USING PARTICIPATION GROUPS TO IMPROVE DIABETES CARE

AUTHOR Alison Pick, MSc, BEd, is clinical audit facilitator, Lambeth PCT.


Background: The Southwark PCT diabetes patient participation groups were established in 2002 to help patients manage their condition better.

Aim: To evaluate the groups to inform their leaders so they can further develop and improve them.

Method: Several methods were used: a patient satisfaction survey; a questionnaire for healthcare professionals who run the groups; and three additional semi-structured interviews with hard-to-reach patients. A qualitative and quantitative methodological approach was used.

Results: The diabetes groups helped patients make changes to diet and exercise patterns and provided users with more information, knowledge and a social network. They received positive feedback, with 67% saying it helped them to get more out of their diabetes check-up and 62% saying it helped them manage their condition better.

Conclusion: This research demonstrated the benefits to patients from the information, learning and social validation that the groups provide. PCTs may wish to consider rolling out similar groups to patients with other long-term conditions.

BACKGROUND

The four diabetes patient participation groups in Southwark PCT in London were established in 2002 to support people with this condition. The groups’ main aims were to:

- Meet National Service Framework (NSF) (Department of Health, 2001) and other national standards;
- Signpost patients to other services and agencies;
- Encourage and empower them through peer support and partnership;
- Promote self-management and networking;
- Link patients to other organisations and groups such as the Expert Patients Programme (EPP).

In June 2006, Southwark PCT patient and public involvement (PPI) team asked me to evaluate its four diabetes groups. Discussions with the PPI team identified four main reasons for evaluating them. These were to:

- Provide evidence of good practice and areas for improvement in running the groups;
- Determine whether the groups’ aims and objectives are being met and whether they need to change;
- Make recommendations for practice to enable group leaders and patients to learn from the process, action plan for the future to maintain and improve group quality, and secure further funding;
- Support the PCT’s work towards Standards for Better Health (DH, 2004).

Aims

The project aimed to:

- Evaluate the groups to inform their leaders so they can further develop and improve the groups;
- Identify patients’ experiences of, and opinions about, participation in the groups in relation to the scheme’s effectiveness;
- To ascertain patients’ and practitioners’ views on improvements to enable the groups to play a more meaningful role in patients’ management of their condition.

METHOD

A literature search was carried out to uncover information on PPI and previous patient participation group evaluations.

Six information sources (academic databases, catalogues of academic libraries – including the King’s Fund, other healthcare sources and organisations, ‘grey’ literature, the internet and a library search by Camden PCT in London) were used to gather information on PPI and evaluations and research carried out in these areas.

The local ethics board confirmed that ethical approval was not necessary as the project was an evaluation. Southwark PCT’s Caldicott Guardian gave advice on data collection methods, access to PPI mailing lists and informed consent.

For PPI to be meaningful, Chambers (2000) argued: ‘The right tools and consultation methods must be used to involve patients and the public in planning and delivering healthcare.’ The diabetes group leaders explained the project to all patients who attended the autumn 2007 meetings. There was an opportunity for discussion and questions. In addition, the autumn edition of the PPI newsletter included an article about the evaluation.

Data collection

A literature search found that a previously designed and validated questionnaire asking the relevant questions was not currently

IMPLICATIONS FOR PRACTICE

- The diabetes patient participation groups help provide people with more knowledge, information and skills in order to manage their diabetes with greater confidence.
- The groups provide a practical approach to managing those with long-term conditions and could be rolled out for other patient groups.
- To set up similar groups, practice nurses should consider approaching their PPI lead or diabetes network lead to discuss implications for funding and administration/leadership of the groups.
- It may also be helpful to carry out a needs assessment of local practices/patients to explore whether a diabetes group would best suit patients’ needs.

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available. Therefore, after consultation with colleagues and two diabetes group leaders, the patient questionnaire was designed. It was distributed to the 624 patients on the group mailing list in November 2006. The overall response rate was 38%, with 234 questionnaires returned.

A second questionnaire plus reminder letter were sent to encourage non-responders in December, because of the low response rate. This letter asked patients to return the questionnaire only if they had not already completed one.

A separate, semi-structured questionnaire (collecting both qualitative and quantitative data) was used to ascertain group leaders' attitudes and views, and explore ways in which the groups could be improved. The response rate was 100%.

To test the reliability of data, interviews were carried out with people from group 1 who had not filled in a questionnaire. The first was a white British person (a minority ethnicity in group 1); the second an irregular group member; and the third had literacy problems. Three were chosen as it was felt this was a manageable number to interview and because users from these population groups are harder to reach. Greenhalgh et al (2005) stated: ‘The most vulnerable groups are harder to reach. Greenhalgh et al.

The questionnaire was piloted with four patients to test clarity and ease of completion. Some minor changes were recommended. As a result, two questions were slightly reworded and the font size was increased from 12 to 14 point.

The qualitative data from the patient and group leader questionnaires was analysed using Burnard’s (1991) 14-step approach. Each group leader received an individual group report showing the results of the patient questionnaire. An overall report for the four groups was also disseminated.

After the questionnaires were analysed, a meeting was held with representatives from three of the four groups. The patient findings were discussed and a detailed action plan for improving the groups was developed. This was later agreed and disseminated.

**RESULTS**

**Patient questionnaires**

The questionnaire consisted of qualitative and quantitative responses. Some questions allowed more than one response. In these cases percentages add up to over 100%.

Respondents gave a variety of reasons for not attending meetings regularly (Table 1). The principal reason was inconvenient time or day (67 responses in total). The second most frequent response was mobility problems (28). The 68 other reasons given included hospital appointments (10 people), work commitments (nine), ill health (six), and child-care commitments (three).

**Group benefits**

Approximately 70% of responses indicated the group had helped patients in different ways, including education, learning and information, medicines management and diet.

**Education and learning:** Eighteen users (8%) stated the groups were successful in sharing information. Comments included that patients felt ‘better informed about the nature of the illness’ and ‘better aware of up-to-date information on various topics’. Sharing information has led to better diabetes management. One reported having ‘learnt more about diabetes – how it can affect your life, what foods to avoid and generally how to care for yourself’.

**Medicines management:** The groups provide a forum to discuss medications. Patients were asked whether they felt they understand and manage their diabetes medicines better since attending the group. Forty-four per cent said the groups had helped them manage medication better; 14% said this was not the case (Table 2).

**Diet:** Patients were asked whether they had made any changes to their diet since attending the group. Fifty-seven per cent reported the groups had helped them change their diet, and only 10% said this had not happened (Table 3, p34). They were also asked whether the groups had helped them to eat more healthily; 65% agreed while 9% said this was not the case (Table 4, p34).

Thirty people said they would like diet and food to be discussed again at future meetings. One mentioned it would be ‘nice to know of a firm which deals with diabetic diets’ and another wanted to learn about ‘diet-weight management programmes’.

The same patient also said that ‘a discussion and information around African foods/diet’ would be helpful.

**Group democracy:** Two people said they valued the group’s democratic nature. Approximately 20% said they benefited from learning from others’ experiences; one person enjoyed ‘meeting people in my predicament and sharing experiences’.

The majority also valued sessions with visiting speakers and healthcare professionals. One commented: ‘Good speakers. Professional lectures.’

The groups appear to have an important role in helping with emotional validation. Users said they helped ‘relieve anxiety’ and ‘[the] meetings make me feel less isolated’.

**Table 1. Reasons for non-attendance**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>125</td>
</tr>
<tr>
<td>Other reasons, please state</td>
<td>68</td>
</tr>
<tr>
<td>Time is inconvenient</td>
<td>36</td>
</tr>
<tr>
<td>Day is inconvenient</td>
<td>31</td>
</tr>
<tr>
<td>I have mobility problems</td>
<td>28</td>
</tr>
<tr>
<td>Group isn’t suited to my cultural needs</td>
<td>6</td>
</tr>
<tr>
<td>Group doesn’t cater for my diabetes</td>
<td>4</td>
</tr>
</tbody>
</table>

**Table 2. Impact on medicines management**

<table>
<thead>
<tr>
<th></th>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response</td>
<td>86</td>
<td>36.5</td>
</tr>
<tr>
<td>Yes, a lot</td>
<td>51</td>
<td>22</td>
</tr>
<tr>
<td>Yes, a little</td>
<td>31</td>
<td>22</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>14</td>
</tr>
<tr>
<td>Not sure</td>
<td>13</td>
<td>5.5</td>
</tr>
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</table>
Possible improvements
These results highlight further ways in which group leaders and PPI teams can improve the meetings. Three patients said they would like to see better signposting to other organisations such as The Ramblers’ Association, exercise and fitness groups, organisations that provide employment advice and free foot-care products and advice. Over 50% wanted more information on diet. Four people also mentioned they would like a recap of the session on feet and footwear. Three said they would like more information on new developments in treating and managing diabetes. Two respondents were concerned about the groups’ administration; one said they did not receive the letter with the meeting date on time. Three said the group leader should use a microphone for amplification. For example: ‘I am hard of hearing and sometimes audio assistance is required.’ Other suggestions included making the group more interactive and using more visual aids such as DVDs.

Some respondents suggested meetings could be held in the evening or during the day and repeated later. Some said they would like more frequent meetings, and two said they should start on time.

Healthcare professional questionnaires
Six group leaders responded from the four patient participation groups. Group leaders 4, 5 and 6 all help to run the same group at one GP practice. The leaders come from a variety of roles – a PPI facilitator, an EPP coordinator, a GP senior partner and three nurse practitioners.

Group benefits
All six leaders believe the groups encouraged patients to engage in their healthcare, participate in health improvement, support change, build partnerships and promote self-management. Five leaders said the groups signpost patients to other services and agencies and help the PCT meet NSF standards and governance targets.

Group leader 5 said the groups ‘provide a forum where people can learn from each others’ experience and expertise’. Group leader 1 said users benefited from receiving ‘practice information, peer support, more in-depth information, specialist speakers and question-and-answer sessions’. Group leader 2 said people gained ‘information and self-management’ and a ‘chance to meet other patients and exchange views… lowering social isolation’. Group leader 4 said patients ‘gain confidence to ask questions and be more active in their own healthcare. They find out about activities and programmes.’

Possible improvements
Group leader 1 suggested the groups could meet more often and needed more secure funding to enable other practitioners to attend. ‘Lack of supporting healthcare professional means no one to answer questions before and after meetings and no one to respond when questions are asked that don’t fit the speaker’s area of expertise.’

Group leader 1 also said more secure funding would enable more frequent meetings and should provide training for primary healthcare professionals running the groups. This leader suggested there should be more emphasis on what people learn from sessions and how they begin changing lifestyles and implementing lessons from the groups. She also mentioned that additional warm-up exercises and ice-breakers at the start might help to put people at ease.

Three leaders said clearer medical explanations could be provided. Group leader 1 said organisers should ‘ensure the speakers arrive earlier so can start on time. Late speakers lead to a rushed agenda.’

Five leaders commented that meeting times could be changed to make them more convenient and that other solutions should be provided, including weekend and more frequent meetings. Group leader 2 said: ‘There is a demand for afternoon/daytime meetings but we do not meet the demand for evening meetings.’ She also pointed out: ‘Demand by patients for these groups has been unexpectedly high and points to a possible gap in services… They are not expensive and provide value for money.’

Five leaders said a microphone should be used at meetings, and group leader 3 said the PCT should fund a public address (PA) system.

Key themes from interviews
Interviews with the following people were carried out:
- A woman of white British ethnic origin in her 60s (this ethnic group is not widely represented in the groups);
- A man in his 60s who does not regularly attend the groups;
- A man in his late 50s who could not read or write.

I wanted to obtain the views of harder-to-reach patients to discover in more detail why people do not attend the groups and what their health benefits are. One participant said the group made a significant difference to their diabetes management. Participant 2 said it had made some difference.

- Participant 1: ‘The groups give her ‘new information and new knowledge that will help me manage my diabetes… All sorts of things are learnt at the lectures. I find them invaluable and long may they go on.’

<table>
<thead>
<tr>
<th>TABLE 3. IMPACT ON DIET</th>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, a little</td>
<td>72</td>
<td>30.5</td>
</tr>
<tr>
<td>Yes, a lot</td>
<td>62</td>
<td>26.5</td>
</tr>
<tr>
<td>No response</td>
<td>56</td>
<td>24</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>Does not apply to me</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Not sure</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>TABLE 4. IMPACT ON HEALTHY EATING</th>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, a little</td>
<td>78</td>
<td>33</td>
</tr>
<tr>
<td>Yes, a lot</td>
<td>74</td>
<td>32</td>
</tr>
<tr>
<td>No response</td>
<td>49</td>
<td>21</td>
</tr>
<tr>
<td>No, it hasn’t helped</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>I’m not sure</td>
<td>12</td>
<td>5</td>
</tr>
</tbody>
</table>
DISCUSSION
The four diabetes groups received positive evaluations. These groups add significant benefit to patients’ health and well-being. They provide education, information and knowledge about how to manage diabetes and give patients more control over their health. The findings were largely similar to two projects generally relevant to my own work.

Craig’s (2004) evaluation of patient participation groups run by GP practices in Wandsworth PCT in London aimed to improve the way GP practices are run and patient care. Patient feedback in my evaluation and Craig’s shows these groups play a valuable role in providing health promotion and healthcare information.

Brown et al’s (2006) focus group study on research priorities produced similar findings. These included the importance of providing good-quality information about diabetes, the major role of groups in promoting effective self-management, and the value of social networks with other patients with diabetes.

Recommendations
The following practical recommendations are designed to maximise the groups’ benefits and reach out to patients with diabetes who do not currently attend the groups.

The timing of meetings is the strongest message from the evaluation. It is clear that many patients are unable to attend because meetings are held during the day. Twilight and/or evening meetings should be arranged to increase attendance.

Mobility problems were a second major reason for non-attendance. Support with transport should be organised as soon as resources allow. This could take a variety of forms – informing patients about the various transport organisations for people with mobility difficulties and collaboration with local voluntary organisations providing drivers for people with disabilities.

The groups are valued for the information and support they provide on issues such as diet, exercise and foot care. These benefits could be strengthened by producing simple leaflets with guidance on these subjects.

Although Southwark PCT already has an information bank on its website, it should consider developing a more easily searchable online toolkit for patients with diabetes.

A web forum could be very useful. This would give patients (especially those who do not attend meetings) an additional voice and enable them to share information and ask questions. This could be developed in conjunction with a national organisation such as Diabetes UK (www.diabetes.org.uk).

Practical arrangements for the groups need to be improved, for example by making a PA system available.

The PPI team should find more secure funding for the scheme. This would enable more frequent meetings to be held and allow relevant healthcare professionals to undertake appropriate training courses.

CONCLUSION
This research has demonstrated the benefits to patients from the information, learning and social validation that the diabetes patient participation groups provide. The evaluation indicates that these groups could be developed and improved by small changes to the administration, better signposting to other helpful organisations and exercise groups, and by running twilight and evening sessions.

REFERENCES


