Resources review

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Patients, carers and staff: talking to each other to improve health-care service delivery

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Background

Involving patients and carers is the mantra used by all health-care organizations from government departments through to local health-care organizations. No mission statement is complete without it. The UK's NHS has invested significantly in patient-focused committees and there are national guidelines available which focus on implementation of programmes for public involvement,¹ as well as more detailed guidance. However, at a local level, organizations can still feel unconfident regarding how to put good intentions into practice. There may be fear, for example, that it is difficult to find the right people and secure a worthwhile outcome without committing disproportionate resources of time and money.

A recent UK government consultation exercise asking the public to state their priorities was at least an attempt to involve them in national policy. The 1997 Mass Observation² Directive, which also asked people about their health priorities, indicated that people on the whole had realistic expectations, whether as patients,

carers or tax-payers. This article describes how one local health-care organization set about addressing these issues primarily through planning and implementing a workshop, and demonstrates how involving patients and carers in service development can be worthwhile.

Introduction

In the UK, Trusts are responsible for providing a range of health services to patients. A Trust may be a single hospital providing acute services, a group of hospitals or community services provided in health centres, clinics and the home, or an ambulance service.³

South Downs Health-care NHS Trust has a Patients' Advisory Forum, which has met regularly since the Trust's formation. This group already provided an opportunity for two-way exchange of views on the Trust's community and mental health services. However, there was felt to be a need to develop this exchange to include a broader range of users and carers. In addition, it was hoped:

- feedback might be obtained from some of the front-line staff at the Trust's 80 different sites;
- voluntary organizations might be more fully involved, as a bridge between professionals and patients; and
- these voluntary organizations would be able to view the patient–professional relationship from both sides and facilitate access to patients and carers who might be interested in taking part.

Workshop

The idea was to plan a 1-day workshop for the triple base of patients, carers and health-care

staff. It took about a year to get from the initial discussion with the Trust Chair to the event itself. Once senior management was persuaded the initiative was both worthwhile and workable, the Medical Director and the Director of Corporate Governance, who is also the Complaints Manager, took an active part in making it happen. The lay member of a local primary care group (PCG) also joined the planning group. Funding was sought from the health authority, though in the end, the Trust funded the exercise in its entirety.

The main theme of the workshop was communication. This included discussions on confidentiality, patient records and complaints procedures. One issue that arose was the question of how discussion could be directed to areas of general concern, which the Trust could address, rather than the focus being on individual experiences or complaints. The planning group came up with the idea of basing discussion around a series of hypothetical scenarios, carefully devised to reflect a number of common experiences with which participants could identify. Small group discussion on these scenarios was the focal point of the day.

The size and composition of the groups proved to be a crucial part of the workshop's success. There were six groups, each of about nine and each with a facilitator, drawn in most cases from within the Trust. There were three staff members in each group, with the remainder being patients, carers and representatives from the local voluntary sector. Some present had surmounted considerable physical and other disabilities to attend (including those who were accompanied by their carers). The health-care staff that attended came from a range of disciplines, and included a telephonist, receptionists, a doctor, health visitors, a consultant psychiatrist and the Trust Chairman (see Fig. 1).

The 14 voluntary groups represented sent staff, volunteers and committee members and Chairs from a range of organizations.

Delegates	Number
Trust staff	24
Patients/Carers	17
Voluntary organisations	14
Primary Care Groups	2
TOTAL	57

Figure 1 Delegates attending the workshop.

Key messages

Essentially, four distinct themes were explored during the workshop. These were: improving communication; improving access to services; developing partnerships with professionals; and developing positive attitudes.

Improving communication

Many of the points made about improving communication were concerned with basic principles that were not always put into practice. Practical suggestions were made, such as developing 'care passports' which would include comments from patients and professionals, and using front-sheet summaries on patients' case notes. There were also suggestions as to how non-confidential information could be made available, including, perhaps surprisingly, a degree of enthusiasm for website and computerized data base solutions. The need for advocacy was given a high priority by a number of patients and carers. The communication needs of particular groups, such as those with hearing impairments, were also discussed.

Patients, carers and staff indicated a desire to have more clarity on confidentiality policies, and there seemed to be a sensitive awareness of the need to keep families and carers informed. The need for 'joined-up documentation' was recognized across different service providers, while

respecting the patient's right to privacy and confidentiality.

Improving access to services

Highlighted in the workshop was the important role of front-line staff such as telephonists and receptionists in facilitating access to services. Many were surprised to hear, for example, that there was not adequate sign-posting to the hospital, which is the Trust's main site, with the result that when people phone for directions, they had on occasions been advised to head for the racecourse! Several people also linked concerns about access to poor information provision, in the context that a lack of knowledge about what is available can impede access to appropriate care.

Powerful examples were given from patients whose access to specific services had fallen short of the ideal. For example, one person described a 2½-year wait for the right wheelchair. Since patients and carers almost invariably gave positive as well as negative feedback, including much praise for the commitment of staff, it was relatively easy for staff to heed their criticisms. The range of patients and carers present also helped identify the different access issues for people in urban and rural communities within the Trust's area.

Developing partnerships with professionals

Patients and carers were very keen to be involved as experts on their own situations and to work closely with the professionals who looked after them. They pointed out that they often had to co-ordinate complex services between hospitals and other services. Staff were generally equally keen to develop effective partnerships with patients, and many had been able to do so in the course of long relationships with their patients.

Developing positive attitudes

The importance of promoting positive attitudes was stressed by many participants. Users, carers

and staff were able to learn from each other about the ways in which caring attitudes can be demonstrated and to discuss how complaints could be dealt with or avoided. There was also useful discussion on perceived barriers to complaining when people feel vulnerable and dependent on a service provider for ongoing care.

All group members agreed that training and staff development were important contributors to positive attitudes. Training in disability awareness for staff at all levels was seen as particularly appropriate. Staff also agreed that there was a need for 'time out' to share good practice and reflect on one's work.

Discussion

Given the pressures on staff time and the considerable demands on the time and energy of patients, carers and voluntary organizations, it is important to consider whether the workshop repaid the effort that was put into making it happen. Although there was no formal evaluation of the event, informal feedback on the day was immensely positive. Many patients and carers made a point of saying that they had enjoyed the day and found it worthwhile, and staff endorsed this view. It certainly seemed worthwhile identifying the common ground and the shared priorities of the different individuals who took part. On the whole, assessments of where improvements were needed were remarkably similar, in spite of the differing roles of service users and service providers. It was also a tangible way to recognize and validate the experience and expertise of people who use the Trust's services and of staff who deliver those services.

It was particularly useful that a variety of staff at all levels and from all disciplines had this opportunity to meet and discuss issues; the inclusion of participants from outside the Trust, including local voluntary organizations and the PCG was very positive.

In financial terms, the event was relatively inexpensive considering its important function, at least compared with some other methods of involving users. The resources required were:

- input from an independent facilitator (including workshop preparation, facilitation and report-writing);
- venue (including room hire, catering and equipment);
- delegates' and carers' transport/expenses to and from the workshop;
- other costs associated with carers;
- resources (including badges, stationary, photocopying, etc.); and
- postage.

However, as many of the patients and carers indicated, the real test of the value of the day will be evident later when it is clearer what the Trust has been able to do to improve communications and service delivery as a result of the workshop. The Medical Director bravely promised to give feedback to participants within a year on progress made in addressing the issues raised.

Conclusions

There are a number of lessons for other health-care organizations wishing to try new ways of involving service users, alongside other stakeholders. The first is simply: have a go. It is not a terribly elaborate idea, but bringing people together for a defined purpose can repay the effort. Secondly, it is important to pay attention to the practicalities, such as selecting an accessible venue, arranging catering, distributing publicity and invitations, identifying resources for patients' and carers' travel expenses, and making arrangements to reimburse people on the day. (In South Downs a very efficient administrator took responsibility for many of these tasks; this contributed greatly to the smooth running of the day.)

It was also extremely helpful (and probably essential) to have ownership and support of the workshop from the top of the organization. The initial enthusiasm at non-executive level was instrumental in sparking off the idea. The continuing support of the Medical Director enabled the event to be seen as important to the whole organization. This was backed up by the attendance of the Trust Chair and Chief

Executive at the workshop itself. Since user involvement is often seen as marginal to corporate priorities (although organizational rhetoric may indicate otherwise), top-level support can do a lot to demonstrate that commitment to involving people is real. In addition to this, the involvement of an external facilitator at the workshop and at the report-writing stage was seen to add independence and helped to make this kind of workshop more credible.

Finally, this workshop confirmed what is already widely known but sometimes disbelieved: patients and carers (and staff too) are realistic and have a sophisticated grasp of some of the obstacles to change. They have a direct stake in the outcome of Trust activities, and their willingness to work co-operatively to make improvements was clearly demonstrated. Patients and carers were often passionate about the problems that arose from what they saw as inadequate resources for the health service, but they were also certain that many of their needs could be met without great additional cost.

In summary, the workshop demonstrated that it is possible to get good value out of a relatively small initiative, and to use it as an effective aid to service development. The lessons that emerged were rarely new, but there were important illustrations, from all sides, of areas where patients, carers and staff can significantly improve communication and service delivery by talking to each other.

References

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- 3 Morris C. *The Pocket Guide to the NHS in England 2001*. NHS Confederation, Birmingham, 2001.