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RESEARCH ARTICLE



Sustaining the benefits of structured education: Participants' experiences of receiving structured individual support during a programme (DAFNE*plus*) informed by behavioural science

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Abstract

Aims: The DAFNE*plus* programme seeks to promote sustained improvements in glycaemic management by incorporating techniques from behavioural science. It includes five sessions of structured individual support delivered over 12 months following group education. As part of a broader evaluation, and to inform decision-making about roll-out in routine care, we explored participants' experiences of, and engagement with, that individual support.

Methods: We interviewed DAFNE*plus* participants (n=28) about their experiences of receiving individual support and the impact they perceived it as having on their self management practices. We analysed data thematically.

Results: Participants described several important ways individual support had helped strengthen their self management, including: consolidating and expanding their understandings of flexible intensive insulin therapy; promoting ongoing review and refinement of behaviour; encouraging continued and effective use of data; and facilitating access to help from healthcare professionals to pre-empt or resolve emergent difficulties. Participants characterised themselves as moving towards independence in self management over the time they received individual support, with their accounts suggesting three key stages in that journey: 'Working with healthcare professionals'; 'Growing sense of responsibility'; and, 'Taking control'. Whilst all portrayed themselves as changed, participants' progress through those stages varied; a few continued to depend heavily on DAFNE*plus* facilitators for advice and/or direction at 12 months.

Conclusions: While all participants benefited from individual support, our findings suggest that some may need, or gain further benefit from, longer-term, tailored support. This has important implications for decision-making about roll-out

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of DAFNE*plus* post-trial and for the development of future programmes seeking to bring about sustainable changes in self management practices.

KEYWORDS

patient experience, process evaluation, qualitative research, self management, structured education, type 1 diabetes

1 | INTRODUCTION

The Dose Adjustment For Normal Eating (DAFNE) and other structured education programmes (SEPs) for people with type 1 diabetes teach participants to use flexible intensive insulin therapy (FIIT).¹ FIIT comprises basal insulin administered once or twice daily, plus quick-acting insulin administered before food (adjusted for carbohydrate content, pre-prandial blood glucose (BG) levels, and anticipated activity/events).^{1,2} Additionally, like other SEPs,¹ DAFNE promotes regular review of BG, insulin and carbohydrate data and teaches participants how to interpret patterns and adjust basal insulin doses and insulin-to-carbohydrate ratios (ICR) to sustain BG levels (inasmuch as possible) within clinically recommended ranges.

While participation in DAFNE and similar SEPs is associated with initial improvements in glycated haemoglobin (HbA1c), these often diminish over time.^{1,3,4} Qualitative research undertaken to understand this glycaemic drift identified important changes in DAFNE graduates' self management practices over time. For instance, while most continued to count carbohydrates and align quick-acting insulin, very few adjusted their basal insulin doses or ICR independently.^{5,6} Explanations for this included: shortfalls in numerical and/or analytical skills; lack of confidence; hesitancy around help-seeking; receipt of postcourse support from healthcare professionals lacking DAFNE expertise; and, deference to such professionals.^{6,7} The research highlighted a need for additional, tailored (one-to-one) support from DAFNE-trained professionals and channels (and encouragement) to contact these professionals between appointments.⁷ Those findings informed development of a revised DAFNEplus programme.

DAFNE*plus* continues to teach FIIT principles but additionally uses clinical and health psychology theories and embedded behaviour change techniques^{8,9} to help participants establish and *sustain* key self management practices. DAFNE*plus* comprises five days of (revised) group education ('the course') and five structured individual support sessions delivered by DAFNE*plus* facilitators over 12 months post-course (see Box 1 for

What's new?

- Group education in flexible intensive insulin therapy is associated with glycaemic benefits, but these often diminish over time.
- To promote sustained improvements, the DAFNE*plus* programme incorporates techniques from behavioural science and offers five sessions of individual support following the initial course. We explored participants' experiences of receiving that individual support.
- Participants identified several ways individual support had enabled and enhanced their self management. They portrayed themselves as moving towards independence in self management whilst receiving it, but few considered themselves to have become fully independent 12 months post-course.
- To consolidate and reinforce the benefits of DAFNE*plus*, some individuals may need longer-term, tailored support.

a fuller description of this component).¹⁰ Additionally, the DAFNE*plus* programme uses bespoke technology (the Glucollector diabetes management platform) to (a) facilitate data visualisation and interpretation through use of multiple, colour-coded display formats (e.g. graphs, charts, daily logs); (b) allow participants to monitor progress between individual support sessions using summary data (e.g. estimated HbA1c, percentage of BG readings in/above/below range); (c) enable joint review of data in individual support sessions; and (d) enable participants and facilitators to communicate between sessions using a messaging function (for further details see Box 2).¹¹

A cluster randomised controlled trial is comparing the effects of DAFNE*plus* to standard DAFNE on HbA1c and diabetes-specific quality-of-life.¹⁰ In line with Medical Research Council guidance, it includes an embedded, mixed-methods process evaluation exploring whether DAFNE*plus* 'works' as intended, (i.e. in line with its programme theory).¹²⁻¹⁴ Elsewhere,

BOX 1 Individual support in the 12 months following the course

Underpinning DAFNE*plus* is the principle that behaviour is a key determinant of BG levels. Three behavioural 'cycles' have been identified as pivotal to effective self management.⁷ These are *routine* (with constituent behaviours including regularly monitoring BG levels, counting carbohydrates and calculating appropriate bolus doses), *reactive* (comprising behavioural responses to challenges including out-of-range BG, ketones and illness) and *reflective* (behaviours associated with evaluation and improvement, e.g. reviewing data, assessing the impact of practices and making adjustments). To achieve optimal self management, people need to master and perform all three behavioural cycles. Periodic professional guidance may still be required (e.g. to respond adaptively to changing life circumstances).

DAFNE*plus* aims to create the conditions for these behavioural cycles and constituent behaviours to be established, with such conditions including: *capability* (e.g. knowledge and skills), *opportunity* (e.g. equipment and access to healthcare professionals) and *motivation* (e.g. positive emotions, aspirations and confidence).¹⁶ The course provides the foundation for that work¹⁵ and introduces participants to supportive technologies including Glucollector (see Box 2). In addition, to reinforce and augment the effects of the course, support sustained behaviour change and promote independence, DAFNE*plus* provides participants with a 12-month period of structured individual support. This provides a vehicle through which facilitators can assess and enhance individuals' grasp and use of FIIT principles, encourage continuing and sustained behaviour change and automaticity, and provide (or signpost participants to) additional support as/where needed.

Individual support takes the form of (five) one-to-one sessions, conducted (in person or remotely) at increasing intervals (2weeks, 6weeks, 3 months, 6 months and 12 months post-course) to encourage progressive independence in self management. Ahead of each session, facilitators send participants an individual support preparation form, asking them to upload and review their data on the Glucollector (or other) diabetes management platform (e.g. LibreView), to note any personally relevant challenges and/or difficulties keeping BG within recommended ranges, and to highlight their priorities for discussion.

Sessions observe a consistent structure, similar to that used during the course, involving reflection, data review and action planning. Together these elements encourage and support participants to try-out, modify and/or automate various clinically relevant behaviours. Throughout, facilitators use techniques such as 'person-centred' and 'solution-focussed' communication to build participants' skills and confidence, boost feelings of achievement and empowerment (around both FIIT and behaviour change), nurture greater autonomy in self management and inoculate against burnout.¹⁷

Typically, facilitators begin sessions by inviting participants to reflect on progress since their last course or individual support session, including with agreed action plans. As on the course, facilitators take an affirmative approach, inviting participants to identify areas where they have experienced success, and thereby connect effort with reward, before exploring any challenges encountered. Where unhelpful beliefs are articulated, facilitators explore these, sometimes using metaphors to introduce an alternative perspective.¹⁷

Then, turning to the available data, facilitators 'coach' participants in pattern identification and interpretation, encouraging and supporting them to consider how information available from Glucollector (or other diabetes management platforms e.g. LibreView) might inform self management practices (e.g. frequency of BG checks, timing of boluses, changes to basal doses and adjustments to ICR/correction factors).

Next, facilitators work with participants to set future goals, break these down into achievable behavioural steps and agree to a refreshed/revised action plan. By helping individuals form concrete ideas about what they need to do to establish behaviours and achieve outcomes, action plans encourage change. Action planning is a key component of both the DAFNE*plus* course and individual support, and is supported by bespoke documents (a workbook covering identification/selection of goals, action steps and generic and personal plans).¹⁷

Finally, facilitators reinforce the message that participants should reach out for help if they are struggling, emphasising that for 12 months all participants will have optional, ad hoc access to their input/advice, via Glucollector's messaging function, text, phone or email.¹⁷

BOX 2 The glucollector platform

During their course, participants were provided with an Accu-Chek Aviva Expert blood glucose meter, instruction on how to upload BG, carbohydrate and insulin data from the meter to the Glucollector website, and training on how to use platform features to review/interpret these data. Participants also using Libre were provided with instruction on how to upload their data to the Glucollector website. Glucollector was designed to motivate, empower and enhance users' confidence to enact FIIT and access timely and appropriate support from healthcare professionals.¹⁰ It included features designed to:

- Enhance data visualisation using bespoke displays (Bubble Chart, Bar Chart, Dot Chart, Daily Log) and colour-coding schemes (for glucose, carbohydrate, quick-acting insulin, basal insulin and ketone data) to facilitate reviewing/interpreting BG readings, identifying patterns and adjusting basal insulin doses/ ICRs. For instance, BG readings between 3.9 and 10.0 mmol/L, which require no action, are highlighted as 'green', whereas a reading of <3 mmol/L is presented as 'red'.
- Enable progress to be monitored over time using summary data displays including: number of readings; average number of readings per day; average BG; estimated HbA1c; percentage above/in/below target range; variability of readings; pie-charts providing weekly, monthly and quarterly summaries of readings above/in/ below target range.
- Provide the means to contact healthcare professionals via the Healthcare Feedback function, used to send/receive a message to/from a designated DAFNE*plus* facilitator to discuss specific questions/issues about diabetes self management.

we report how DAFNE*plus* course attendance improved participants' knowledge and understanding of FIIT and promoted cognitive and emotional changes that positively influenced their confidence and motivation to use this regimen.¹⁵ Here, we report participants' experiences of the individual support component, and their views about whether, how and why it helped influence, support and/or enhance their diabetes self management. Our objectives were to establish if this component of DAFNE*plus* worked as intended (i.e. in line with the programme theory)¹⁴ and inform decision-making about intervention rollout post-trial.

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2 | METHODS

2.1 | Overview

As detailed in a companion paper,¹⁵ we initially used a longitudinal design, interviewing DAFNE*plus* participants at four time-points (immediately before and after the course, and then three and 12 months later). Following suspension of trial recruitment due to the SARS-CoV-2 pandemic, we moved to a cross-sectional design, interviewing existing participants at 12 months only, as this allowed us to include individuals in the process evaluation who were already taking part in the trial but not the existing longitudinal work. This decision was made to ensure the process evaluation was completed in the event the trial did not restart. Research ethics approvals were secured as part of the wider trial (18/SW/0100).

2.2 | Participants and recruitment

Participants consented to the qualitative study alongside enrolling in the trial. We sampled purposively to ensure diversity with respect to age, gender, occupation, education, diabetes duration and site. In line with trial criteria for programme completion, participants needed to have attended \geq 3 individual support sessions to be eligible for the qualitative study. Interviews continued until we reached data saturation (i.e. additional data no longer extended our findings).

2.3 | Data collection

An experienced qualitative (non-clinical) researcher (DR) conducted all interviews. These were guided by topic guides (Box 3) informed by previous research on participants' experiences of DAFNE courses, ^{5–7,18,19} work undertaken during DAFNE*plus* piloting, ²⁰ and input from clinical and behavioural scientist colleagues involved in developing the individual support sessions and accompanying programme theory. ¹⁴ This was done to help ensure the areas explored captured the data needed to establish whether DAFNE*plus* worked as intended. ¹⁴ Longitudinal and cross-sectional interviews explored the same topics. Participants were encouraged to raise issues they considered important, including



BOX 3 Topics (relevant to this analysis) explored in interviews

Pre-course experiences of managing diabetes

- Background information: age, occupation, living arrangements, caring responsibilities, hobbies/interests and diabetes duration.
- Feelings about having diabetes and experiences of self management prior to DAFNE*plus*, including the following:
 - Diet, use of BG monitoring/Libre/CGM, calculation of insulin doses, target range, response to out-of-range readings, and dealing with hypo- and/or hyper-glycaemia.
 - Recording and reviewing BG levels (and other data); whether and how data review informed self management decisions.
 - Experiences of attending and receiving support at routine clinical appointments.
 - Interactions with and involvement of healthcare professionals to inform diabetes management.
 - Views on their own abilities and the patient/participant role in managing diabetes.

Post-course experiences of managing diabetes

- Changes in life circumstances (potentially) affecting diabetes management post-course.
- Feelings about having diabetes, their role and abilities in managing diabetes post-course, and if/how this changed over time.
- Day-to-day management of diabetes, including: diet, BG monitoring, calculation of insulin doses, target range, response to out-of-range readings, and dealing with hypo- and/or hyper-glycaemia.
- Recording and reviewing BG and other data (using Glucollector); whether and how data review informed (changes to) self management practices (e.g. timing of insulin doses, approaches to physical activity); whether, when and how data review prompted participants to contact DAFNE*plus* facilitators for support.
- Making changes to basal insulin doses and/or ICR (if, when, how, with whose support).
- HbA1c over the last 12 months and support needed to maintain or (further) improve this.
- Feelings about and response to difficulties and setbacks in diabetes management; whether and how participants sought support to address setbacks.

Experiences of IS sessions (and other support received from facilitators)

- Experiences of and views on individual support received over the 12 months.
- Whether and how their self management changed in advance of individual support appointments.
- Discussions within individual support sessions: format of sessions; topics raised; use of action plans; use of Glucollector to review data.
- Participant and facilitator role(s) and contribution to decision-making about changes to diabetes management practices, and whether/how these changed over time/individual support sessions.
- Impact of individual support discussions on management of diabetes outside sessions, including changes to self management practices, behaviours, routines, and making adjustments to ICR, corrections, basal insulin doses and timing of bolus doses.
- Process of decision-making about changes to diabetes management, including basal insulin and ICR adjustments, and willingness to make these <u>without</u> facilitator input/support.
- Feelings about using FIIT and managing diabetes between individual support sessions, including as the gaps between those sessions increased.
- Contact with facilitators or other healthcare professionals between individual support sessions (reasons for initiating contact, or not; issues discussed; any contact *from* facilitators).
- Views about concluding the individual support sessions and managing diabetes going forward (including making changes to self management, ICR or basal insulin and returning to routine care).
- Views about needing/seeking support from healthcare professionals after DAFNE*plus* (i.e. when receiving routine clinical care).



those unanticipated at the study outset (allowing exploration of unintended intervention consequences arising from intervention receipt).¹² We revised guides between interviews, to take account of individuals' prior responses and emergent findings. Telephone interviews (1–2 hours) took place between January 2019 and March 2021, and were digitally recorded and transcribed verbatim.

2.4 | Data analysis

Three experienced qualitative researchers (RIH, DR and JL) undertook data analysis. Our analysis focused on 12-month accounts and was informed by our reading of data collected in interviews undertaken at earlier time points (e.g. pre- and post-course), where that was available. We used a thematic approach to identify descriptive and analytical themes²¹ relevant to understanding whether the individual support sessions worked as intended and if there were any unintended consequences to receiving individual support. Initially, analysis involved close and repeated reading of transcripts to identify content germane to individual support; this was collated using NVivo 20 (QSR International, Doncaster, Australia). That material was then further scrutinised, coded and compared to identify and refine themes and sub-themes.²² The researchers prepared independent analytical reports before meeting to discuss and agree key findings.

3 | RESULTS

We undertook 12-month interviews with 28 participants (seven of whom we had interviewed previously: pre-course, post-course and at 3 months; the remaining 21were interviewed at 12 months only). For further information about the sample, see Table 1.

At 12 months, participants portrayed themselves and their self management practices as changed in various ways by participation in DAFNE*plus*. While many of these changes were initiated during the course,¹⁵ participants described how the individual support component had made important and distinctive contributions. Below, we describe how participants perceived individual support as having enhanced their self management and how they characterised themselves as having moved *towards* independence in self management, albeit to varying degrees. See Tables S2A for supplementary quotations. diabetes.

Mean. SD. Characteristic %^a (range) n Female 12 42.9 Married/co-habiting 18 64.3 Occupational classification^b Managers, directors and senior officials 3 10.7 Professional occupations 6 21.4 Associate professional occupations 14.3 4 Administrative and secretarial 7.1 2 occupations Skilled trades occupations 1 3.6 Caring, leisure and other service 3 10.7 occupations Sales and customer service occupations 2 7.1 Process, plant and machine operatives Elementary occupations 3 10.7 Retired 10.7 3 Student 1 3.6 Educational attainment^e Below upper secondary (GCSEs) 8 28.6 Upper secondary (A' levels) 7 25.0 Tertiary (undergraduate degree) 9 32.1 Tertiary (postgraduate degree) 4 14.3 Ethnicity White, British 24 85.7 White, other nationality 2 7.1 Other 2 7.1 Age at time of (first) interview; years 44.2 ± 13.5 (18-67) 14.4 ± 10.2 Diabetes duration; years since diagnosis (1-41)Baseline HbA1c mmol/mol 64 ± 12 (40 - 82)% 8.0 ± 1.1 (5.8 - 9.7)Previous attendance at a DAFNE course 4 14.3 Glucose monitoring (at 12 months) Accu-Chek Aviva Expert meter 21.4 6 Expert meter and Libre 17 60.7 17.9 Libre only 5

^aPercentages may not equal 100% due to rounding.

^bCompiled using the Office for National Statistics Standard Occupational Classification (SOC) 2020.

^cCompiled using the International Standard Classification of Education (ISCED).

3.1 | Individual support enhancing self management

3.1.1 | Consolidating and expanding participants' understanding of FIIT

Participants described how individual support sessions had provided valuable opportunities to confirm and consolidate their understandings of FIIT. Many reported difficulties assimilating all the information provided during their course and therefore welcoming opportunities to revisit it:

> It's about consolidating learning. I think there's a lot of learning...to take on board... (and) by the end of the day, people are physically and mentally tired. So you do need that follow-up...to refresh what you've done.

(028)

Participants also appreciated being able to tailor their discussion and learning to their personal circumstances (Table S2A) and extend their knowledge of topics of personal relevance (e.g. managing prolonged exercise, determining the glycaemic index of different types of food).

3.1.2 | Promoting ongoing review and refinement of behaviour

Participants described how, through inviting reflection on their achievements and progress, in ways initiated during the course,¹⁵ the individual support sessions had helped them develop or reinforce positive attitudes and mindsets that supported use of FIIT. Many reported welcoming the emphasis given to identifying successes in the first part of the individual support sessions (Table S2A), observing how facilitators' focus upon accomplishments (and reassurance that they were 'on the right track' (006) even if setbacks or difficulties had occurred) had enhanced their confidence and motivation:

There was a big bit of emphasis on...What positives have you taken lately? What's going well? And (that) maybe just kinda changes the mind-set of how you think about it...and that probably helped.

(004)

Participants further noted how facilitators had helped them capitalise on this positivity by using action planning at the end of the sessions to identify further realistic and sustainable changes they could make to support self management. This included developing routines to help ensure they weighed foods (e.g. pasta and potatoes) and counted carbohydrates more consistently and carefully:

> It's always (about) a plan...You're doing well. What are you gonna do to do it better? And... my plan (was)...I'll do the (carbohydrate) counting and I'll make a note of it...How often?...I'll do it every meal.

> > (012)

Others reported how their action plans had included commitments to check BG more regularly or correct less frequently (where 'stacking' was a concern (Table S2A)).

Some further noted how the sessions had introduced a sense of accountability, which had helped keep them focused and on track with implementing their plans between appointments:

> (Because) this (individual support appointment) was coming up. I'm like, Shit, I better get my act together...(If) I had all these actions against my name, and if I've not done them, I feel like I'm letting (Facilitator) down.

> > (001)

Indeed, a few speculated that their motivation and self management practices might drift once they were no longer held to account by facilitators (Table S2A).

3.1.3 | Encouraging sustained and effective use of data

Participants observed how the prospect of attending individual support sessions and having facilitators scrutinize their data (on Glucollector) had encouraged them to upload and review data before each session:

> Now that it's (individual support session) coming up I'm like: Right, I better upload that data. I better get a good look at this and see where I am, because otherwise...you're wasting your time at the meeting, and you're wasting the nurse's time.

> > (001)

As well as benefiting from being able to see their data in colour-coded and graphical formats (Table S2A), they observed how, through dialogue, facilitators had helped them become more confident and adept at pattern-identification and interpretation (Table S2A). Participants further observed how facilitators had

sought to empower them when they reviewed their data together by using carefully worded questions to elicit their ideas about the issues underlying recurrent, outof-target readings:

They didn't—they don't just give you the answer, they will help you work out the answer. (011)

Some observed how, as they became more skilled and confident identifying patterns, they had also started to formulate solutions between and/or in preparation for sessions. In doing so, participants noted how facilitators had promoted and supported independent solution formulation by encouraging them to put forward ideas about whether and what changes the data invited:

> Near the end...it was probably more like... "What have <u>you</u> noticed? What do <u>you</u> think you can change?" Rather than them being like, "Oh, we've noticed this. We've noticed that"...it made you think a bit more.

> > (004)

3.1.4 | Facilitating access to help

Participants additionally described how individual support sessions had provided a forum in which issues or difficulties could be identified and addressed. They highlighted the value of expert input; for example, with interpreting their data (Table S2A), with some further observing how facilitators' ability to recognise and alert them to behavioural drift had helped keep them focused and on track:

> They could see, Okay, yeah...you're going back to your old ways here! You're not doing this, you're not doing that...And I think that is so important to have that after DAFNE, just to make sure that you're on the straight and narrow.

> > (017)

Participants also highlighted benefits to being able to access facilitators' advice between sessions, via Glucollector's messaging function, email, text and/or phone (Table S2A). They noted how having these channels to seek facilitators' input had helped them successfully manage events such as viral infections and 'nip (small problems) in the bud' (017).

Some participants noted how their openness to conceiving and making changes (e.g. to the timing of a pre-meal bolus or size of a basal insulin dose) had been facilitated by knowing they had future individual support sessions scheduled and, hence, could check with facilitators whether they had adopted appropriate courses of action (Table S2A). Additionally, having ad hoc access to facilitators (and, hence, a safety net) between individual support sessions also appeared to have increased some individuals' openness to making independent adjustments between scheduled appointments:

> I had quite a few ways of reaching them (between sessions)...It was something else to make you feel confident...having a go at things yourself, because...if I needed to check anything...I could.

> > (007)

Some further observed how due to ease of access, and encouragement to do so, they had become more inclined to seek advice and support from facilitators between sessions:

> The whole DAFNE-thing has given me more confidence to speak to those people...you're not on your own, you know, and that's what they're there for.

> > (017)

3.2 | Moving towards independence

Participants characterised themselves as having moved towards independence over the time they received individual support, with accounts suggesting three key stages. Progress through those stages, however, appeared to vary with a minority of participants only progressing to Stage 1, the majority reaching Stage 2 and a minority getting to Stage 3.

3.2.1 | Stage 1: Working with healthcare professionals

Participants often portrayed themselves as, historically, having assumed passive and dependent roles in diabetes consultations, wherein:

With my consultant I felt like a little schoolgirl... being told, this is what you do, this is what you don't do.

(006)

These participants reported subtle but important changes to the ways they had interacted with healthcare

professionals over the year of receiving individual support. Those changes included emerging perceptions of themselves as active agents, who collaborated with facilitators to improve their diabetes management:

> I feel as though...me and (Facilitator) have been working together on getting my health better.

> > (009)

Participants highlighted how dialogue with facilitators, in conjunction with joint data reviews, had helped them connect behaviours (e.g. after-dinner snacking, meal timings) with subsequent out-of-target BG levels and identify changes they might make. While participants, at this stage, described having become more informed and thoughtful about their diabetes management, and having a better awareness of patterns/issues in their data (Table S2B), they also reported being limited in their ability to problem-solve:

> (At) first...there was bits I was missing, you know, I didn't have the thoughts I do now, that thinking process of: Something's wrong, I'll do this about it.

> > (025)

Hence, at Stage 1, participants described relying heavily on facilitators for direction and guidance (Table S2B); in particular, around basal dose and ICR adjustments. Indeed, some expressed deep reluctance to conceive or make such changes independently:

> Changing of your basal... I'm thinking, I daren't do that! I ain't altering mine until I get told by me specialist nurse...I'd rather just... take her advice...They're trying to teach us like to think about doing it ourselves, and I'm thinking: Not a chance!

> > (009)

3.2.2 | Stage 2: Growing sense of responsibility

Participants' accounts often suggested further change over time; in particular, an emerging sense of responsibility for their diabetes management:

> What's changed...is me taking more responsibility...The nurse kinda handed over the reins...gave (me) the knowledge and all that to be able to control my insulin intake...my

ratios and all that. Whereas in the past, I was expecting the doctor to tell me how to do that.

(001)

Participants described how this change in perspective had occurred in tandem with a shift in the dynamic of individual support sessions (invited and encouraged by facilitators) and other (i.e. ad hoc) contacts. Whilst continuing to welcome facilitators' input, in particular to receive reassurance that they had interpreted their data correctly (Table S2b), they talked of increasingly putting forward their own ideas about both problems and solutions, and exploring these with facilitators, rather than awaiting their direction:

> I would sometimes just contact them and say: "I'm (thinking of) putting up me breakfast ratio, because I'm a bit high in the morning"... And then they'll have a look at my data, and say, "Oh, just do it".

> > (019)

Some further observed how the increasing intervals between sessions had encouraged them to experiment with self management practices (e.g. timing of bolus insulin doses) and to engage in more independent decision-making:

> (It was) good actually, the gaps getting longer and longer, because... it gives you more confidence...puts you more in control (because) you have to work it out yourself, which is a good thing.

> > (027)

Additionally, some noted how their confidence and willingness to experiment had been enhanced by having access to summary data on Glucollector (e.g. percentage in/above/below range, predicted HbA1c). As these participants suggested, access to these data had enabled them to monitor their progress between individual support sessions without being reliant on healthcare professionals for information (e.g. HbA1c results) (Table S2b). As a consequence, they had been able to affirm independently whether they were self-managing their diabetes effectively ('if there's lots of greens (i.e. readings in target range) on it (pie chart), you know you're fine... it's worth sticking with what you're doing' (002)) or needed to consider making further changes.

At Stage 2, participants typically described feeling relatively comfortable making some changes (e.g. modest tweaks to basal insulin doses) independently, but still

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things. Participants who had reached Stage 2 expressed more mixed views. Whilst most described favouring some continued structured contact with facilitators, for example periodic telephone reviews (Table S2B), others reported just wanting to know they could access facilitators' support when needed. Many Stage 2 participants described an increased readiness to request help (see above), though a few indicated continued hesitancy and/or a high threshold for doing so: In all the time I've had this—13, 14 years— I've never once rang a hospital. Never ever...I just plod along...I don't feel as though I need to bother them.

(024)

Participants who reached Stage 3 expressed a more consistent view: these individuals (who typically described having an understanding of and aptitude for dose adjustment principles prior to attending DAFNEplus [Table S2B]) reported feeling equipped to independently self-manage going forward and strongly preferred just seeking help if/when needed:

> There's always tweaks that you can make, but ones that I'd be confident enough to make myself...I wouldn't want to be having an appointment, for the sake of having an appointment. (011)

DISCUSSION 4

Our study sought to understand DAFNEplus participants' experiences of the individual support component and how they perceived this as having influenced their self management. Our findings suggest that participants' experiences of receiving individual support were generally positive and gave rise to a range of benefits. Reassuringly, these benefits appear broadly in line with the programme theory (i.e. how DAFNEplus, and the individual support component in particular, was envisaged as bringing about change).^{8,9,14} Specifically, our findings highlight individual support-related changes in the theorised conditions of effective diabetes self management

preferring to discuss more substantial changes with facilitators before making them:

> I'd felt my sugar were high, that things weren't working ... So I just thought I'd do (raise) it by half (a unit)...I still think it needs to be more...but that's one of the things I was gonna wait for, until I...see them...I don't mind changing it to a certain extent, but then I don't want to do anything radical... without having a chat.

> > (024)

3.2.3 Stage 3: Taking control

Participants who reached Stage 3 talked of feeling 'in control' (002) and credited DAFNEplus with providing them with the confidence and tools for independent self management (Table S2B). They described independently trialling more complex 'routine' behaviours (e.g. splitting boluses, reducing an insulin dose in anticipation of alcohol consumption), managing any BG excursions effectively, and confidently adjusting basal insulin doses and ICR themselves, in response to independent, self-directed reviews of their data:

> I'd been a lot more confident in making those changes myself...working out your own ratios is quite, is actually really helpful, because I then had a confidence to be able to take more insulin if I needed to. Or to split my doses, and just start thinking about timings, and stacking, and just having that knowledge. (015)

While these individuals reflected positively on early individual support sessions, some viewed their value as diminishing over time (Table S2B), with scheduled sessions eventually becoming 'slightly superfluous' (022) to their needs.

Support needs at the end of the 3.2.4 DAFNEplus programme

Participants' views on their support needs going forward correlated closely with the stage they had reached in their journey towards independence. Those who remained firmly in Stage 1 (who typically described struggling to grasp the principles of adjusting ICRs and basal insulin doses during the course [Table S2B]), generally expressed enthusiasm for ongoing and regular one-to-one support:

DIARFTIC

When all this DAFNE-thing's over, and I go back to my normal specialist nurse...I('ll) probably see her, probably once every six months...that's not enough...with me not being such a confident person with changing

(009)

practices: 'capability', 'opportunity' and 'motivation'.¹⁶ These changes include improvements in participants': (1) FIIT knowledge and (data interpretation/pattern spotting) skills ('capability'); (2) confidence, autonomy and ability to access timely support from appropriate healthcare professionals when needed ('opportunity'); and (3) perceptions of the value of enacting FIIT principles ('motivation').¹⁴

Our findings also illuminate how, albeit to varying degrees, individual support helped participants build on these changed conditions to establish (or embed) a repertoire of important diabetes self management behaviours. Participants consistently described how individual support had helped them consolidate 'routine' and 'reactive' cycle behaviours (see Box 1),⁸ such as performing regular BG checks and correcting high BG levels appropriately. Often, they also observed how individual support, in conjunction with use of the Glucollector data management platform or LibreView, had helped encourage and enable them to become more confident undertaking more complex 'reflective' cycle behaviours, including reviewing and interpreting data to inform adjustments to basal insulin doses and/or ICR. As others have observed, these reflective behaviours are critical to effective diabetes self management but hard to establish.⁸ Reflective cycle adjustments require individuals to process complex data collected over several days or weeks, and monitor the consequences of any adjustments (e.g. on BG levels) over an extended period of time. Successfully doing this requires individuals to have sufficient insulin, BG, nutrition and activity level data to enable pattern recognition and then to be able to interpret patterns in order to determine how to adjust basal insulin doses..²³

Earlier research into the barriers to adjustment behaviours in the reflective cycle found that DAFNE participants often lacked confidence making decisions independently of healthcare professionals. This was possibly due to there being insufficient time in the original five-day DAFNE group-based programme to practice data review, interpretation and determination of insulin dose adjustments under supervision.^{6,7,19} Consistent with the programme theory for DAFNE*plus*,¹⁴ our findings suggest that individual support sessions provided participants with the time needed to gather a sufficient body of data to support pattern identification, as well as opportunities to practice their skills with reflective cycle adjustment while being supported by appropriately trained healthcare professionals.

Other specific features of individual support may also have been instrumental in helping to establish these reflective cycle behaviours. In particular, notwithstanding participants' positive feedback on the group aspect of the DAFNE*plus* course,¹⁵ the one-to-one format, as previously recommended,^{7,19} seems to have been important. Participants said they valued the bespoke learning opportunities this format allowed and the scope it offered to focus on their individual achievements, data, aspirations and concerns. Their accounts also highlighted the potential efficacy of more granular features of individual support. This includes the emphasis placed on recognising and praising accomplishments, coaching and empowerment—these all appeared to play key roles in fostering and nurturing reflective cycle behaviours which were first cultivated on the course.¹⁵

Additionally, the incentive to review and use data independently as inter-session intervals increased, and the reassurance easy access to expert assistance provided, appear to have been important and effective features of individual support. These benefits, afforded by individual support, were enhanced by participants' use of the Glucollector platform. Specifically, we have highlighted how this kind of platform fostered more autonomous decision-making by facilitating pattern spotting and data interpretation, and enabled participants to independently assess and monitor their progress over time. Hence, arguably, the potential efficacy of a type 1 diabetes structured education programme such as DAFNEplus will be contingent upon use of this or a similar platform (e.g. LibreView) in the future. This is an important consideration both for potential roll-out of DAFNEplus post-trial, and for the design and delivery of future SEPs seeking to promote type 1 diabetes self management.

Our data suggest that, in contrast to standard-DAFNE graduates (who rarely reported reflective behaviour at 12-months),⁶ most DAFNEplus participants engaged in some self management behaviours associated with the reflective behavioural cycle. Nevertheless, only a small minority expressed complete confidence adjusting basal insulin doses and ICR independently. Many viewed themselves as continuing to need some level of oversight or support at 12 months, and our data suggest a few might never master independent dose adjustment. While it remains possible that participants' skills and confidence will continue to grow over time, our findings suggest that some could benefit from individual support for longer than 12 months. Thus, if DAFNEplus were to be rolled-out post-trial, consideration should be given to whether, and how, such longer-term support might be provided. Given the variability in participants' perceived needs at 12 months, a differentiated model could be considered, allowing facilitators to direct their (limited) time and resources towards those with greater need for support (or prioritising this group for access to hybrid closed-loop technology) and inviting others who are managing their diabetes more autonomously to request help/advice as needed. For the latter group, a

patient initiated follow-up (PIFU) model (already in use in some UK centres), which allows patients the flexibility to arrange follow-up care as and when this appears useful for them, could provide an appropriate mechanism. Care would, however, need to be taken to determine this model's suitability for any given individual, ideally using a shared-decision-making approach/process, in line with guidance on PIFU implementation.²⁴ Further research, including a health economic analysis, would also be needed to assess the workforce implications (feasibility, acceptability and cost-effectiveness) of any favoured approaches.

Finally, a common criticism of structured education programmes has been that more consideration needs to be given to participants' transition back into standard care following programme completion. To augment the work of DAFNEplus and similar programmes, there might be merit in exploring if/how routine care contacts (e.g. annual reviews) could incorporate key aspects of individual support (e.g. affirmative language, and review of behaviours and data to inform action planning and encourage independent decision-making). Ideally, professionals familiar with DAFNEplus principles and practices would deliver those routine contacts, though this would create some additional training needs. The programme team is currently exploring mechanisms for sharing action-planning content with standard DAFNE educators: funding permitting, other condensed training modules could potentially be developed and used to cascade DAFNEplus principles to wider diabetes healthcare teams.

4.1 | Strengths and limitations

Our analysis makes an important contribution to the wider process evaluation and addresses others' calls²⁵ to clarify the support people need to sustain the benefits of attending type 1 diabetes SEPs. As discussed elsewhere,¹⁵ the onset of the SARS-CoV-2 pandemic prompted a pragmatic design change (from longitudinal to cross-sectional interviews). While this may have caused some loss of depth in our data, it permitted an increase in participant diversity and numbers and, hence, the breadth of perspectives captured.¹⁵ Indeed, we successfully recruited participants from across different occupational/educational groups. However, in line with the wider trial, our sample was skewed towards White participants; hence, further research may be needed to capture the perspectives of non-White and other seldom heard groups. Additionally, to inform successful roll-out, it may be important to capture the views of those who took part in less than three individual support sessions, or disengaged entirely from the programme, as it is possible that such participants might

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have found individual support a less positive and useful experience. As our focus on was participants' experiences of the DAFNE*plus* programme, we only interviewed them up to 12 months. In light of the findings reported here, an additional study has been developed to explore participants' longer-term experiences and support needs. Facilitator perspectives on DAFNE*plus* have also been reported separately.²⁶

5 | CONCLUSION

Our study suggests that the individual support component of DAFNE*plus* worked broadly as intended, with all participants appearing to benefit from it to varying degrees. Fundamentally, our findings support prior assertions that 'continued support matters'^{7,25} following participation in type 1 diabetes SEPs, albeit to some participants more than others. Indeed, our study suggests some participants may need, or experience additional gains from, longerterm, tailored support. These findings have implications for decision-making about roll-out of DAFNE*plus* posttrial and development of future programmes seeking to promote sustainable behaviour change to support diabetes self management.

AUTHOR CONTRIBUTIONS

JL conceived and designed this sub-study. DR collected the data, which was then analysed by RIH, DR and JL. RIH and JL drafted the manuscript, with input from DR. All authors reviewed, edited and approved the final version.

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CONFLICT OF INTEREST STATEMENT

PMC has received speaker fees from Roche. SH has served on advisory boards and consulted with Eli Lilly, Zealand Pharma, Zucara Pharma and has served on speaker panels for NovoNordisk. JE has served on advisory boards and/or received speaker fees for Abbott, Dexcom, Insulet, NovoNordisk, Roche and Sanofi SA. RIH, DR, NdZ, DC and JL have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

The datasets generated and analysed in the course of this study are not publicly available due to risks to individual privacy. However, they are available, via the corresponding author, on reasonable request.

CONSENT TO PARTICIPATE AND FOR PUBLICATION

All research participants provided written informed consent including for anonymized information to be published in this article.

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REFERENCES

- 1. Heller SR, Gianfrancesco C, Taylor C, Elliott J. What are the characteristics of the best type 1 diabetes patient education programmes (from diagnosis to long-term care), do they improve outcomes and what is required to make them more effective? *Diabet Med.* 2020;37:545-554.
- 2. DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *BMJ*. 2002;325(7367):746.
- 3. Plank J, Köhler G, Rakovac I, et al. Long-term evaluation of a structured outpatient education programme for intensified insulin therapy in patients with Type 1 diabetes: a 12-year follow-up. *Diabetologia*. 2004;47:1370-1375.
- 4. Speight J, Amiel SA, Bradley C, et al. Long-term biomedical and psychosocial outcomes following DAFNE (Dose Adjustment for Normal Eating) structured education to promote intensive insulin therapy in adults with sub-optimally controlled type 1 diabetes. *Diabetes Res Clin Pract*. 2010;89:22-29.
- Lawton J, Rankin D, Cooke D, et al. Dose adjustment for normal eating: a qualitative longitudinal exploration of the food and eating practices of type 1 diabetes patients converted to flexible intensive insulin therapy in the UK. *Diabetes Res Clin Pract.* 2011;91:87-93.
- Lawton J, Rankin D, Cooke D, et al. Patients' experiences of adjusting insulin doses when implementing flexible intensive insulin therapy: a longitudinal, qualitative investigation. *Diabetes Res Clin Pract*. 2012;98:236-242.
- 7. Rankin D, Cooke D, Elliott J, Heller S, Lawton J. Supporting self-management after attending a structured education

programme: a qualitative longitudinal investigation of type 1 diabetes patients' experiences and views. *BMC Public Health*. 2012;12:652.

- 8. Hamilton K, Stanton-Fay SH, Chadwick PM, et al. Sustained type 1 diabetes self-management: specifying the behaviours involved and their influences. *Diabet Med.* 2021;38:e14430.
- Stanton-Fay SH, Hamilton K, Chadwick PM, et al. The DAFNEplus programme for sustained type 1 diabetes selfmanagement: intervention development using the Behaviour Change Wheel. *Diabet Med.* 2021;38:e14548.
- Coates E, Amiel S, Baird W, et al. A protocol for a cluster randomised controlled trial of the DAFNE*plus* (Dose Adjustment For Normal Eating) intervention compared with 5x1 DAFNE: a lifelong approach to promote effective self-management in adults with type 1 diabetes. *BMJ Open*. 2021;11:3040438.
- DAFNEplus: Glucollector Logic Model. https://www.sheffield. ac.uk/media/41996/download–Download section (Accessed 29th November 2023).
- Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337:a1655.
- Skivington K, Matthews L, Simpson SA, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*. 2021;374:n2061.
- The DAFNEplus Programme Theory. https://www.sheffield.ac. uk/media/41995/download - Download section (Accessed 29th November 2023).
- Lawton J, Chadwick PM, de Zoysa N, et al. Participants' Experiences of Attending a Structured Education Course (DAFNE*plus*) Informed by Behavioural Science. Accepted by Diabetic Medicine.
- 16. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci.* 2011;6:42.
- DAFNEplus. Individual Support Logic Model. https://www. sheffield.ac.uk/media/45456/download - Download section (Accessed 29th November 2023)
- Rankin D, Cooke D, Heller S, et al. Experiences of using blood glucose targets when following an intensive insulin regimen: a qualitative longitudinal investigation involving patients with type 1 diabetes. *Diabet Med.* 2012;29:1079-1084.
- Campbell F, Lawton J, Rankin D, et al. Follow-up support for effective type 1 diabetes self-management (the FUSED model): a systematic review and meta-ethnography of the barriers, facilitators and recommendations for sustaining self-management skills after attending a structured education programme. *BMC Health Serv Res.* 2018;18:898.
- 20. Breckenridge JP, Gianfranceso C, de Zoysa N, et al. Mobilising knowledge between practitioners and researchers to iteratively refine a complex intervention (DAFNE*plus*) pre-trial: protocol for a structured, collaborative working group process. *Pilot Feasibility Stud*. 2018;4:120.
- 21. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3:77-101.
- 22. Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Sage; 1990.
- 23. Choudhary P, Genovese S, Reach G. Blood glucose pattern management in diabetes: creating order from disorder. *J Diabetes Sci Technol.* 2013;7:1575-1584.



- 24. NHS England and NHS Improvement. Implementing patient initiated follow-up: Guidance for local health and care systems. 2021. Available from: https://www.england. nhs.uk/wp-content/uploads/2022/05/B0801-implementi ng-patient-initiated-follow-up-guidance-1.pdf. Accessed: 24/07/23.
- 25. Casey D, Murphy K, Lawton J, White FF, Dineen S. A longitudinal qualitative study examining the factors impacting on the ability of persons with T1DM to assimilate the Dose Adjustment For Normal Eating (DAFNE) principles into daily living and how these factors change over time. *BMC Public Health.* 2011;11:672.
- 26. Lawton J, Rankin D, Scott E, et al. From educator to facilitator: healthcare professionals' experiences of, and views about, delivering a type 1 diabetes structured education programme (DAFNE plus) informed by behavioural science. Accepted by Diabetic Medicine, Subject to Minor Revisions.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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