AN EVALUATION OF THE FIRST USER FORUM AT THE

PAIN RELIEF CLINIC, EAST BIRMINGHAM HOSPITAL

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Introduction

East Birmingham Hospital's first user forum was organised as part of a project to develop a patient-centred approach in the outpatient department. The assistant unit general manager (patient services and planning) was also interested in piloting the method as a way of obtaining the views of service users, and so an independent evaluation was requested.

The aim of the evaluation was to assess the value of the forum as a method for obtaining user views. For this purpose value was defined in terms of acceptability to patients, ease of organisation, and the usefulness of the information obtained from a management perspective, and from the point of view of the Community Health Council (CHC) as a consumer representative. These indicators of value were based upon an overview of the role of user feedback in the NHS (McIver and Carr-Hill, 1989; McIver, 1991). To this end, the evaluation was carried out in the following way:

1. The evaluator observed the forum as it took place.

2. After the forum finished, users were asked to complete a short questionnaire of three questions (i) What did you like most about the patient's forum today?, (ii) What did you like least about the patient's forum today?, and (iii) Given the choice, would you prefer to give your views on the health service you are receiving by taking part in: (please tick) A survey (by completing a questionnaire); A patient's forum (similar to today); I would prefer not to give my views.

3. The evaluator stayed for the de-briefing session with the facilitators and asked them for their views on the forum.

4. The outpatient department manager and other health service staff

involved were asked about the usefulness of the subsequent report produced by the CHC members who acted as facilitators.

5. The hospital management were asked to provide an action plan of what they intended to do as a result of the information collected during the user forum.

Observation

The forum was attended by 28 users and two relatives. All were treated to a buffet lunch before being divided into four groups. Three groups convened in one large room and one group in a small private room. Members of East Birmingham and Solihull CHCs acted as facilitators.

The organisation of the forum seemed to fall between two different models of group discussion. On the one hand, there is the 'focus group' as used in market research, where a group of about eight people are convened to discuss a series of issues (Goldman and McDonald, 1987; Walker, 1985). On the other hand, there is the health forum, a group of people who meet regularly to discuss local health issues (Jones, 1989; Roberts and Lee, 1990; Halford, 1988; Winn (ed), 1990).

The market research method is aimed at providing qualitative information about consumer opinions, experiences, feelings and perceptions, whilst what might be considered to be a community development approach, the forum is designed to involve consumers and citizens in planning and evaluating services. In practice in the NHS, health forums act as advisory bodies so the relationship they have with NHS management is not

that different to that of the group discussion which acts as a source of information. However, the distinction should be maintained because otherwise the potential for forums to be more, encouraging user participation and decision-making in health care, may be lost (Maxwell and Weaver, 1984; Hallett, 1987). A forum is a group of users/clients/citizens/carers etc which meets regularly and has its own agenda. A discussion group is convened by a facilitator for a particular purpose and the event is guided by a checklist of issues to be covered.

The East Birmingham user forum is much closer to the focus group model as it has met only once, with facilitators using a checklist of questions/topics. Future groups run in this way should be termed discussion groups by preference to avoid confusion with health forums existing elsewhere.

The focused group discussion is a well established method and guidelines on procedure exist. The facilitators managed extremely well in the circumstances but they are advised to read up on techniques to enable them to improve their performance, (see Goldman and McDonald, 1987; Walker, 1985, for example).

Questionnaire

Of the 30 questionnaires distributed, 29 were returned completed. The non-respondent was a woman who left early because she was in pain. In answer to the question about what was liked most about the forum, many people mentioned the opportunity to express views and listen to the

experiences of others. For example:

- "I liked the freedom of speech."

- "Having a good moan with other people in pain."

- "It was very openly discussed, and I thought that everyone listened to everyone else. In fact it was long overdue."

- "We were allowed to put our own views and opinions."

- "It was possible to discuss points in a free and easy and constructive manner."

All except one person were able to say what they liked about the forum but far fewer were able to think of something they disliked. Only ten people responded to this question with comments other than 'nothing' or a blank. Of these, three mentioned the noise from other groups, four mentioned problems with other patients 'dominating the conversation', 'whining' or being 'boring', one mentioned having to sit still for some time, another complained about being directed to the wrong place, and one complained about the fact that continuous talking is not sufficient and 'action is required'.

The majority of people present - 22 - indicated that they preferred the forum to a survey. One person ticked both survey and forum, and six people indicated that they preferred a survey. The group discussion method seems to be very acceptable from the users' point of view.

Facilitators' viewpoint

The facilitators were all members or staff from East Birmingham and

Solihull CHCs. They were concerned about the fact that hospital managers stayed and took part in the group discussions, as they felt that this may have stopped those taking part from expressing themselves fully. If this was the case, it did not come out in the questionnaires, in fact there were indications that users did not clearly distinguish between CHC members and hospital staff. For example, a few made comments such as:

- "How friendly and helpful all the staff were and a lovely lunch."
- "Friendly staff whom we felt able to talk to."

If this finding is supported by research elsewhere, it is an interesting and important one, because it implies that in the right setting users are able to give views to health service staff without feeling worried about the consequences of what they say. These users were chronic pain sufferers and so were likely to be returning to the outpatient clinic for some time to come, yet they apparently felt confident about expressing their views. This may not have extended to all comments, however, because it was mentioned that in one group a participant named a particular doctor and then 'took it back'.

Managers said they stayed for the discussions because it was a learning experience for them, both in terms of hearing the views of service users and in being in a situation with users where they were not in control. Other health authorities have found it beneficial to train and use staff to obtain feedback for the same reason, and also because it helps encourage ownership of projects amongst staff. There is the additional advantage of increasing and maintaining staff skills and the subsequent costs savings this may bring.

The issue of who best carries out user feedback work, whether direct service providers, other NHS staff or someone independent such as a CHC member, research agency or consultant, is one which needs further investigation and discussion but the answer is likely to depend upon the circumstance and the type of service user involved. For example, users of maternity services may feel more able to express their views to staff than elderly patients suffering from dementia - yet the latter may give their views more easily to those they know and feel more relaxed with than to a stranger. Some people may feel able to comment about the environment (because it is not personal) but unable to mention poor staff attitudes because of fear of retribution or being classed as 'difficult'. It is probably best to assume that users may feel intimidated by staff involvement in feedback sessions as CHC members here did, but those unable to use independent workers should not feel that this prevents them from carrying out user feedback projects. With some thought they may be able to create a non-threatening environment for users.

Facilitators also mentioned the fact that several users had hearing problems and this made the discussion very difficult for them, particularly as the room was very noisy because three groups were meeting there at once. They made the point that in future it would be important to find out if anyone had hearing difficulties at the start so that their needs could be catered to.

In one group a woman had brought a list of comments and suggestions which the facilitators thought was a very good idea. They agreed that it would be useful to ask participants at future discussions to do this.

There was some concern about what could be done with comments made about other service areas, such as inpatients, but it was clear that as the groups were not set up to collect this information, it was not collected in a systematic fashion and so was more anecdotal than the rest. Also as other managers were not involved it would be difficult to convey the information in an acceptable way.

The facilitators were very aware that although they received some training prior to the session, they learnt a considerable amount at the event itself. The technique was one which required plenty of practice. This applied to the organisation of the session as well as the discussion itself. There was some debate about the appropriateness of the length of time of the discussion and also the content of the checklist. Also the debriefing session itself was examined and the facilitators felt it was best to discuss the form of the session rather than the content, which would appear in the report.

The general view was that it was a useful exercise and they would like to start using the method regularly with different groups of service users.

Management view

The mangers present were treating the event as a learning experience, both in terms of finding out user views and also the value of the group discussion method. They were keen that the report produced by the CHC facilitators should contain as much information as possible so that those concerned with the outpatient project would be able to consider what it

was feasible to change.

A six page report was sent by the CHCs to the outpatient project manager several weeks after the forum.

Management action

Shortly after the report was sent, the outpatient project was contacted to find out views on the usefulness of the report and any decisions about future action. Staff changes were causing delays but the report had been well received and had provided a wealth of information to work with.

Approximately eight months after the users' forum, an Action Plan was received. It showed that a number of changes had already taken place and that others had been suggested to the staff members responsible. This had been achieved by circulating a list of points to those concerned and asking for (i) an indication of where future research was required to establish the real situation, (ii) suggestions for action where it was known that things could be done, and (iii) the name of the person who was willing to implement the required change.

Some of the changes implemented or in process were:
- basic counselling training for all staff;
- plasters available and used to cover needle sites;
- doctors to wear name badges or introduce themselves by name;
- patients to be made aware of the chaperone facility;
- the creation of a patient information pack;

- information about the pain clinic and its work to be conveyed to GPs;

- request for funds to improve waiting facilities;

- the development of a clinic Nurse Specialist and Group Pain Management

  programme to answer the need for information and teach techniques for

  the self-management of pain.

Conclusion

Despite the difficulties involved in running three discussion groups in

one large room, lack of knowledge about the technique, some confusion

over procedure, and staff changes, the first user forum at East

Birmingham Hospital can be said to have been successful. This is

because:

1. It was acceptable to patients, most of whom seemed to enjoy the

    occasion.

2. As an independent agency with the role of 'patients' friend' the CHC

    facilitators valued the event as a way of getting detailed

    information about user views and experiences. They found the method

    within their scope after only a small amount of training.

3. The method compares well with others in terms of ease of organisation

    and cost. A free room or rooms is needed which is not necessary

    using the survey method and this could prove difficult as it did

    here, but it had the advantage of not disrupting the working routine

    of staff in the outpatient department as the handing out of

    questionnaires often does. There may also be some difficulty in

    recruiting participants to group discussions in some service areas,

    although this was not a problem with pain clinic users. In any case,

obtaining a good response rate can also be a problem in surveys where the number of respondents is more important because the method is quantitative. A qualitative method such as the group discussion does not depend upon large numbers of respondents because its aim is to collect a range of views rather than a representative sample. Also only a small amount of training is needed to equip those who already have some interviewing skill to facilitate a group discussion. Questionnaires require detailed expertise at the design and analysis stages unless a suitable 'off the shelf' model can be obtained (see McIver, 1991 for further information about different methods of getting user views).

4. Management were able to recommend and in many cases implement changes suggested by information obtained from users during the forum.

Suggestions for future action

Those considering organising group discussions with service users may like to learn form the experience at East Birmingham Hospital and bear in mind the following points:

1. Read about the different types of group work and decide on the nature of the group in advance. Will it be a focus group or user forum?

2. Plan the different stages necessary and make it clear who is responsible for carrying out each task. This is particularly important if other agencies, such as CHCs or voluntary organisations, are involved.

3. Think especially about the final stage of disseminating information:

to staff in a way in which it can be acted upon, and also <u>feedback to</u> <u>users</u> on what the discussion achieved. This will encourage future good relations between service users and staff.

4. Consider using more than one method of obtaining feedback, not only to increase the range of information obtained and get the views of different types of user, but also in order to compare the different methods in terms of cost, ease of administration and organisation, usefulness of information obtained, ability of information obtained to suggest improvements in service quality, usefulness in raising staff awareness about issues important to users etc.

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