

# BMJ Open Recruitment and retention in a 10-month social network-based intervention promoting diabetes self-management in socioeconomically deprived patients: a qualitative process evaluation

Charlotte Vissenberg,<sup>1</sup> Vera Nierkens,<sup>1</sup> Paul J M Uitewaal,<sup>2</sup>  
Barend J C Middelkoop,<sup>3</sup> Karien Stronks<sup>1</sup>

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<sup>1</sup>Department of Public Health, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

<sup>2</sup>Department of Public Health, The Hague's Public Health, The Hague, The Netherlands

<sup>3</sup>Department of Public Health, Leiden University Medical Centre, Leiden, The Netherlands

## Correspondence to

Ms Charlotte Vissenberg;  
[c.vissenberg@amc.uva.nl](mailto:c.vissenberg@amc.uva.nl)

## ABSTRACT

**Objectives** Socioeconomically deprived patients with type 2 diabetes often face challenges with self-management, resulting in more diabetes-related complications.

However, these groups are often under-represented in self-management interventions. Evidence on effective recruitment and retention strategies is growing, but lacking for intensive self-management interventions. This study aims to explore recruitment, retention and effective intervention strategies in a 10-month group-based intervention among Dutch, Moroccan, Turkish and Surinamese patients from socioeconomically deprived neighbourhoods.

**Methods** Participants were recruited through general practitioners (GPs) and participated in a 10-month social network-based intervention (10 groups, n=69): *Powerful Together with Diabetes*. This intervention also targeted the significant others of participants and aimed to increase social support for self-management and to decrease social influences hindering self-management. A qualitative process evaluation was conducted. Retention was measured using log books kept by group leaders. Further, we conducted 17 in-depth interviews with participants (multiethnic sample) and 18 with group leaders. Interviews were transcribed, coded and analysed using framework analyses.

**Results** The GP's letter and reminder calls, an informational meeting and the intervention's informal nature facilitated recruitment. During the first months, positive group atmosphere, the intervention's perceived usefulness, opportunities to socialise and a reduction in practical barriers facilitated retention. After the first months, conflicting responsibilities and changes in the intervention's nature and planning hindered retention. Calls from group leaders and the prospect of a diploma helped participants overcome these barriers.

**Conclusion** To promote retention in lengthy self-management interventions, it seems important that patients feel they are going on an outing to a social gathering that is enjoyable, recreational, useful and easy to attend. However, rewards and intensive personal recruitment and retention strategies remained necessary throughout the entire intervention period.

## Strength and limitations of this study

- Through its use of qualitative methods, this study provides us with an exploration of factors that affect recruitment for and retention during interventions according to participants.
- This study indicates what health promoters can do to recruit and retain participants for lengthy lifestyle interventions.
- We did not interview patients who refused participation or dropped out of the intervention. Asking these patients which factors facilitated or hindered recruitment and retention would have strengthened this study.

**Trial registration number** Dutch Trial Register NTR1886; Results.

## INTRODUCTION

Patients from socioeconomically deprived neighbourhoods are disproportionately affected by type 2 diabetes mellitus (type 2DM) and its related complications.<sup>1</sup> Managing type 2DM requires a number of extensive self-management behaviours regarding diet, medication adherence, physical activity and often the monitoring of blood glucose levels. Complying with and maintaining such complex health regimens appear to be challenging, especially for socioeconomically deprived patients.<sup>2-4</sup> Self-management interventions have been shown to be effective in improving metabolic control and health outcomes.<sup>5,6</sup> However, in socioeconomically deprived groups, participation rates and retention rates are relatively low.<sup>7,8</sup> Previous studies have emphasised that intervention studies targeting patients in

lower socioeconomic groups need specific strategies to promote recruitment and retention.<sup>6</sup>

Experimental studies have indicated that important factors affecting recruitment and retention in diabetes self-management (DSM) and other interventions are generally a lack of transportation, interference with responsibilities at home or in the community, lack of time, attitudes towards research affiliated with the intervention, financial costs and burdensome procedures.<sup>9–11</sup>

In addition, for ethnic minority and socioeconomically disadvantaged populations, specific barriers to recruitment and retention in these types of interventions are difficulties with maintaining participant contact, a lack of acceptability, feasibility and cultural appropriateness to community values, distrust, other priorities of participants, practical barriers, having to take care of others, financial barriers and a lack of child care.<sup>6 12–14</sup>

Recent studies show that in order to improve recruitment, more intensive recruitment strategies are needed, as people in these groups appear to need more time and more face-to-face contact before they understand and support the intervention's aim and the accompanying evaluation.<sup>9 15 16</sup> The way an intervention is presented needs to be taken into account as well. Emphasising the benefit for other similar patients and addressing patients' concerns seem to be important to increase confidence regarding participation. In addition, an intervention might be made more appealing by emphasising the practical exercises and group discussions rather than the more cognitive aspects (eg, planning, reflection). There are indications that a general practitioner (GP) referral might be a good strategy to convincing those in lower socioeconomic groups to participate.<sup>9 17</sup>

To improve retention, community and/or participant involvement is advised to ensure that the intervention is culturally appropriate and better tailored to the needs of the target population. Also, reducing practical and language barriers, cash incentives and building a relationship with participants seems to benefit retention.<sup>9 14–16 18 19</sup> Further, multiple tracking, reminder and contact procedures are necessary.<sup>14 15</sup> Finally, it seems important to take the composition of the intervention groups into account. It is important that participants not be too different from each other because this might cause misunderstandings or frighten people if they become aware of diabetes-related complications and problems they had no previous knowledge of.<sup>20 21</sup>

In this paper, we examine *Powerful Together with Diabetes*, a 10-month social network-based intervention for patients with type 2 DM from various ethnic origins living in socioeconomically deprived neighbourhoods in the Netherlands. The above-mentioned studies often do not distinguish between factors that affect the recruitment and retention for the intervention under study on the one hand and the recruitment and retention for the accompanying study procedures on the other hand. In our study, we will explicitly focus on the recruitment and retention from an intervention perspective. In addition,

also the type of intervention we evaluate is interesting in view of the literature. More specifically, to our knowledge, little is known about effective recruitment and retention strategies for these kind of *intensive* lengthy DSM interventions among patients with type 1 diabetes living in socioeconomically deprived neighbourhoods.

During the development of *Powerful Together with Diabetes*, recruitment and retention played an important role, and specific methods and strategies were incorporated to facilitate this based on previous findings from the literature and theory.<sup>22</sup> In this paper, we study which factors and/ or intervention strategies facilitated or hindered recruitment and retention in *Powerful Together with Diabetes* according to the participants and their group leaders.

## METHOD

### Setting and intervention

The study was carried out in four cities in the Netherlands: Amsterdam, Utrecht, The Hague and Zaandam. People with type 2DM who lived in socioeconomically deprived neighbourhoods in these cities were offered a 10-month social network-based intervention: *Powerful Together with Diabetes*.<sup>22</sup> Neighbourhoods were selected using an official Dutch government ranking of socioeconomically deprived neighbourhoods. These neighbourhoods are characterised by lower-quality living conditions than those in other neighbourhoods due to an accumulation of problems: high unemployment rates, low income levels, high crime rates, deterioration, safety concerns and a lack of relevant social networks and social contacts.<sup>23</sup>

The intervention was specifically developed for patients from socioeconomically deprived neighbourhoods and culturally targeted to the Turkish, Moroccan and Surinamese patients in this group. The intervention was developed based on our formative research and different theories such as the theory of self-regulation, different self-management theories and the transactional model of stress and coping, relapse prevention and social learning theories.<sup>22 24–28</sup> We further describe the development of the intervention elsewhere.<sup>22</sup>

This intervention aimed to improve DSM by focusing on increasing social support for self-management among group members and significant others and by reducing social influences that hinder self-management. The entire programme lasted 10 months and consisted of 24 group meetings for the participants, 6 group meetings for their significant others and 2 social network therapy sessions during which both participants and their significant others were present. There were two phases. Phase 1 (the first 13 meetings, months 1–3) focused on the basic tools needed to manage diabetes, such as creating positive outcome expectations, moral norms, increasing knowledge, skills and self-efficacy, facilitating social support and recognising and dealing with psychosocial mechanisms that hinder optimal DSM (such as peer pressure and existing social norms). Phase 2 (meetings 14–24, months

4–10) focused on putting the tools gathered in phase 1 to use, developing and practising self-management skills until the participants had a solid set of coping skills that would enable them to optimally manage their diabetes in the long term.

Ten groups (five ethnic Dutch (hereafter referred to as Dutch), two Turkish, two Moroccan and one Surinamese group) with a total of 69 patients participated in the intervention from August 2010 to December 2011. The Turkish and Moroccan groups consisted of separate groups for men and women; both men and women were included in the Surinamese group. Each group was led by a group leader matched with the participants on ethnicity and gender. The group leaders were recruited through an advertisement and selected based on their prior experiences with group-based education. The leaders of the Dutch groups were diabetes nurses, GPs' assistants and nurse practitioners. The leaders of the Moroccan, Turkish and Surinamese groups were migrant health workers.

This intervention was evaluated in a trial that is described elsewhere.<sup>22</sup> An experimental non-randomised design with an intervention and a control group was used. The intervention was compared with standard group-based diabetes education to be able to determine the additive value of actively intervening on social support, social influences and the immediate social environment of patients at the same time. The intervention group received *Powerful Together with Diabetes*, the control group received *Know Your Sugar* (see figure 1). This study has been approved by the Medical Ethics Committee of the Academic Medical Center in Amsterdam, the Netherlands.

Previous evaluations indicated that this intervention seemed to increase social support and reduce social influences that hinder DSM for participants.<sup>29</sup> An effect on the primary outcome (HbA1c and quality of life) could not be studied, as we were only able to recruit half of the required number of participants. We refer to a previous paper for a further explanation.<sup>29</sup>

### Strategies to promote recruitment and retention

We based our strategies to promote recruitment and retention on the literature and our needs assessment.<sup>22</sup> To promote recruitment, informational meetings were organised to inform people about the intervention and answer their questions and so increase support for and understanding of the intervention. To increase motivation, each patient received a letter from their GP inviting them to participate and then two phone calls to remind them of the meeting. To encourage participation, we focused on the more practical aspects of the intervention (such as the specific content of the meetings) and helping other patients during the informational meeting rather than on the more cognitive elements (the behavioural goals of the intervention) and patients could also try out some of the activities. So they could understand what the intervention would be like, they exercised together and played a shortened version of the nutritional game, in which participants learn which dishes and foods they can

eat as often as they like and which dishes need to be eaten in limited quantities. Finally, only phase 1 (the first 13 weeks) was emphasised to keep the intervention's length from discouraging people. The meetings were held in the intervention location and the group leader was present so he or she could get acquainted with the participants.

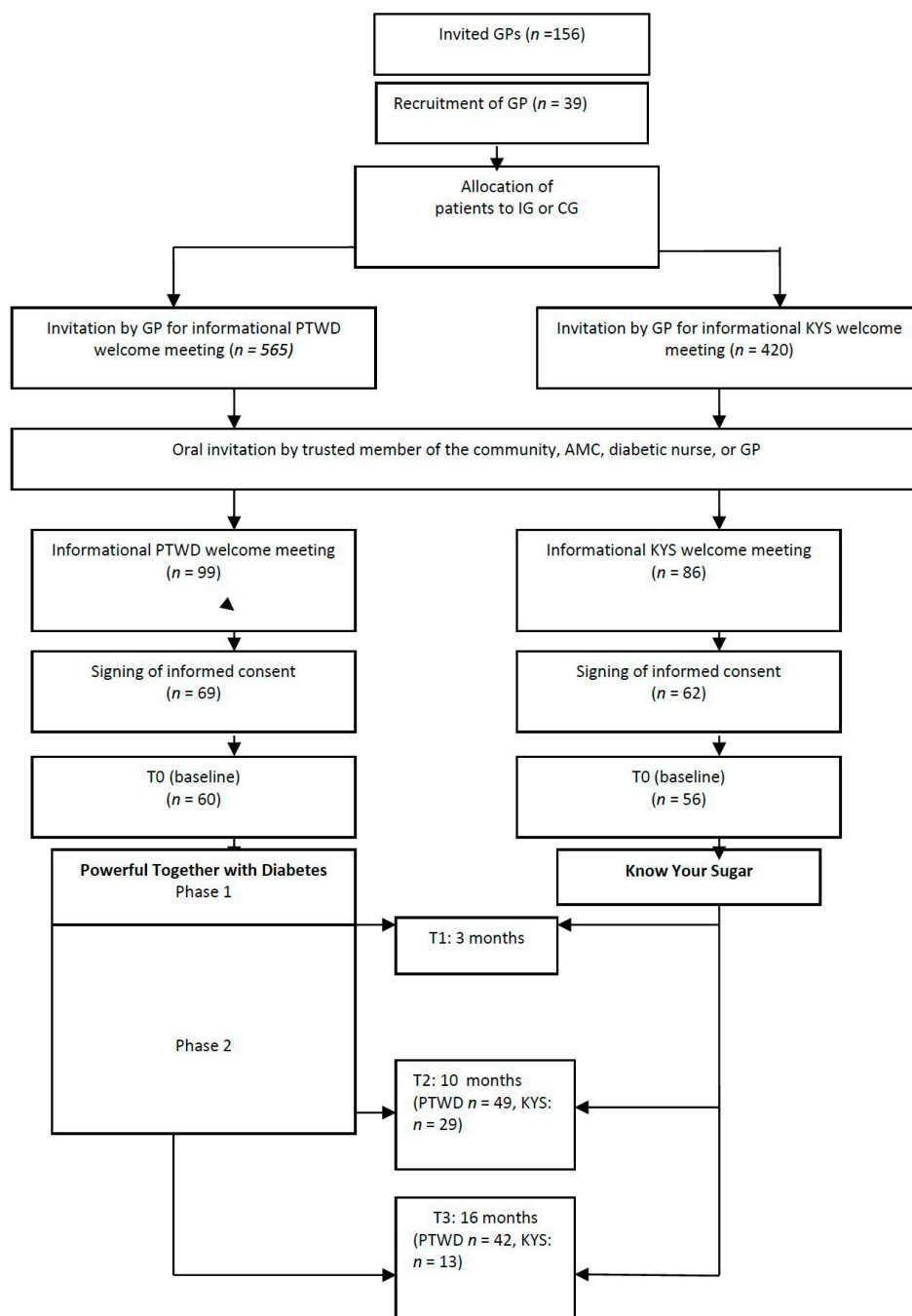
To promote retention, practical barriers were reduced: the intervention was free of charge, within walking distance of participants' homes and the time and day were chosen by the participants and could be changed during the intervention. In cooperation with Turkish, Moroccan and Surinamese lay health advisors and Dutch diabetic nurses and GP assistants as well as by pretesting some intervention components, the intervention was culturally targeted to the different groups. More specifically, the intervention was held in the mother tongue of the participants. In addition, we changed the outline of the intervention to make it compatible with the ethnic minority participants' annual visits to their countries of origin and the celebration of Ramadan. We also culturally tailored the content of the intervention components to the different cultural groups, for example, by incorporating sociocultural values and barriers to DSM and adapting the materials to fit the needs of the different cultural groups.<sup>22</sup>

Furthermore, matching the intervention groups on gender and ethnicity did not result in homogeneous groups, for example, with regard to diabetes-related complications. Therefore, we focused on mutual understanding instead. To increase mutual understanding, particular attention was paid to creating a pleasant atmosphere in the groups to facilitate group bonding and mutual trust. Strategies included providing tea and coffee, energisers, sharing news, exercising together and paying attention to specific group rules (giving appropriate feedback, the confidence pact, communication), shared goals and participatory problem solving.

Also, participants could obtain a diploma at the end of each phase when they took part in sufficient meetings. Finally, retention was promoted by making the intervention useful and interesting. Strategies included increasing relevance by adapting the intervention to the needs of participants by personalising the intervention and giving the participants compliments. See table 1 for an overview of the goals and strategies for improving retention.

### Study design of current study

The quasi-experimental trial was accompanied by a process evaluation. The process evaluation aimed to study the costs, the retention rate of the intervention, factors affecting recruitment and retention and the intervention fidelity.<sup>30</sup> This paper reports on the retention rate and factors affecting recruitment and retention. These were studied using a mixed methods design using logbooks (quantitative data) and qualitative semistructured interviews with participants and group leaders. The qualitative study was based on a phenomenological approach, which focuses on the subjective meaning of social action by trying to interpret people's actions and their social



**Figure 1**

world from their point of view.<sup>31</sup> We conducted qualitative in-depth semistructured interviews with participants (n=17) and their group leaders (n=9).

#### Recruitment of respondents

Our aim was to interview two participants per group. Because this was a hard-to-reach study population, we asked the group leaders to select and invite two respondents from their groups: participants who had been attending the intervention regularly and who had significant others who were also participating in the intervention.

In total, 17 participants from 8 intervention groups agreed to be interviewed (11 Dutch, 2 Turkish women, 2 Moroccan men and 2 Surinamese). These respondents broadly reflected the wider trial population in terms of age, gender, duration of diabetes and glycaemia control (see [table 2](#)). Four participants (the Moroccan women and the Turkish men) declined because they lacked the time, were on holiday or felt they had already spent enough time on the study procedures (filling out questionnaires and having the physical examination). Response among group leaders (n=9) was 100%.

**Table 1** Overview of subgoals and strategies of *Powerful Together with Diabetes* to improve retention

General objective	Subgoals	Intervention strategies
1. Participants keep participating during the intervention	Participants think the intervention suits them, that it is important to participate and expect to benefit from participating in the intervention (outcome expectations, perceived norms, moral norms) Participants feel supported by their group members and their significant others to participate (self-efficacy, skills, social support) Participants are motivated to attend by other participants and their significant others (social influence)	Increasing relevance 1. Collection of questions: to guarantee that the meeting fits the needs of the participants, the group leaders start with a short description of the meeting and write down the participants' questions on this topic. At the end of the meeting, the group leader checks whether all questions have been addressed. 2. Direct influence of participants on intervention strategies such as role-playing exercises and letter of the week (a fictional letter received from someone with diabetes who has a problem that needs to be solved. The participants are invited to brainstorm together about the problem and help solve the problem), so strategies can be adjusted by the group leader to their needs. 3. Personalising the intervention: intervention focuses on the participant. For example, participants were invited to ask their questions, to bring their own medications, to cook something for the group and got personalised feedback. Summarising results and complimenting participants: to help participants feel they have spent their time well, helped each other and have learnt a lot, and at the end of each meeting, the group leader summarises what the participants have learnt. Group leaders also tell the participants how appreciative they are of all their achievements. Reducing practical barriers to participate during the intervention 1. Flexibility in time and day of meetings and adjusting meetings to holidays, Ramadan and so on. 2. Location of intervention in walking distance from participants' homes 3. Low-key intervention locations such as well-known community centres. 4. Well-known migrant health workers with long working histories as group leaders. 5. Calling participants before each meeting to make them remember the meeting and to stimulate participation. 6. Dealing with resistance/barriers to participate from significant others is a returning subject of the meetings. 7. During the meetings for significant others stimulating a significant other to participate is one of the subjects.
2. Participants experience the atmosphere in their group as pleasant and positive	Participants feel a connection with group members, expect to feel good after attending and have the feeling that their group members think it is pleasant to see each other again (outcome expectations, perceived norms, moral norms) Participants are able to maintain a positive atmosphere in their group and are able to discuss inappropriate or unpleasant behaviour by group members together by giving each other positive feedback (self-efficacy, skills, social support) Participants stimulate each other to maintain a positive atmosphere in their group	Strategies to stimulate social support and group bonding 1. Always tea and coffee present during the meetings and time to drink tea and coffee before the start of the intervention. 2. Energisers (intermezzos) during the intervention that last 5–10 min to stimulate bonding between group members. Examples: passing ball along and giving the person who receives the ball a compliment, playing 'web of life' (a game illustrating that we need each other), keeping a balloon up in the air together and so on. 3. Participants share their positive news of the week with each other to get to know each other and to be more open to new information (self-affirmation). This news could be anything, as long as it was experienced as being positive by the participant. 4. Rules for giving and receiving feedback: participants learn how to give appropriate feedback. 5. Exercising together: meant to get participants acquainted with physical activity but also to stimulate group bonding by making sure everyone mixed (opportunity to chat with person other than person next to you, interact with group leader).
3. Participants think the meetings are fun and useful	Participants think the intervention suits them, that it is important to participate and expect to benefit from participating in the intervention (outcome expectations, perceived norms, moral norms) Participants feel like they and their group members have learnt new things after each meeting and feel like participating is part of their personal development (perceived cultural norms and moral norms)	Strategies to stimulate social support and group bonding 1. Always tea and coffee present during the meetings and time to drink tea and coffee before the start of the intervention. 2. Energisers (intermezzos) during the intervention that last 5–10 min to stimulate bonding between group members. Examples: passing ball along and giving the person who receives the ball a compliment, playing 'web of life' (a game illustrating that we need each other), keeping a balloon up in the air together and so on. 3. Participants share their positive news of the week with each other to get to know each other and to be more open to new information (self-affirmation). This news could be anything, as long as it was experienced as being positive by the participant. 4. Rules for giving and receiving feedback: participants learn how to give appropriate feedback. 5. Exercising together: meant to get participants acquainted with physical activity but also to stimulate group bonding by making sure everyone mixed (opportunity to chat with person other than person next to you, interact with group leader).

Continued

Table 1 Continued

General objective	Subgoals	Intervention strategies
4. Participants trust each other and feel safe with each other	Participants expect that they can trust their group members and that they are trusted by their group members despite hindrance from their significant others (outcome expectations, perceived norms, moral norms) Participants feel confident that they can trust their group members, feel supported to exchange confident information and agree on appointments about the exchange of confident information in their group (self-efficacy, social support, social influence)	<p>Team building and human relations</p> <p>Establishing shared goals and engendering commitment: exercises in which participants had to team up together and also shared goals to achieve as a group: a cookbook, getting both diplomas (phase 1 and phase 2), walking longer and further together each meeting. Strategies to stimulate social support and group bonding</p> <p>1. Creating non-judgemental small groups: making a confidentiality pact in the group (what is discussed in this group, stays in this group), rules for giving and receiving feedback (participants learn how to give appropriated feedback) and also rules about communication in the group (letting each other finish their sentences and listening to each other).</p> <p>2. Forming coalitions/participatory problem solving: most intervention strategies included games in which the participants had to form coalitions, have group discussions or team up together to stimulate group bonding.</p> <p>3. Stimulate communication and mobilising social support: participants share their positive news of the week with each other to get to know each other and to be more open to new information (self-affirmation), and group leader regularly compliments the participants on the pleasant atmosphere.</p>

	Intervention group (n=17)	Group leaders (n=9)
Age (SD)		
Gender	60.5 (7.86)	Unknown
Female	73.3%	67%
Total household income per month		
€454–€1270	18.8%	Unknown
€1270–€1906	37.5%	
More than €1906	31.3%	
Would rather not say	12.5%	
Ethnicity		
Ethnic Dutch	47%	44.5% (n=4)
Surinamese	23.5%	11.1% (n=1)
Turkish	11.8%	22.2% (n=2)
Moroccan	11.8%	22.2% (n=2)
Other	5.9%	0%
Missing	0%	0%
Education		
No formal education/ primary education	37.6%	
Lower secondary vocational education or preparatory secondary vocational education	25%	
Profession		
Migrant health workers		55.6% (n=5)
GP assistant		22.2% (n=2)
Nurse practitioner		11.1% (n=1)
Diabetes nurse		11.1% (n=1)
How would you describe the state of your diabetes?		
Very good	33.3%	
Good	46.7%	
Okay	13.3%	
Poor		
Very poor		
HbA1c at baseline mmol/mol (SD)	60 mmol/mol (7.6% (0.63))	
Duration of diabetes in years (SD)	8.23 (6.2)	

One participant unexpectedly brought another group member to the interview.

#### Data collection

A logbook was kept of the calls made to participants following the letter from their GP. To measure the retention rate, the group leaders kept a separate logbook

in which they recorded the names of the participants (n=69) present at each meeting. The interviews with the participants (n=17) were conducted from September 2011 to January 2012 and lasted 40–60 min. To prevent memory bias, respondents were interviewed directly after the intervention ended. The interviews with the group leaders (n=9) lasted approximately 60–90 min. They were interviewed once during and once directly after the intervention.

The interviews took place in the respondents' first language either in their homes or in a community centre, if they preferred. The interviewers introduced themselves with little background information and emphasised they had no competing interest while conducting the interviews. They focused their introduction on wanting to evaluate the intervention and wanting to hear all (both positive and negative) experiences with the intervention. The interviews were audiotaped and transcribed with the respondents' consent. The interviews were conducted by CV and MJK (both researchers) with the help of an interpreter (Turkish interviews) or a Moroccan interviewer who had received training prior to the data collection. The Moroccan interviewer met the respondents before during other study procedures. The respondents met CV and MJK during the observations in the intervention. Also, CV and MJK had regular contact with the group leaders during the implementation of the intervention.

A topic guide was used during all of the interviews, and this was continually revised as new findings emerged. Relevant topics for participants included the recruitment process, experiences with the informational meeting, participation of significant others and experiences with different parts of the intervention. Relevant topics for group leaders included participants' progress during the intervention, facilitators and barriers during implementation and successful and unsuccessful elements of the intervention (see online supplementary files 1 and 2). After the interview, field notes were made to remember the setting and the impression the respondent made on the researcher.

### Analysis

Retention rate was defined as the percentage of meetings attended in phase 1 and phase 2, respectively. Missing values were regarded as meetings participants did not attend. The last meeting of each phase consisted of a celebration during which participants would receive their diplomas, and because the group leaders did not take attendance during these meetings, they were excluded from the analyses (table 3).

The interviews with participants and their group leaders were coded and analysed with MAX Qualitative Data Analysis (MAXQDA) using framework analyses.<sup>32</sup> A set of codes was developed based on previous research and the implemented intervention strategies during the intervention. After coding the interviews, these codes were grouped into categories. The interviews with the group leaders were used to check and consolidate the

**Table 3** Retention Powerful Together with Diabetes

	Retention among all participants in <i>Powerful Together with Diabetes</i> in % (n=69)	Retention among participants in qualitative substudy in % (n=17)
<b>Meetings phase 1</b>		
All 12 meetings	13.0 (n=9)	11.8 (n=2)
9–11 meetings	46.4 (n=32)	52.9 (n=9)
6–8 meetings	24.6 (n=17)	23.5 (n=4)
0–5 meetings	16.0 (n=11)	11.8 (n=2)
<b>Meetings phase 2</b>		
All 10 meetings	10.1 (n=7)	29.4 (n=5)
8–9 meetings	26.1 (n=18)	17.6 (n=3)
6–7 meetings	14.5 (n=10)	29.4 (n=5)
0–5 meetings	49.3 (n=34)	23.6 (n=4)
<b>Meetings for significant others</b>		
All 6 meetings	2.9 (n=2)	5.9 (n=1)
4–5 meetings	13.1 (n=9)	23.5 (n=4)
2–3 meetings	18.8 (n=13)	29.4 (n=5)
0–1 meeting	65.2 (n=45)	41.2 (n=7)
<b>Social network therapy sessions</b>		
Both meetings	21.7 (n=15)	29.4 (n=5)
1 meeting	17.4 (n=12)	17.7 (n=3)
None	60.9 (n=42)	52.9 (n=9)

findings that emerged from the interviews with participants through data triangulation. After determining relevant patterns in the interviews with participants, we checked if we could confirm these patterns with the interviews of the group leaders.

## RESULTS

### Study population and retention

In general, the participants (n=69) were predominantly female, were around 60 years of age and had had diabetes for a longer period of time (table 2). 56.3% had an income of €454–€1906 per month, which is considered low in the Netherlands (in comparison, the minimum wage for a two person household is €1537 per month).

In phase 1, 59.4% of the participants (n=69) were present at  $\geq 9$  meetings. In phase 2, the corresponding percentage was 36.2%. Of the participants, 16% had one or more significant others who were present at  $\geq 4$  of the relevant meetings and 39.1% of the participants were present at one or more social network meetings with one of their significant others. Although these significant others were predominantly husbands or wives (n=13), sometimes respondents invited a niece, an in-law, a daughter or a neighbour (n=5) to the intervention as

well. The respondents in the qualitative study (n=17) had higher retention in phase 2 and the meetings for significant others than the overall study population (table 3).

We describe the factors that affect recruitment of participants and their significant others, followed by the factors affecting retention according to the respondents (n=17) and the group leaders (n=9).

### Factors affecting recruitment of participants

In short, important factors that affected recruitment were the GP letter, calling of the participants, participants' attitude towards diabetes, the informal nature of the intervention and the presence of other activities organised for the target population in the neighbourhood. The informational meeting seemed to play an important role in the recruitment as well.

### The GP letter, calling of the participants, participants' attitude towards diabetes, representation of the intervention and other activities organised for the target population in the neighbourhood

After receiving a letter from their GPs, patients were called to remind them of the informational meeting. When they were called the first time (a week after receiving the letter), the majority had not yet opened or read it. During the second call (1 or 2 days before the informational meeting), most patients needed to be reminded about the meeting or had some additional questions about the location or time.

Most respondents went to the informational meeting because they had a positive attitude towards diabetes, they thought diabetes was important and wanted to know more about it. Only the Dutch respondents mentioned that they went to the informational meeting because their GP had sent them a letter. The Moroccan group leaders indicated that a letter from the GP might convince Moroccan husbands to let their wives participate.

The informal nature of the intervention also seemed to influence people's decision to participate. The Dutch group leaders said the participants had busy lives filled with family and work-related responsibilities that left almost no time for themselves. They indicated that the invitation provided participants with a legitimate excuse to get out of the house, meet other people and create time for themselves.

Finally, the Moroccan group leaders indicated that Moroccan women are more likely to participate in interventions than Moroccan men because only a limited number of activities are organised specifically for them in the neighbourhood. In contrary, Moroccan men can often choose from multiple activities and tend to be more selective and to participate for reasons other than learning about diabetes.

When you say, 'Yes, we're going to come and give a class', they say things like, 'Will there be coffee and tea? Will there be something to eat? Will we get something?' See what I mean? Because that's how

some organisations do things, and that way, you spoil the target group. (Male Moroccan group leader)

### The informational meeting

The informational meeting influenced the decision to participate as well. Most respondents enjoyed meeting the other participants and the group leader. After the informational meeting some respondents decided the intervention would be worthwhile. Other respondents and the group leaders said that the nutritional game during the informational meeting made them more curious about diabetes and nutrition.

For everyone who came to our group, it was the informational meeting that got them there—everyone actually told me that they found out that peanut butter is a healthy sandwich spread. And that was such an eye-opener. 'Well, then I should be able to learn even more.' (Dutch group leader)

According to both group leaders and participants, the informational meeting's focus on just the first phase of the intervention (3 months) encouraged participation.

I heard that too: 'If I'd known it was going to last 10 months, I never would have gone.' (Dutch group leader)

### Factors affecting recruitment of significant others

Participation by significant others in the meetings organised for them was rather low. The main factor affecting the recruitment of significant others was the willingness of participants to invite their significant others. They often did not want to burden their relatives, did not know who to invite, did not want relatives to meddle in their self-management or experienced feelings of shame which prevented them from inviting significant others.

To the extent that significant others participated, it was usually because they were asked to go.

He said, sure, I'll go. That was on Monday evening then, if there was a meeting. Yes. No, he didn't mind. (Dutch woman)

Other respondents indicated they did not ask their significant others to participate because they did not want to bother them. The group leaders had different explanations for the participants' hesitance to invite significant others: some participants had no social network and did not know who to invite, while others were hesitant to ask for help or did not want to burden their relatives. They needed extra guidance and encouragement from their group leader to do this. Further, some participants had shared so much information and intimate details about their marriages and daily lives with group members that this kept them from inviting their relatives.

They've talked so much about the group, themselves and also about their partners that they're a little hesitant to invite these people to family meetings.... You really know a lot. (Dutch group leader)



Finally, some participants were afraid their relatives would meddle with their diabetes management if they attended the family meetings. This was confirmed by the group leaders.

Because now of course they can do something from time to time and their partner won't know if it's right or wrong. But that would put an end to that. For example, there was one man who suddenly had to start going for a walk in the evening because his wife heard how good that was. Well, he didn't like it one bit that I'd said that [laughter]. (Dutch group leader)

The Turkish, Moroccan and Surinamese group leaders indicated that the participants in their groups simply did not want to have family meetings for close relatives (husbands and wives). They thought that shame might be an important factor in this. The female Turkish and male Moroccan group leaders said that especially the home visits during the intervention were a problem, which was why they decided to either have them in a community centre or not at all.

Because [when you visit them at home, ed.] everything's out in the open. And even though they know me now, it's still different [than family, ed.]. A stranger comes into your home and you see everything. How they live, their nice things and their awful things. And that can be painful. (Turkish female group leader).

### Factors affecting retention in phase 1

As indicated above, 59.4% of the participants participated in almost all of the meetings in phase 1; this was 36.2% in phase 2. The factors that affected retention seemed to change over the course of the intervention. During the first months (phase 1), retention appeared to be fostered by the atmosphere in the group (created by the intervention length, the energisers and by exercising together), the opportunity to socialise or get out of the house, experiencing the intervention as useful and having practical barriers taken into account.

#### The atmosphere in the group

All participants emphasised how pleasant the atmosphere was in their group, which kept them participating or made participation easier. They enjoyed the social contacts with group members, the exchange of information and advice and the conversations that evolved. This was also the case for the relatives who attended the family meetings. Most group leaders emphasised that they felt like they had a special connection with their group and to know their group members very well.

Well, that's the strange thing—at first I thought, wait a minute, like 24 times. But we all enjoyed it so much and had such a good time, you just don't want to miss it. So as far as that goes, I didn't think it was too long, no. (Dutch woman).

According to the group leaders, this can be explained by the length of the intervention that allowed participants to get to know each other very well and form attachments. Further, participants and group leaders often mentioned the energisers, which made the participants laugh and feel good about themselves (eg, giving each other compliments) and exercising together.

The atmosphere was really good—we were always laughing. Because they would have a CD and you'd start to move and you know how that goes, it was really funny. For example, there was a woman sitting next to me, she's over 80, and [...] she said 'I didn't do any homework at all'. And then you really had to laugh. And one person [...] we call her the 'flying goalie' [because she drives her mobility scooter so fast, ed.]. Ha ha, yes, it's a really nice group. (Surinamese woman, Dutch group)

Both respondents and group leaders said that exercising together was lots of fun and provided the participants with opportunities to chat with different people in their groups, which facilitated group bonding.

#### The opportunity to socialise or get out of the house

The intervention seemed especially attractive to people with limited social contacts. The possibility of socialising with others or getting out of the house appeared to encourage participants to attend all of the meetings. The Turkish women indicated they often feel lonely and that the intervention provided them with the opportunity to meet up with people like themselves and make new friends. According to the Dutch respondents, the intervention was an outing for them, which gave them something fun to do and somewhere to go.

I: Because you said you had to make an effort to go towards the end.... So what motivated you to keep showing up?

R: Well, to uh ... I just kept going to uh ... also because I uh, because you learned something from it. And also because you, what do you call it, well... it's hard, but... for me it was also an outing. [...] Because it got me out of the house. Because I sometimes tend to stay inside. Then you got to go somewhere. (Dutch man)

A side effect of the positive atmosphere was that the majority of respondents indicated they did not like it when other group members stopped coming. This made them feel uncomfortable and ambivalent about their own participation. The group leaders confirmed that the absence of others made it almost impossible to motivate the remaining group members to keep attending.

#### Experiencing the intervention as useful

Almost all participants indicated they learnt many new things during the intervention and that the intervention was very useful, which made them curious about other things they could learn. According to the respondents, this was also an important facilitator for the significant

others. The majority of the participants said their relatives had enjoyed learning useful new things. The group leaders also indicated that most relatives saw the intervention as an eye-opener.

My husband never says much. But what he does do is go straight for the peanut butter and also straight for the wine—wine had to be bought, peanut butter had to be bought. He didn't touch his beer. Well, that's quite something in itself, because usually my husband doesn't let himself be influenced by anything at all. (Dutch woman)

#### Having practical barriers taken into account

Other facilitators for retention were the location of the community centre and the flexibility of the group leaders. Both participants and group leaders said they appreciated that the intervention location was within walking distance, making it easy to reach without having to pay for public transportation.

Both participants and group leaders mentioned flexibility as an important facilitator for retention. The Dutch participants and group leaders were satisfied that the energisers, content and games could be adapted to their preferences, which kept them motivated. This was not mentioned in the Turkish, Moroccan or Surinamese groups.

Like when we played that game where we threw the string, those kinds of things. Then we would be like, really? It was kind of silly. We didn't think it was such a big success, not as a group either.... 'Come on, we're not in nursery school.' [laughter] Well of course, especially in the beginning, you want to be cooperative. But at a certain moment it was like, what do you think? Well, you know, we just talk it over, like we're used to doing. (Dutch woman)

The Dutch participants also complimented the group leaders on being flexible when they were delayed or unable to come to a meeting. The group leaders confirmed that they changed the time and day and also the time between meetings, to make it easier for group members to attend.

Sometimes I'm a little late, I call P. [group leader], sorry P., I'm still in the train.... Oh, no problem... see you in a bit. Things like that. Or if I had to work overtime, I'd say, well, next week you can let me know what you talked about, you can let me know (Dutch woman)

The Dutch group leaders also explained that they sometimes had to be flexible with the programme because of situations that needed special attention (eg, the death of a participant) to keep participants from dropping out.

The Dutch group leader explains how she had to deal with an argument a participant and her husband (who showed up unexpectedly at the community centre) had in front of the other group members:

R: I thought, 'Well, we're not going to be able to get around to the purpose of tonight's meeting [learning about diabetes, ed.]' I have to deal with a problem, because otherwise she's not going to come back—she [other participant] won't dare show up again and...

#### Factors affecting retention in phase 2

After the first months (phase 2), the length of the intervention meant that conflicting responsibilities as well as changes in the nature of the intervention and its planning affected retention. Calling the participants and the prospect of receiving a diploma seemed to stimulate retention.

#### Conflicting responsibilities

Both group leaders and participants said they were also very busy with other things that needed their attention (things that were unexpected or could no longer be postponed), which made it harder to keep participating in both group and family meetings. In the Dutch groups, reasons for missing numerous meetings included appointments with others or with health professionals (participants often had multiple conditions), changes in work schedules and illness (either becoming ill themselves or a spouse developing a chronic illness and needing care).

Yes, it was uh, almost a year. At a certain point it got to be a lot, because in the morning it was swimming. In the afternoon you went there to class. So, and I uh, also went to the general practitioner for my blood sugar. And you also had to go to the diabetes doctor, anyway, you had to go for your blood sugar, you had to go again and things like that. (Dutch man)

Among the Turkish men, reasons mentioned for longer absences were holidays in Turkey, changes in work schedules, problems with teenage children and going abroad to arrange a marriage. Turkish and Moroccan women mentioned wedding preparations (arranging the dowry, planning the event), the month of Ramadan (having to do a lot of cooking) and holidays in Turkey. According to the Turkish and Moroccan group leaders, it is difficult to get in touch with the participants again after the holidays. Those in the Surinamese group mentioned holidays and having to leave suddenly for Suriname to take care of relatives there.

#### Changes in the nature of the intervention and its planning

In phase 2 (meetings 14–24), the participants had to keep a diary, choose behavioural goals and make action plans which they then had to put into practice in daily life. Both group leaders and participants indicated that phase 2 was more difficult, more work and less fun. This is reflected in the much lower retention rate in phase 2, as indicated in [table 3](#). In this phase, only one-third of the participants managed to attend nearly all of the meetings. For some participants, phase 2 meant they had to change behaviour they did not want to change.

And before that of course it was, 'Oh, nice, we get to go to the meetings. We'll learn something there.'

And then they'd come home and that would be that. And, well, sure, everyone has their own lives, don't they, and taking care of the grandchildren, working, that not all of them feel like working on their goal too [in Phase 2]. (Dutch group leader)

Both group leaders and respondents from the Dutch groups said that because the meetings gradually became less frequent—going from once a week to once every 2 weeks and then to monthly—the meetings became harder to remember. When the meetings were weekly, it was easier to keep track of the day and time (because it was usually the same every week) and because there was less time between meetings, there was more regular contact with the group leader.

When participants were finding it hard to keep going to the meetings, they mentioned that getting a call from the group leader and their desire to receive both diplomas helped them to keep going.

#### Calling the participants

The Turkish, Moroccan and Surinamese women all mentioned the group leader's calls between meetings as a reason to keep participating in the intervention. This was confirmed by the leaders of the Turkish and Moroccan female groups and the Surinamese group. They said it was necessary to phone the participants between meetings throughout the entire intervention to hear how they were doing and to remind them of the upcoming meeting.

Well, you know, I thought that what you've done till now was good. And calling people, you know, and that someone reminds you that you have to come to class.... Yes, every time, K. (group leader) just did it, time after time. (Surinamese woman).

In the Dutch groups, though, the participants asked the group leaders not to call between meetings because they felt this was unnecessary. The group leaders called only when someone was absent and to provide that participant with the information they missed; participants mentioned this as being a facilitator for participation. Calling did not seem to affect retention in the Turkish and Moroccan male groups. The Moroccan group leader said that participants often did not answer their phones and that they often promised to come but then would not show up. The Turkish group leader said that when he called, participants would ask him about many other things (eg, filling out a tax form). He would remind them about the intervention, but they would often forget to come.

#### The diploma

According to the group leaders, the diploma contributed to retention. During the interviews, participants would often show their diploma or mention that they had earned it without being prompted.

They were incredibly proud of them (the diplomas). Some of them framed it and are waiting for diploma number two.... (laughter) Because there are people

in the group who've never had a diploma before in their life. (Dutch group leader)

## DISCUSSION

When recruiting people from socioeconomically deprived neighbourhoods to participate in an intensive and lengthy self-management intervention, an invitation from the GP and calling the participants after sending a letter seemed important. Recruiting significant others proved to be more difficult, because of the resistance towards their participation among the participants: they did not want to bother their significant others, had no one to invite or feared inviting them because of the personal matters they discussed during the intervention. Among Surinamese, Turkish and Moroccan participants, shame also seemed a barrier to invite significant others.

Factors influencing retention seemed to change over the course of the intervention. During the first months (phase 1), the positive atmosphere and the social contacts with group members seemed important. The intervention provided the participants with an outing or with the opportunity to socialise with people like themselves. Further, participants experienced the intervention as useful and thought it was helpful that practical barriers were taken into account and adjustable to their preferences.

After the first months (phase 2), the length of the intervention made it more difficult for the participants to balance conflicting responsibilities. In addition, the nature of the intervention and its planning changed, which might have led to decreased motivation among participants. Phase 2 of the intervention was more difficult, more work and less fun. Also, the meetings became less frequent, which made them harder to remember. Factors that helped participants overcome these difficulties were getting a call from the group leader and their desire to receive both diplomas.

#### Strengths and weaknesses

Through its use of qualitative methods, this study provides us with an exploration of factors that affect recruitment for and retention during interventions. It also explores intervention strategies that could contribute to optimising recruitment and retention when implementing a lengthy self-management intervention. However, because no Turkish men or Moroccan women were included, the results cannot be generalised to all ethnic groups in this study.

Furthermore, patients who refused to participate or dropped out of the intervention were not included in this study because of ethical and practical constraints. Including also these patients would have strengthened this study.

Though this process evaluation shows that it is possible to motivate people to participate in a lengthy intensive self-management intervention, overall participation in the intervention was relatively low. Unfortunately, we do

not know the reasons for this, but this study as well as other studies indicates that an invitation alone is not enough and that it is necessary to actively reach out to potential participants and encourage them to come.<sup>9 15 16</sup> Future studies should take an intensive recruitment period into account and try to have a large pool of potential participants, for which we did not have the means, that can be invited.

### This study in relation to other studies

The informational meeting seems to have helped convince patients to participate by showing them what they could expect, who the other group members would be and what the intervention would be like in reality. Thoolen *et al* also show that focusing on the practical exercises might make the intervention more appealing to this target population than focusing on what will be learnt.<sup>9</sup>

The pleasant atmosphere and the social interactions between group members and the group leader were important facilitators to retention. In this social network intervention, we paid a lot of attention to getting to know each other, facilitating group bonding and the exchange of social support. A previous evaluation showed that the intervention increased social support among participants.<sup>29</sup> It is likely that this social network component of the intervention, besides getting to know and understand each other, facilitated retention as well.

Other studies also report the importance of enjoying the intervention and the opportunity to participate in an activity or engage in meaningful social interactions.<sup>33–35</sup> This might also explain why the second phase of the intervention, which was more difficult, affected retention. During this phase, participants were required to do homework and were asked to change behaviour they did not want to change, which might have meant they enjoyed it less. The energisers, the length of the intervention and going on walks together contributed to the positive atmosphere and social interactions. However, those who continued to participate might also have been those with sufficient social skills to participate in a group intervention and who therefore benefitted more from these strategies.

This study shows that the decision to participate also depends on the desire to get out of the house, meet other people and do something fun and recreational. People who live in socioeconomically deprived neighbourhoods, including those from ethnic minority groups, often have busy lives with multiple social roles to fulfil.<sup>11 36</sup> Although lack of time is often reported as a barrier to participation,<sup>8 9 37</sup> this study indicates that this will not necessarily keep people from participating, and seeing the intervention as something that adds to their daily lives (something fun to do) might help people overcome this barrier. This indicates the importance of the enjoyable and social elements of health promotion programmes. When designing interventions, these should not be overlooked.

The informational meeting also seemed to facilitate participation. Other studies have shown that a lack of

awareness at the time of consent might facilitate dropout because participants are not well informed and do not fully understand what participation entails and what is being asked of them.<sup>38</sup> This meeting seemed to have increased curiosity about the intervention and to have enabled possible participants to get a clear picture of what the intervention would involve and what the other participants and the group leader would be like.

Adapting the intervention to the preferences of the participants (eg, the content of the role-playing exercises) contributed to retention, something that has also been observed in other behaviour-related interventions.<sup>35</sup> However, this was reported only by the Dutch respondents, which might have been due to the group leaders' backgrounds. Adapting the intervention while maintaining the original goals is challenging and requires a thorough knowledge of the intervention and its intended purpose. In the Dutch intervention group, the group leaders were diabetes nurses, nurse practitioners and GPs' assistants, whereas in the Turkish, Moroccan and Surinamese groups, they were migrant health workers. Migrant health workers are usually trained in group-based health education, whereas diabetes nurses, nurse practitioners and GPs' assistants have higher educational levels and may have more experience in using different strategies to help patients attain their goals. This underlines the importance of experienced staff to the success of a complex intervention like *Powerful Together with Diabetes*.

Also, monitoring participation and calling participants if they were absent or to remind them of the upcoming meeting was an effective retention strategy. We know from the interviews with the group leaders that keeping a diary or planning ahead was a challenge for the majority of participants. This could also explain the drop in retention in phase 2, where the meetings were held at less regular intervals.

Finally, this study seems to indicate that some recruitment and retention strategies were more appropriate for certain subgroups than for others. For example, a letter from the GP might convince Moroccan men to let their wives participate, while Moroccan men tended to take other events and the conditions of the intervention (will there be food, what else am I receiving) into account when deciding on their own participation. This might also be the case for the Turkish men, since both Moroccan and Turkish group leaders reported it was difficult to reach and convince participants to keep participating during the intervention and reported to be asked about a lot of other things during the intervention (eg, filling out tax forms, difficulties with raising children) that had no relation with diabetes.

The intervention seemed especially attractive for people with limited social contacts. For example, the intervention seemed to serve the needs of Turkish women, who reported a need to make new friends. On the other hand, in the Turkish, Moroccan and Surinamese groups, we encountered feelings of shame towards people's own

social network, which affected the invitation of significant others and the organisation of home visits.

Also, though we made the intervention compatible with important cultural norms and practices (eg, long holidays abroad in certain groups, month of Ramadan in Muslim groups) these still proved to be barriers to retention. For we did not take into account that these events, also need a lot of preparation, especially for the women. It therefore seems especially difficult to get in touch again with participants before and after these events. Only the Turkish and Moroccan women and the Surinamese respondents wanted to be called by the group leader throughout the whole intervention, which underlines the importance of the intensive retention strategies. Also, the Surinamese, Turkish and Moroccan groups more often reported unexpected family responsibilities as a barrier to retention (taking care of relatives abroad, arranging a marriage). These findings should be taken into account in future interventions.

In conclusion, an invitation from the GP followed by reminder calls seem necessary to motivate socioeconomically deprived patients with type 2 DM to go to an informational meeting in advance of a lengthy self-management intervention. This meeting also appears necessary to convince them to participate. Furthermore, to promote retention, it seems important that participants feel they are going on an outing to a social gathering that is enjoyable, recreational, useful and easy to attend. However, rewards and intensive personal retention strategies remain necessary throughout the entire intervention period. Recruiting significant others appears to be more challenging and seems to require the cooperation of the participants. Some recruitment and retention strategies seem more appropriate for certain groups, such as the GP letter, calling the participants, the informal nature of the intervention and practical barriers that need to be taken into account. It is important to incorporate the above-mentioned recruitment and retention strategies into the intervention design, since these strategies require more time and financial resources and create additional conditions for the layout of the intervention.

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