacts and with organising sessions at local venues..
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8 9 10 11 12 **Conclusion**

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14 In conclusion, this study has demonstrated that a 3.5 hour diabetes education session,
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16 following the United States developed 'Empowerment' approach, is associated with an
17
18 increase in knowledge and is well accepted and appreciated by participants. The study poses
19
20 the question whether a regular session like this should be arranged for all patients with type 2
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22 diabetes, and if it were, whether this would lead to significant improvements in patients'
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24 effectiveness in managing their diabetes.
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30 31 **Additional information**

32
33 We thank Peers for Progress and the Clinical Research Network for financial support, the
34
35 Primary Care Research Network and Medical Research Council Units for assistance with
36
37 recruitment and Takeda for educational materials. We also thank Caroline Taylor, Anne
38
39 Marie Monk and Kim Mercer for administrative support and James Brimicombe for
40
41 assistance with the database. We thank Simon Cohn for assistance with the study including
42
43 support for the qualitative analyses. We declare no competing interests. Ethics approval was
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45 received from the Cambridgeshire REC2 Committee.
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Table 1 Clinical & demographic characteristics of participants completing the pre & post knowledge questionnaire

Characteristics	n=578
Age	65±10
%Male	56.7%
BMI	31.7±5.6
Non-British origin	7.6%
Educational Qualifications	
None	19.0%
Secondary	33.4%
University	26.0%
Other	21.5%
Attended diabetes education session before	54.8%
Diabetes duration (years)	9±11
Insulin treatment	18.4%
HbA1c mmol/mol (%)	57±14 (7.4%)
PHQ8	4.4±4.9
EQ5D	0.77±0.26
Diabetes self-efficacy	58±16
Diabetes knowledge score	11±3
Diabetes distress	6±4

Data shown are mean±SD or %

Table 2 Change in knowledge scores before and after the session

Questions	Before	After	Difference
Which of the following nutrients contains the most energy (calories or kilojoules)? <ol style="list-style-type: none"> 1. Protein 2. Fat 3. Carbohydrate 4. All these nutrients contain the same amounts of energy 5. Don't know 	27.0%	35.1%	p<0.001
Which of the following food does not have a high fibre content? <ol style="list-style-type: none"> 1. Cheese 2. Bran cereal 3. Broccoli 4. Wholemeal bread 5. Don't know 	82.4%	84.9%	ns
Diabetic persons can drink unlimited quantities of: <ol style="list-style-type: none"> 1. Whole milk 2. Fruit juice with no added sugar 3. Lemonade 4. None of the above 5. Don't know 	58.5%	74.4%	p<0.001
The normal non-diabetic range of blood glucose is: <ol style="list-style-type: none"> 1. 2-4 mmol/L 2. 4-8 mmol/L 3. 9-12 mmol/L 4. 12-16 mmol/L 5. Don't know 	72.3%	91.5%	P<0.001
Glucose tests are most likely to be highest: <ol style="list-style-type: none"> 1. Before breakfast 2. After breakfast 3. After exercising 4. Late at night 5. Don't know 	53.1%	59.9%	<0.01

1 2 3 4 5 6 7 8 9 10	Being overweight:	69.4%	81.8%	<.001
11 12 13 14 15 16 17 18 19 20 21	<ol style="list-style-type: none"> 1. <u>Stops your insulin from working properly</u> 2. Stops you making insulin 3. Makes you produce too much insulin 4. Does not affect your insulin 5. Don't know 			
22 23 24 25 26 27 28 29 30 31 32 33 34 35 36	How often should people with diabetes exercise?	93.4%	93.9%	ns
37 38 39 40 41 42 43 44 45 46	<ol style="list-style-type: none"> 1. Never, as their blood sugar level would get out of control if they did 2. Only if their blood sugar level is very low, to help bring it back to normal 3. Only if their blood sugar level is very high, to help bring it back to normal 4. On a regular basis, to help control their weight and blood sugar level 5. <u>Don't know</u> 			
47 48 49 50 51 52 53 54 55 56 57 58 59 60	Glycosylated haemoglobin (Haemoglobin A1c) is a test that is a measure of your average blood glucose level for the past:	60.2%	79.8%	p<0.001
	<ol style="list-style-type: none"> 1. Day 2. Week 3. <u>6-12 Weeks</u> 4. 6 months 			
	The best way to take care of your feet is to:	92.6%	94.3%	ns
	<ol style="list-style-type: none"> 1. <u>Look at them and wash them each day</u> 2. Massage them with alcohol each day 3. Soak them for one hour each day 4. Buy shoes a size larger than usual 			
	Which of the following is not part of the annual review:	78.9%	86.7%	p<0.001
	<ol style="list-style-type: none"> 1. HbA1c 2. Blood fats 3. Blood pressure 4. Foot examination 5. <u>Lung function</u> 6. Eye screening 7. Kidney test 			
	Overall	69±19	78±18	<.001

Table 3 Participant Quotes

Themes	Quotes
Dissecting Diet-health professional advice	<p>PB3: But I was told not to eat the ripe ones [bananas] by the diabetes specialist nurse at the surgery. She also said don't have bananas and grapes on the same day – I can have one or the other.</p> <p>Ed1: That's not true. You can have them on the same day, you just have to space them out.</p>
Dissecting Diet-advice from others	<p>PF6: Runner beans and French beans, they're meant to be a no-no, aren't they?</p> <p>Ed4: No, I wouldn't say that. We've got no reason to think runner or French beans are bad for your blood glucose. Quite the opposite - they're good for you. I've never heard of that before.</p> <p>PF2: It's the things that grow underground that you have to worry about - it's all sugar, isn't it? I mean, that's the gardeners' rule.</p> <p>Ed4: I see your point, [PF2], but with many foods it's not true, like carrots. They have some carbs in them, but we don't break it down, so we don't count it. When we break down foods in labs, we find every last chemical. But our bodies aren't labs - they don't get everything out of food, so some things remain. With carrots, and as we said about broccoli earlier, the sugar doesn't get accessed.</p>
Group consultations	<p>PH6: I have a pork pie on the golf course – I usually feel a little faint around hole 9.</p> <p>Ed4: And what food group is that?</p> <p>PH6: All 3, I think.</p> <p>Ed4: Yes, but not much carbohydrate, so it won't help you – it's mostly fat and protein.</p> <p>PH6: Ah yes, ok.</p> <p>Ed4: You need to talk to your GP – It might be that when you exercise, you need to reduce the tablets.</p>
Experiencing health services	<p>PBA3: My diabetes nurse is a little Rottweiler, if the levels go up, she's on it! A right task master! She's great – I feel she keeps me on track.</p> <p>PBA7: You must go to the same surgery as me – she's a cracker, isn't she?</p> <p>PBA9: Well I don't know what you're talking about – my nurse never tells me any of these numbers – I've not heard of this HABC thing.</p> <p>Ed2: Unfortunately not every health professional takes the time to explain these different tests and numbers. But they should!</p> <p>PBA2: You should ask – it's your body. I think I'm at the same practice as you and I asked and they gave me one of these record cards – I have all the numbers for the last few years.</p>
Peer Support	<p>PY3: And I often forget to take my tablets – they're usually right in front of me, but I still forget.</p> <p>PY5: You should get a pill box.</p> <p>PY4: Yeah, mine's fantastic. I put it next to the kettle – keeps it in my mind!</p> <p>PY3: A wonderful idea!</p>

Participants are labelled by their interview number

Table 4 Quotes relating to Clinical Grounding of Educators

Participants	Quotes
PC2	What about testing? We haven't spoken about this. I don't test, but I did to start with. My GP won't let me now - he tells me that those on pills don't need to test, as they can't adjust their medication.
Ed.3	That's often said - it's the NHS position on testing at the moment.
PC3	I don't agree with it all - we should be given test strips. I was given them when I was first diagnosed and I used them to work out how different foods affected me. It was so useful. It still helps now.
PC2	Yes, I always felt that would be useful, but one doesn't like to question the doctor!
Ed.3	Absolutely, I understand - and, yes, [speaking to PC3], you're right. We often do this kind of thing with the patients in the clinic. It helps some get control. But for many it is true that there is no need to test.
PC3	Okay, that makes sense. I guess not everyone gets something from the strips, but I know I do. Maybe I'm like those you see in your clinic.

Participants are labelled by their interview number