

Patient engagement with a diabetes self-management intervention

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Title:

“Patient engagement with a diabetes self-management intervention”

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Abstract:**Objectives:**

To explore how people living with type 2 diabetes self-manage their condition in everyday life and the impact of the Diabetes Manual Programme, a one-to-one structured educational intervention aiming to increase skills and confidence for self-management.

Method: Semi-structured interviews with 12 participants on the Diabetes Manual trial, sampled purposively according to baseline self-efficacy and educational attainment.

Results: When describing their experience of living with diabetes, there was little difference between intervention and control participants, although those who had received the programme talked more about the use of blood glucose self-assessment. Programme users were grouped into three categories, Programme Engagers (n=2), Programme Browsers (n=4), and Information Seekers (n=6). Of the two participants engaging with the programme, one described a very positive experience, the other felt unsupported by their practice. None noticed a difference in the approach used by their health professional. Participants' approach to the Diabetes Manual programme suggests they will continue to use it as a resource in the future.

Conclusion: Participants used the Diabetes Manual programme in different ways, choosing the timing and depth of engagement. Their experience suggests that the programme requires close communication and openness towards collaborative approaches to improve skills and confidence for self-management.

Keywords:

Diabetes

Qualitative

Chronic Illness

Health Education

Primary Care

Introduction

Diabetes is a condition that demands a complex multi-faceted strategy of self-management, including attention to diet, physical activity, medication and blood glucose self monitoring.¹⁻² People with diabetes need to incorporate these items into their day-to-day lives. Qualitative studies have identified two different kinds of interaction between diabetes self-management and other aspects of life. Some people living with diabetes try to adhere strictly to recommended regimens, and restrictions e.g. on diet and routines are normalised as an important part of day-to-day life.³⁻⁴ Others aim for flexible management of their condition, where spontaneous eating and drinking is counterbalanced with exercise, return to healthy eating or adjusting medications.⁵ This increased flexibility is described as part of 'growing up as a diabetic.'⁶ While both these strategies can lead to good blood glucose control,⁷⁻⁸ flexible self-management has also been associated with improved quality of life, a feeling of confidence, less guilt and greater acceptance of diabetes.⁵

In the United Kingdom (UK), the past decade has seen a trend towards providing primary care based, nurse-delivered diabetes services with patient education and self-management at the forefront which mirrors world-wide development.⁹⁻¹⁰ The emphasis on autonomy and flexibility in self-management is therefore supported by health policy, which aims at a greater involvement of the person with diabetes in deciding goals and strategies for diabetes management.¹¹ However, this patient centred approach is in conflict with an established, more directive approach which can lead to the person with diabetes feeling they will be reprimanded for not achieving blood glucose targets and therefore resorting to strategies such as lying to the health professional or increasing medication before testing.² Some patients may hold themselves morally responsible for following health providers' instructions, with (perceived) health consequences of lapses in self-management seen as 'punishments'.¹²⁻¹³ Those aiming to increase openness and collaborative approaches in diabetes care will need to be aware of the need to actively overcome these unhelpful patterns of interaction as the directive approach to care is embedded in the training and socialization of most health care professionals.¹⁴

In the UK, educational programmes for people living with diabetes have similarly shifted from traditional, didactic interventions to collaborative goal setting, and such collaborative interventions have been shown to be more effective.¹⁵ Health professionals are expected to work with people living with diabetes to develop their confidence, skills and knowledge, engage in shared decision making and to provide theory-based structured education.^{11 16-17} UK based educational interventions such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) enable the patient to deal with their individual situation and such group interventions facilitate peer to peer learning and sharing.¹⁸⁻¹⁹ The Diabetes Manual programme was developed to provide an alternative one-to-one approach, closely modelled on the successful Heart Manual²⁰ and designed to increase skills and confidence for self-management of type 2 diabetes.²¹ The team hypothesised that the Diabetes Manual would improve psychosocial outcomes in line with those demonstrated by the Heart Manual studies.^{20 22} The theoretical framework was self-efficacy theory with component elements designed to support self-efficacy.

The Diabetes Manual programme was designed to be offered during consultations between patients and their primary care provider for diabetes. It has five components:

- i) two-day training for health professionals to deliver the programme with a special focus on listening skills and supporting, non-directive communication with the patients
- ii) a patient workbook containing information and goal setting exercises around topics such as diet and physical activity to be completed over 3 months
- iii) a relaxation CD
- iv) a frequently asked questions and programme overview CD for patients and carers
- v) telephone support from a health professional in weeks 1,5 and 11.

The main study, a cluster randomised trial with waiting list control to test the effectiveness of the Diabetes Manual programme on self-efficacy, diabetes-related distress, HbA1c levels and risk factors for heart disease was conducted during 2005/6.²¹ The programme was delivered by primary care nurses in the United Kingdom's National Health Service who had already received additional training in diabetes care. A sample of 245 patients with an HbA1c over 7% (i.e. higher than ideal blood glucose levels) were recruited by nurses in participating practices. HbA1c is a measure of the amount of glucose attached to haemoglobin cells in the blood stream and provides an assessment of the average amount of glucose circulating in the blood over the previous 8-12 weeks. It is the recommended measurement of glycaemic control internationally in the form of a simple blood test and is a common measure of treatment efficacy in both clinical practice and research. Practices (rather than patients) were randomised to the intervention and control arms of the trial. Patients in the intervention group immediately started the Diabetes Manual programme; after data collection at 6 months, those in the control group were able to also start the programme.

Methods

Aims

The overall aim of the nested qualitative study was to explore how participants self-managed their diabetes in everyday life and the impact of the Diabetes Manual Programme. The specific aims were to: 1) compare interviews from intervention and control group participants to identify similarities and differences in their diabetes self- management, and 2) describe the variations in the use of the Diabetes Manual Programme as reported by the intervention group participants.

Sample and Participants

From the 245 trial participants in the main study, a purposive 10% sample of 26 participants, all of whom had initially consented to being approached were invited for interview for the nested qualitative study. This small sample size was chosen due to restrictions in the study timeframe and limited availability of interviewers as all but one of the research team were blinded to group allocation. For recruitment we had access to the baseline clinical trial data and during analysis to the baseline and 6-month follow up trial data. Participant sampling aimed for equal numbers of participants who had had access to the Diabetes Manual programme (intervention group) and those who had not yet had access to the Diabetes Manual programme (control group). We recruited patients with a wide range of self-efficacy scores, as measured by the 11-point Diabetes Management Self-efficacy Scale (DMSES) at baseline,²¹ and a range of educational attainment. Additionally, we aimed for diversity of age, gender and ethnic origin, and a variety of locations across the trial area.

Of the 26 participants invited, 25 agreed to interview. Three completed interviews could not be used as the recording was very poor. Of the resulting 22, 12 were in the intervention group

and 10 in the control group. 13 were male and 9 female, with an age range of 25-80 years (mean: 61 years) and with self-efficacy scores ranging from 47-150 (mean: 107.3). 10 were from the control group and 12 from the intervention group. Their self-declared ethnicity was White British (n=15), Caribbean (n=3), Indian (n=2) and Irish (n=2).

Design

The qualitative study was based on semi-structured interviews with trial participants that focused on obtaining description of day-to-day living with diabetes, as successful self-management may depend on developing a set of routines and problem-solving strategies.²³ We did not intend to assess participants' educational achievements as the programme aimed to raise patient self-efficacy rather than diabetes knowledge. To avoid marginalising other emerging data on the lives of participants while they engaged with the Diabetes Manual programme, we did not ask about their experience of the programme until the end of the interview. The study followed the principles of 'grounded' qualitative research as we aimed to elicit emerging themes to understand the experiences of the participants rather than to test pre-determined theories.²⁴ However, as we collected patient accounts for a very specific purpose (understanding the impact of the Diabetes Manual programme) rather than with an explicit aim of new theory building, the methodological approach fulfils the criteria for 'grounded description' rather than grounded theory.²⁵

Ethical considerations

Ethical approval was granted by the Northern and Yorkshire Multi-Centre Research Ethics Committee in June 2004. Concurrent consent was obtained for both the clinical trial and interview study. Consent was confirmed at commencement of interviews.

Data Collection

The study interviews were conducted October 2005 to June 2006 within a two-week window following participants' completion of the 6-month follow-up questionnaire and prior to clinical follow-up. We chose this timing to reduce any influence of the interview on completion of the questionnaire. The interviews were undertaken by five researchers who were not otherwise involved in the trial, to preserve trial blinding. Researchers were part of a collaborative research development team and engaged in ongoing discussion; they were also given a detailed set of instructions outlining the aim of the study and the rationale behind elements of the interview schedule. AL led the interviewing team and conducted 10 interviews; other researchers undertook six, four, and two of the interviews. The interview schedule explored the patients' experience and understanding of diabetes including the impact of diabetes on their lives; strategies for self-management and how these developed over time; sources of information, advice and health care, and the role of their health professionals in managing diabetes. The same issues were explored with participants in the intervention and the control group. At the end of the interview, all participants were asked whether they had made any changes, however small, to their diabetes management. If the Manual was not mentioned by patients who had received it, they were asked a general question about their use of the programme. After initial analysis of 10 transcripts, we amended the interview schedule to add further detail on changes to diabetes management and participants' understanding on blood tests. All interviews were audio recorded, except for two where the participant declined so detailed field notes were taken. Field notes were also taken to supplement recorded interviews, for example noting blood glucose readings shared with the interviewer. All data was transcribed and anything that could identify the individual removed during transcription. Participants were given a pseudonym beginning with their alphabetical identifier, reflecting their gender and ethnicity.

Data analysis

QSR N-VIVO International software²⁶ was used for data handling which allowed both thematic and case comparison across the data set. SW checked transcripts against audio recordings where there were gaps in the transcripts or the transcription seemed unclear. Interview data was coded thematically, as this approach was best suited to evaluative health research.²⁷ The authors each read at least 40% of the transcripts and contributed to three rounds of analysis discussions where they developed and refined the coding scheme. SW (a researcher in self management) and AL (an experienced qualitative researcher) jointly coded the first interview transcript to check the validity of the coding, SW then proceeded to code the interviews using the coding scheme; coding was continually reviewed by the research team. Some of the themes were implicit in interview questions particularly about the Manual programme, but emerging themes such as the interaction between the self-management of diabetes and other conditions or meanings attached to the manner in which patients were given their HbA1C results by their practice were also included.

In the first stage of our analysis we compared the data from both intervention and control group participants collected early in the interview when talking about self-management of their diabetes and identified where there were differences and similarities between the groups. Then, SW and AL examined the data from the 12 intervention group participants where they talked about the use of the Diabetes Manual programme, and compared each participant with the others in the intervention group, in terms of their use of programme components: those completed by the patient (diaries, goal setting exercises, the optional use of self testing of blood glucose for self-management), and support elements (audiotapes, nurse support calls). In the following, we will present results of our analysis. While the comparison of the intervention and control group draws on all the interviews conducted, examples of Diabetes Manual use are taken from interviews with intervention group participants. Some discussed the Manual only briefly and when prompted; others explained in detail how they had used it.

Results

Comparison of intervention and control groups

We were unable to identify major differences between how intervention and control group participants talked about their knowledge and habits regarding diet, exercise or medication. However, there were some differences in use and understanding of blood test results (blood glucose self-testing and HbA1c tests undertaken by the nurse). Most participants (intervention and control) reported some use of self-testing. All the participants from the intervention group said that they self-tested their blood most days whereas this was mentioned less frequently amongst the control group. Four of the intervention group participants mentioned the link between physical activity or diet and their blood sugar levels and three of these described taking action to reduce their blood sugar levels.

I try to keep it around 5 to 6 maximum, don't I? If I do a test and it's higher then I cut something out on the meal side [Harry – Intervention]

Three participants (2 intervention, 1 control) logged their HbA1c results together with their self-test results. Of these, one participant in the intervention group (Gillian) actively related HbA1c results to her self-test results and anticipated improvements in her own results slowly feeding through to HbA1c levels as a result of her actions. For both intervention and control

participants, self-testing results seemed more meaningful than HbA1c results. Most participants either did not know or could not remember their HbA1c or believed that both types of test results were similar. Five participants (one in the intervention and four in the control group) said that their general practice did not tell them their HbA1C result and they thought this indicated that their diabetes must be adequately controlled:

I went last week and they didn't say nothing about it and I forget to ask to be honest. I think it's alright. They would have said. [Ursula – control].

[...] they don't tell me, no, and that's another thing that I can't understand. I mean they just say that, you know, they never say anything, so you presume that everything's alright. [Adrian – control]

Our findings suggest that more participants in the intervention group understood and acted on their self-test results than in the control group. However, when talking about blood testing the participants in the intervention group did not specifically talk about the Manual so we have no evidence that this was the results of exposure to the Manual. HbA1C results remained remote for most intervention and control participants.

Use of the self completed components of the Diabetes Manual

The 12 participants in the intervention group chose to engage with the programme to different extents. From the interview data we developed three categories (see table).

Table 1: Categories of engagement with the Diabetes Manual

Category of User	Characteristics	participants
Information Seeker	Reported reading the manual or using it for reference but minor or no mention of attempted or realised behavioural change. No mention of goal setting.	Frederick, Ian, Harry, Lewis, Neil, Zara
Programme Browser	In addition to reading the Manual, Browsers had engaged more fully with at least one aspect of the programme. Evidence of increased knowledge and planned or attempted lifestyle change. Described setting goals but no specific changes made to achieve them was reported.	Gillian, Jessica, Monica, Walid
Programme Engager	Participants reported completely following the programme and demonstrated increases in knowledge and behavioural changes (e.g. changes in diet, increased exercise). However, only Vanessa described setting goals	Keith, Vanessa

Information Seeker

Five participants had used the Manual as a source of information or for confirming information:

The wife keeps it on hand, and refers to it when she is not sure of anything. [Ian]

The more information you've got the more it helps you cope with it [diabetes]. [Harry]

Some but not all participants in this category used the worksheets provided in the Manual for recording their information. This focus on written information caused some difficulties for those who described themselves as uncomfortable with reading large amounts of text. The Diabetes Manual encourages patients to reflect on their current levels of confidence for changing aspects of their daily life such as eating patterns, taking them through a process of eliminating and ultimately choosing behavioural goals. However, of the 'Information Seekers', only Harry mentioned a goal when asked how he saw his future with diabetes. In his case, his goals were to avoid going onto insulin injections and to "[...] *try to stay as healthy as I can and live as long as I can*". He did not state how he intended to achieve this.

Programme Browser

Five participants reported a more thorough use of the Manual: "*I keep my book handy, it's always out, it's never away and I've read it four or five times*" [Monica]. They engaged with at least one aspect of the programme. This could include the use of worksheet as a diary, to record exercise and other aspects of diabetes management which acted as an encouragement to participants to increase their exercise:

[...] if you have the time to work your way through [the Manual] like a little diary [...] it's something that will just egg you on a bit more and just give you that little bit more of a push and think 'I did that last week, so I'll try and make it a bit better this week. [Gillian]

Before this Manual and everything it was the mechanical side – you have to do exercise and you have to do this and you have to do that and then thinking comes into the instances, so I started doing it and then I get used to the walking and I do still walk half an hour or exercise half an hour. [Walid]

Other aspects of the Manual such as the home exercise plan and the (optional) blood glucose record sheets prompted programme browsers to reflect on the interactions between food, exercise and blood glucose in their everyday lives:

I filled them in every day and then if my blood sugar went up I thought 'Well, what did I eat?' and I did find it quite useful. [Jessica]

I can go on the exercise bike – I was 24 which was really high and I got myself down to 8.5 and that was for 15 minutes! [Monica]

All of the participants who we categorised as 'Programme Browsers' had set non-specific goals such as losing weight or eating more healthily. One participant was keen to avoid having to go onto insulin: "*I really, really don't want that, so it's a real personal goal to stay away from that bit of it!*" However, only Monica described working toward her goals: "*Well I have set my goals. I've started to eat more healthier, I packed up my smoking.*"

Programme Engager

Two participants had more fully engaged with the Diabetes Manual programme, integrating several aspects into their everyday life. However, their experience was different, one quite problematic, the other very positive. One participant (Keith) reported following the programme of activities, blood sugar monitoring and healthy eating for seven weeks. However, he did not mention any specific goals he had set. He attributed a reduction in his blood sugars to following the programme:

I take my blood fairly regularly but not every day and I find it's too high, I watch what I eat for probably a couple of days. I mean that catalogue I had off you, it's very hard, but I think if you could stick to it, I think you're right, I wouldn't need the tablets. [...] I did it, I think for 7 weeks and found out I was really low all the time.

His blood sugar level was sometimes so low he felt he had to eat sugar to raise his blood sugar to an acceptable level:

I thought 'Well this ain't right. I'll have a couple of biscuits to bring it up' and that's what I used to do, but I think if you stuck to that I wouldn't need the tablets. In fact I think it was the tablets what was sending me down because I wasn't balancing them out [with sugar from food] I was – just keep taking me tablets.

To assist in interpreting this patient's account we looked at his clinical data at baseline and 6 months after starting the programme. His HbA1c had reduced from 12.6 to 10.2; between these two measurements, a rosiglitazone had been added to the sulphonylurea and metformin he was already taking. HbA1c measurement results relate to average blood glucose levels over the previous 3 months. Self test results may therefore have picked up on phases of low blood glucose during the 7 weeks he engaged with the Diabetes Manual.

A second participant, Vanessa, had also engaged with the programme, completing her weekly worksheets, eating more healthily and increasing her exercise. She had increased the amount of walking that she did and, following one of the suggestions in the manual, danced to music at home as a form of exercise.

I think [the Manual] really has helped me because, as I say, I don't think I'd have probably done the exercise that I do now, you know. I did think 'Oh yes, I'm tired so I'll sit down' but I don't do that now. I think 'I must do this exercise and I must get up and do it' and when I've done it I feel much better. [Vanessa]

She attributed the increase in exercise to following the Diabetes Manual and valued the behaviour change that she had made:

It's doing this study and now I've started doing it, I feel as though I've got to keep doing it.

She had set a goal to lose weight thorough initiating a programme of home exercise and increased walking and had lost weight, which she attributed to increasing her exercise:

I can tell you that friends that know me have looked at me lately and said 'you've lost some weight you know' and I saw [friend] the other day and she said 'I saw you cleaning the car, you have lost some weight'. So I think it must be because I'm moving about more, you know and really making the effort to do it.

Although some Programme Browsers had engaged to some degree with the Manual as illustrated with the quotations, the interviews with these two participants suggested a different level of engagement to the browsers, with a more sustained effort and greater impact on everyday life. These two case studies also suggest the importance of life context for engaging with the Manual. Although both Vanessa and Keith were motivated to make changes in their life, Keith said he could not sustain the changes and felt not supported by his surgery. In contrast, Vanessa was familiar with peer support programmes such as Weight

Watchers and started making life changes even before embarking on the Manual (such as replacing coffee with slippery elm tea, changing to a less sedentary job). These accounts of using the Manual underline the need for the supporting health professional to elicit and build on existing attempts at change, discuss the sustainability of goals and self test results and possible changes in medication.

Use of supportive components of the Manual

Audiotapes

Only one participant (Jessica) commented that she had used the information audiotape. She was concerned that diabetes might affect her eyesight and the audiotape had increased her awareness of this potential problem. However, three participants (Gillian, Vanessa and Walid) had made use of the relaxation tape and were all positive in their responses to this with one woman clearly benefiting from the relaxation tape to combat her high stress levels:

Well, it tells you what to do and how you can, you know, deal with stress and how you learn to deal with it, you know by breathing up through your nose and sort of letting it out. You can do that in a room full of people there and they don't even know that you're doing it, you know. [Vanessa]

Structured Nurse Telephone Support

The Structured Nurse Telephone Support consisted of supportive telephone calls to participants at weeks 1, 5 and 11 of the 12-week programme. Even after prompting, only one interview participant mentioned the role played by the practice nurse in supporting them through the programme, appreciating the nurse taking an interest:

[the nurse] rang me on the phone to ask about things [...] I felt as though somebody was interested. Yes, I felt somebody was interested in how I was getting on, which was good. It's almost like a Weight Watchers thing! If you go to Weight Watchers and you've got somebody there that you can sort of talk to, I think it helps you no end. [Vanessa]

Six of the eleven nurses in the clinical trial aimed to complete a telephone pro forma for each telephone call made to participants. From these we know that one 'information seeker' was telephoned by a nurse, as were three of the 'Programme Browsers' and both the 'Programme Engagers.' It is possible that other participants did not receive all the planned nurse telephone support or that the nurse did not fill out the proforma following the call.

Participants were asked general questions about consultations with their health professionals to explore whether they received directive advice or were empowered to participate in decision making:

They like it a little bit lower. I mean, on average it works out about eight doesn't it over the three-month period? But they always say 'Well, we need it down to five' but to get it down to five I think you'd have to live in a cage. [Harry]

And I said 'Yes, I'll try.' I said, 'I don't see the point in coming to see a doctor if you're not going to take his advice'. [Jessica]

Well, it's all my responsibility really. If they keep giving me the tablets I'll take 'em. [Keith]

Although most participants described their health professional as helpful and approachable, none indicated they had noticed any change in their nurses' approach. Keith described feeling disempowered as he managed to lower blood sugars but felt that he was not 'allowed' to lower his medication. None reported shared decision making with most saying that it was their responsibility to try to follow the instructions of doctors and nurses.

Discussion

Study Limitations

Although 22 participants were interviewed, our findings on engagement with the intervention is based on interviews with only 12 participants so may not represent the full diversity of usage. We were also unable to verify whether all participants from the intervention groups received the nurse telephone support.

Discussion of findings

Participants chose to engage with different aspects of the Manual programme, with few engaging fully with all aspects of the programme. There was very little difference between the intervention and control group's accounts of living with diabetes except for some difference in patients' understanding of the results of blood sugar self-monitoring. This suggests that the health care intervention was marginal to the participant's day-to-day lives. A similar study of people living with diabetes and involved in a trial of DESMOND, a UK based group intervention for diabetes, similarly found very little difference between the accounts of those who attended DESMOND and those in the control group.¹³ This is perhaps not surprising, as living with diabetes has been likened to a 'marathon' where changes may be very slow and need to be sustainable in the long term.²⁸

Within the intervention group, by taking the interview data as a whole, we were able to classify people according to the level of engagement with the intervention. We had previously found a diverse spectrum of engagement (from almost none to very strong) with the programme from analysis of the brief telephone pro-forma collected by the trial nurses.²¹ Using our much richer interview data we developed categories of overall engagement. Very few participants had engaged fully with the programme, which may at least in part explain why the clinical trial did not show a significant reduction in HbA1c within the timeframe of the trial.²¹ It is possible that the Diabetes Manual may be helpful in the longer term for participants using it as a source of information to dip into or to browse through for ideas for future changes. The interviews suggest that participants found it difficult to integrate the changes suggested by the Diabetes Manual into their day-to-day lives. Even among those who set their own goals, some delayed their implementation.

When completing the Diabetes Manual programme, participants chose what components of the programme to use (e.g. informative sections, diaries, audio CDs), how to use them and the timing of their use. The impact on health outcome of providing this choice within a complex intervention needs further investigation. Participants valued the information and support they received from their health professionals but had not noticed any change in the approach taken by their nurse. It may be that the nurses had difficulty changing their approach to patients despite their training. Other studies have found a directive approach by health professionals persists in locations where patient empowerment was part of the official policy²⁹ and where health professionals had been trained in empowering approaches.³⁰ Our study showed that participants chose to engage with the programme according to their needs (e.g. more information, motivation to persist with exercise, sustained changes in lifestyle). Those developing similar educational interventions should respect these choices and make sure that those enrolled receive ongoing, non-directive support.

Conclusion

Participants could be categorised into Programme Engagers, Programme Browsers and Information Seekers. The Diabetes Manual programme was used by them in different ways,

with few engaging fully with all aspects of the programme. Different participants valued different aspects of the programme, but most found it difficult to integrate new patterns of behaviour into their day-to-day lives. However, as the Diabetes Manual and audio CDs remain in the possession of each person, they remain accessible as a resource. This may be the major advantage of this programme over group interventions leaving the choice of timing and depth of engagement to the individual. Findings from this research will inform ongoing research into the barriers and facilitators to implementing the behaviour change counselling component of the Diabetes Manual.

Ongoing work to further strengthen the Diabetes Manual includes a study to enhance the psychological support components offered to people with diabetes and the development of a web based programme. Further research questions include investigation of the impacts and effects of these additional components on health, wellbeing and behaviour. Methods to assess engagement with behaviour change interventions need to be developed and validated so researchers and clinicians can develop greater understanding of the strengths and limitations of these complex interventions. This study demonstrates that people engage in behaviour change interventions in different ways and these differences may account for the range of outcomes experienced by participants.

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