

CLINICAL GOVERNANCE

July 2000

Bulletin

Patient experience

Editorial

Myriam Lugon¹ and Gabriel Scally²

¹Medical Director, Forest Healthcare NHS Trust, London; ²Regional Director of Public Health, NHS Executive South West, Bristol

The introduction of clinical governance into health care in the UK has already had a major impact. Health care organisations across the country are reviewing the systems they have in place to ensure that patients receive high-quality clinical care. The energy and enthusiasm that have gone into the task of producing cultural change are remarkable and, although the pattern is variable, many striking examples of good practice are becoming apparent. One of the concepts at the core of clinical governance is that of learning from experience – both good and bad. The purpose of the *Clinical Governance Bulletin* is to provide a vehicle for the sharing of experience gained in the task of improving clinical care so that others can learn from it. We also hope that it will be a source of information on what is happening in the field of clinical governance and act as a signpost to other sources of information.

For the first issue we have chosen the theme of patient experience, a subject that is of increasing importance as we seek to modernise health care systems. The way in which the public – whether users, carers or interested citizens – contribute as co-producers of health care is increasingly being seen as a test of the maturity and openness of

the NHS. We will be seeking to cover the main themes of clinical governance but not in a restrictive or compartmentalised fashion. The next issue will be on the subject of risk management and the one following on clinical effectiveness.

We would very much like to encourage you to submit contributions to the *Bulletin* or to make the suggestion to colleagues. Papers submitted should be orientated around one or more of the themes indicated on page 5. We are anxious that papers submitted should be practically orientated, of wide application and should draw out clearly the key lessons to be learnt. We wish the *Clinical Governance Bulletin* to be seen as a multi-disciplinary vehicle for the sharing of experience and would therefore wish to encourage contributions from across the clinical spectrum and, in particular, from multidisciplinary teams.

As well as your contributions aimed at sharing experience, we would also very much welcome your views on the *Bulletin* and how it can be improved and developed, so that we can achieve its primary purpose, which is to support the efforts of all those involved in implementing clinical governance in the NHS.

In this issue

- 1 Editorial
- 2 User involvement in clinical governance: good practice guidance and examples
- 3 Learning from the patient experience: evaluating service quality from the perspective of patients and carers
- 4 A method for involving users in the accreditation of cancer services
- 6 Patient experience
- 8 Assessing patient experience in partnership with a community health council
- 9 Cost-effective quality service – dementia care support
- 10 Harnessing patient involvement – the challenges in determining patient satisfaction
- 11 WhoWhatWhere?
- 11 Involving patients – an opportunity for the whole organisation



The ROYAL
SOCIETY of
MEDICINE
PRESS Limited

User involvement in clinical governance: good practice guidance and examples

Marcia Kelson

Senior Research Fellow, College of Health, St Margaret's House, 21 Old Ford Road, London E2 9PL

- **Government policy recommends that NHS organisations should involve users across the full range of their activities.**
- **There are publications available with advice on how to secure user involvement in some of the activities that underpin clinical governance.**
- **The Commission for Health Improvement has been charged with reviewing clinical governance arrangements. Patients' experience will be central to its reviews, as a key test of the effectiveness of arrangements for clinical governance.**

The Department of Health is engaged in a widespread programme of reforms to modernise the NHS, and has a commitment to building a health service that is responsive to the needs of patients and the wider public. Key policy documents invariably recommend that NHS organisations should involve users (patients, service users, carers, patients' representatives and the public) across the range of their activities, with the expectation that user involvement will become integral to their work. User involvement encompasses:

- the involvement of individuals (e.g. the central role of patients in decisions about their own health and care);
- involvement at a more collective level (representatives of patients and the public, for example, actively contributing to NHS policy and planning decisions).

Within the context of clinical governance, recent NHS guidance¹ recommends that 'clinicians, patients, users, carers and the public can come together to discuss the elements of good quality care and how to deliver it consistently and appropriately'. In developing an integrated approach to patient and public involvement, the guidance indicates that NHS organisations should:

- include user representatives on clinical governance committees or groups;
- involve users in quality improvement programmes (e.g. in all stages of the clinical audit process);
- provide training for both NHS professionals and users on effective patient and public involvement.

Publications

There are now several publications available to help those grappling with how best to secure user involvement in some of the activities that underpin clinical governance.

*Developing Effective User Involvement Strategies*²

This booklet discusses why user involvement is important, whom it may be appropriate to involve, different aims and objectives for user involvement, and organisational factors that contribute to developing effective user involvement strategies. The booklet also includes 'do's and don't's and checklists to help organisations evaluate existing user involvement activities.

*Patient Involvement in Clinical Audit*³

This booklet emphasises the need to encourage active patient input into all stages of the audit process (e.g. selecting audit topics, setting criteria and standards, monitoring treatment and care, disseminating findings and implementing change). The booklet provides practical, real examples to show how different methods have been used by NHS organisations to involve patients actively in clinical audit and related activities.

*Involving Older People in Local Clinical Audit*⁴

Linked to national sentinel audits, the focus of this booklet is on securing more active participation by older people in audit. Older people

are a very heterogeneous group, so that levels of involvement suitable for some subgroups of older people will not be appropriate or feasible for others. The booklet considers how to engage the views of as wide a range of older people as possible, including:

- frail older people
- older people from black and ethnic minorities
- older people with physical, sensory or communication problems
- older people with dementia
- older people with learning disabilities
- older people with mental health problems
- carers of older people

*Public Involvement*⁵

This manual draws on the practical experiences of three South Thames health authorities. The second edition, updated to address public involvement issues relating to new initiatives, including clinical governance, health improvement zones, primary care groups and health action zones, focuses on:

- national policy
- planning and choosing the right methods for public involvement
- the pros and cons of various public involvement approaches

Commission for Health Improvement

The Commission for Health Improvement (CHI) has been charged with reviewing clinical governance arrangements in all NHS trusts, health authorities, primary care trusts and special health authorities and is currently developing the framework for its review methods. In judging performance, patients' experience will be central to CHI reviews, based on the rationale that it provides one of the key tests of effectiveness of the management arrangements for clinical governance. As well as looking at what

actually happens to patients, CHI reviews will examine patients' and carers' views and comments. It is hoped that the resources described above may be helpful for local NHS organisations keen to secure increasingly effective user input to their own clinical governance arrangements and to help prepare for forthcoming CHI reviews.

References

1 Department of Health. *Patient and Public Involvement in the New NHS*. Wetherby: Department of Health, 1999

- 2 Kelson M. *User Involvement: A Guide to Developing Effective User Involvement Strategies in the NHS*. London: College of Health, 1997
- 3 Kelson M. *Promoting Patient Involvement in Clinical Audit: Practical Guidance on Achieving Effective Involvement*. London: College of Health, 1998
- 4 Kelson M. *National Sentinel Audits Involving Older People: A Guide to Involving Older People in Local Clinical Audit Activity*. London: College of Health; Oxford: RCN Institute, 1999
- 5 Barker J, Bullen M, de Vile J. *Reference Manual for Public Involvement*. 2nd edn. Bromley: Bromley Health, 1999

Clinical Governance Bulletin
© 2000 The Royal Society of Medicine Press Limited. Apart from any fair dealing for the purposes of research or private study, or criticism or review, as permitted under the UK Copyright, Designs and Patents Act, 1988, no part of this publication may be reproduced, stored, or transmitted, in any form or by any means, without the prior permission in writing of the publishers.

Learning from the patient experience: evaluating service quality from the perspective of patients and carers

Margaret Tozer

Chief Officer, North West Anglia Community Health Council, 6 Post Office Lane, Wisbech, Cambridgeshire PE13 1HG (currently on secondment to the Commission for Health Improvement)

- A lack of information and communication reinforces low expectations of the NHS. This is reflected in anxieties about waiting times and a perception that individual needs are not recognised, such as support for carers and choices for people with mental health problems.
- Patients wish to be actively involved in decisions about treatment and care, including discussions about the alternatives available to them.
- It is important not to make assumptions about people and to respect them for their own self-knowledge and their wish to maintain independence, especially for people with a disability.

It is well recognised that many failures in service quality are due to complicated or inappropriate systems, rather than people making mistakes. Ovretveit¹, in reviewing health service quality, also suggested that for quality to become a reality in the NHS, three interrelated areas must be addressed:

- client quality
- professional quality
- management quality

These views concord with the philosophy of the Commission for Health Improvement (CHI), which will review the way clinical teams work together to care for their patients and the policies and management arrangements in place to support clinical teams in providing effective care. Central to CHI work will be the patient experience.

Understanding the patient experience

Understanding what is important to patients and carers, and the patient experience, can be achieved using a variety of methods. An enormous amount of literature is available describing which techniques are appropriate to the aims of the study of patient experience²⁻⁴.

The following describes personal experience of such a study, involving work with members of a community health council (CHC) using:

- questionnaire surveys
- in-depth interviews
- observation
- focus groups

The aim of the study was to evaluate information and communication between staff and

patients and their carers – an issue of concern documented since 1966⁵.

Questionnaire surveys provide standard data that are easy to count and summarise but are usually most effective when the questionnaire focuses on areas of concern previously identified by patients or their carers.

Questionnaire surveys have identified two particularly important points:

- understanding the purpose of the consultation helps patients and their families feel more in control and to contribute to decisions about treatment and care;
- written information supports discussion between clinical staff and patients, for example regarding what to do in the first months following an operation.

Research has shown that while the majority of respondents to surveys express satisfaction with their care, those same patients will express criticism, when asked, about more specific aspects of their care. Thus, unless validated, a questionnaire may provide an inaccurate picture.

These difficulties may be overcome by the use of one-to-one *in-depth interviews*, in which open

questions allow people to discuss what is important to them. This method has been successfully used by the CHC in combination with *observation*, a 'fly on the wall' technique to observe the delivery of care in an outpatient department.

Interviews highlighted that:

- waiting created anxiety and a reluctance to organise other aspects of life in case a call came to go into hospital;
- accurate information about treatment and care – oral communication supported by written information – reduces anxiety and helps make the patient feel more in control;
- respecting and valuing the views and feelings of health service users is vital, especially those living with a long-term chronic illness or disability, who may understand their condition better than the clinician.

Observation identified that:

- poor signing resulted in patients and visitors losing their way and returning to the receptionist to clarify directions;
- volunteers, although available to assist patients and visitors in finding their way, were not easily identifiable;
- the way in which seating was arranged in the outpatient department meant it was possible in some areas to overhear conversations between doctors and patients – something which it

was subsequently discovered patients were aware of and this constrained questions and discussion about diagnosis, treatment and care.

Some people, however, are reluctant to express a view individually and may feel more comfortable doing so within a group. People feel empowered in groups to express needs and opinions they would not feel able to express as individuals. In these circumstances *focus groups* involving 6–12 people who share a common experience are appropriate. Although the use of focus groups in the CHC work aimed to inform the planning and development of services, specific issues about information and communication were identified.

Focus groups with older people highlighted:

- inadequate information and discussion with carers in relation to discharge arrangements – this resulted in little acknowledgement of the needs of carers, such as poor provision of respite care, which carers felt should be an integral part of a care plan;
- a fear of being refused treatment on the basis of age;
- frustration at being labelled 'old' through the organisation of wards, such as wards designated for the over-65s, where older people were admitted for acute episodes of illness but were otherwise normally well.

Focus groups for people with mental health problems highlighted:

- a preference for counselling and talking therapies;
- frustration with the early use of medication and feelings that treatments were not fully discussed with the patient;
- the need for a single point of reference for information (for both patients and families), including access to someone out-of-hours who understood individual needs – that is, 24-hour crisis support.

Conclusions

The methods described above enable organisations to validate research undertaken elsewhere. The work described revealed that information and communication remained important aspects of quality and issues relevant to local people.

References

- 1 Ovretveit J. *Health Service Quality*. Oxford: Blackwell, 1992
- 2 College of Health. *Consumer Audit Guidelines*. London: College of Health, 1992
- 3 Bowling A. *Research Methods in Health. Investigating Health and Health Services*. Buckingham: Open University Press, 1997
- 4 Krueger RA. *Focus Groups: A Practical Guide for Applied Research*. London: Sage, 1995
- 5 McIver S. *Obtaining Views of Health Services Users About Quality of Information*. London: King's Fund Centre, 1993

A method for involving users in the accreditation of cancer services

Nicola Coe¹, Mary Barnes² and Jo Purvis³

¹Health and Health Care Evaluation Manager, Somerset Health Authority, Wellsprings Road, Taunton, Somerset TA2 7PQ, email nicola.coe@staff.somerset-ha.swest.nhs.uk; ²Cancer Development Manager, Avon, Somerset and Wiltshire Cancer Services, Bristol; ³Communications Manager, Somerset Health Authority, Taunton, Somerset

- The use of separate focus groups specific to different tumour sites is a good method of eliciting user views of services.
- User involvement is an important component in the accreditation of cancer services.
- It is important to enlist the support of doctors and managers

in hospitals and primary care so they welcome the survey and are committed to improving services for patients.

The 1995 Calman Hine report, *A Policy Framework for Commissioning Cancer Services*, stated as one of its general principles that the develop-

ment of cancer services should be patient centred and should take account of the views and preferences of patients' families and carers, as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication

Contributions

Clinical Governance Bulletin is a bi-monthly publication for clinicians and managers working in trusts, health authorities and PCGs and aims to communicate practical examples, pool shared experience and highlight and disseminate best practice on a broad range of issues in health management. Themed issues will address:

- Patient experience
- Clinical effectiveness
- Resource effectiveness
- Communication
- Risk management
- Effective teamwork and learning
- Strategic effectiveness
- Clinical information

Contributions that are practical and relevant to everyday practice are welcomed. They should be 500–800 words in length, with a maximum of five references in Vancouver (numerical) style. Please send your contribution, by post (with floppy disk) or email, to one of the Editors:

Dr Myriam Lugon, Medical Director, Forest Healthcare NHS Trust,
Whipps Cross Road, Leytonstone, London E11 1NR
(tel. 020 8535 6912, fax 020 8535 6931, email MLugon@compuserve.com)

Dr Gabriel Scally, Regional Director of Public Health, NHS Executive South West, Westward House, Lime Kiln Close, Stoke Gifford, Bristol BS34 8SR
(tel. 0117 984 1810, fax. 0117 984 1841, email gscally@doh.gov.uk)

between professionals and patients is required.

User involvement has become increasingly important in the evaluation of the quality of health services and other researchers have investigated specific aspects of the quality of care received by cancer patients.

Most often, general user satisfaction (or dissatisfaction) has been evaluated by means of self-completed questionnaires, although it has been argued that these methods tend to underestimate the level of dissatisfaction. A focus group method has become increasingly popular, especially in evaluations of mental health services.

Since 1997 Somerset Health Authority has been undertaking a series of reviews of its main cancer sites. The reviews were initiated in order to identify areas where improvements for service users could be made.

The involvement of patients (and carers) is considered integral to the accreditation process in Avon, Somerset and Wiltshire, and for colorectal and gynaecological cancers has followed the method described in this paper.

Method

Involving the trusts

Initially, only the two NHS trusts in Somerset were involved in obtaining

the views of users of the colorectal cancer service, although it still informed accreditation of colorectal cancer services in Avon and Wiltshire. However, as the method proved to be of great value, not only to feed into the accreditation process but also for the trusts involved, it was decided to extend the consultation to the other two counties in the collaborative group (i.e. Avon and Wiltshire).

To enable users of gynaecological cancer services from all areas to have an opportunity to contribute and given limited resources, a sample of the trusts was selected. One trust was chosen at random from Somerset and Wiltshire and two from Avon, because of its larger population. The trusts selected were: United Bristol Healthcare NHS Trust (St Michael's Hospital), Royal United Hospital Bath NHS Trust, Salisbury Healthcare NHS Trust, and Taunton and Somerset NHS Trust.

Approval was sought and received from the local research ethics committees covering these areas.

Obtaining a sampling frame

The name, address and diagnostic details of all patients who had been diagnosed with a form of gynaecological cancer between 1997 and 1998 were obtained through the Regional Cancer Organisation and the Regional Cancer Registry. A total of 100 names were then randomly selected to allow for

refusal, by the patient, consultant or the GP.

Patient and practitioner services in Avon, Somerset and Wiltshire health authorities were contacted to find out which practice the patient was registered with. The senior partner at each relevant practice was written to with details of the study and a proposed list of patient contacts. Practices were then telephoned to ensure that there were no reasons why the selected patients should not be contacted.

Gynaecological cancer lead clinicians from the four trusts were sent a list of their patients and requested to write to them individually, if the consultant thought it appropriate to do so, explaining the study and enclosing a reply form to be returned to the health authority if that patient was happy to take part. The number of patients in the original sample was reduced at this stage owing to those considered very elderly or unwell being removed.

In total, 27 women (all service users) responded to the questionnaire and 23 women were able to take part in an independently facilitated group or individual interview. Fifteen women had been diagnosed with endometrial cancer, six with ovarian cancer and two with cervical cancer.

Collecting the data

A topic guide was developed through a series of briefings with key personnel working in cancer services. The briefings informed the research team about typical pathways in cancer care, the types of investigative and surgical procedures performed, what happened following discharge, follow-up therapy such as chemotherapy or radiotherapy and what may have happened to the patient throughout this process.

Each woman who had responded was contacted and a series of local focus groups arranged. Most were able to attend one close to the trust at which they had received most of their care. Some were unable or too unwell to attend a group, although still wished to participate. Individual interviews were set up for these women.

The groups and individual interviews were arranged at times convenient to the participants. An independent facilitator moderated the groups and interviews, each lasting about an hour.

Analysis

The discussions that took place within the groups and at the interviews were tape recorded and transcribed. A summative analysis was reported as stages of the pathway (e.g. first symptoms, getting referred, diagnostic tests, breaking bad news, etc.). Quotations from the transcripts were annotated with the trust from which the patient received her care. This was useful specifically to the individual trusts, although no comparative analysis between trusts was made.

Integration of user views into the accreditation process

The report from the user consultation was presented to external assessors and an expert panel made up of lead clinicians, GPs, the community health council, Cancer Intelligence and senior managers from trusts and health authorities. The external assessors had an opportunity to meet some of the women who had taken part to discuss the results, which enabled them to focus on the patient perspective during the accreditation visits to the trusts. The final report was also distributed to all general practices in the three areas.

Discussion

This method of involving users in evaluating the quality of the care

given to cancer patients has been very effective for a number of reasons.

The trusts involved were interested in the results and how their services could be improved. The results affected the recommendations made by the accreditation team during the reviews of colorectal cancer services and are expected similarly to affect gynaecology services. The following recommendations from the report have been acted upon:

- improvements in information;
- specialist nurses available at the time of diagnosis to offer ongoing support and counselling;
- a reduction in waiting times;
- better liaison between the trusts and primary care;
- improved facilities within the trusts for patients receiving treatment.

There has also been a commitment by health authorities to encourage patients to present earlier with symptoms that might suggest colorectal cancer. This will make a difference to future users.

In many ways, it also seemed that the discussions were of benefit not only for the purpose of accreditation but also for the users who took part, many of whom said they had found

the experience interesting and therapeutic; they were often able to speak for the first time about their experiences of the health services they had received, although this had not been an original aim of the study.

There were a number of elements of the method used that were of benefit in ensuring that the study ran smoothly:

- it was important that the consultants within the trusts were supportive of the process and willing to endorse the value of taking part by sending invitations to participate to their patients;
- it was also important that key managers were committed to improving services and welcomed the results, even when critical, as an opportunity to make a difference to the care of their patients;
- the flexibility of arrangements for the groups was also important and ensured that every effort was made to talk to those patients who wanted to be involved.

It is planned to continue the use of this method, with the possibility of extending the process to allow a trust-sensitive report to be produced to benefit both the accreditation process and the individual trust.

Patient experience

Kieran Sweeney

Lecturer in General Practice and Health Services Research, School of Postgraduate Medicine and Health Sciences, 1st Floor, Noy Scott House, Haldon View Terrace, Wonford, Exeter EX2 5EQ

- 'The public' can be considered at various levels in health care: at the macro level, the community level (for a trust), the local level (for a general practice) and finally at the individual level (for clinicians) – this helps us choose the most appropriate method for engaging with them.
- There are good examples in the literature of how the public can contribute to the health care debate. In general the public response depends on the way in which they are engaged.
- The individual consultation is often overlooked as the most frequently used mechanism for

engaging the public in the form of the patient. Doctors and nurses engage the public every working day in this way.

- There is increasing interest in asking the public to comment on health care professionals' interpersonal skills in consultations, using a robust instrument (the DISQ).

Clinical governance is at the heart of the new NHS. Quality and accountability are its enduring features, and the statutory responsibility on all health care professionals to be involved in a quality agenda will ensure that

clinical governance is not a passing whim. Patients come top of the quality agenda. Being accountable to them, listening to them, consulting them and involving them in the development of quality initiatives are defining features of this sea change in NHS policy. Of course, this sounds appealing: we are all in favour of motherhood and apple pie. But how do we do it? What does listening to the public entail? How can patients' views be captured, evaluated and incorporated into a quality agenda?

Patients are the public. Patients are local citizens, the general practitioner's registered population.

Patients are you and I – unique, private individuals. Thinking about ‘patients’ from the macro to the micro level helps define the most productive ways of capturing their elusive but richly informative views.

The first national survey of NHS patients is the most obvious recent example of public consultation at the macro level. A 20-page questionnaire was posted unsolicited to a large cross-section of people, who were asked to give their views on a range of questions about general practice. The survey was able to demonstrate that these views differed as a function of age, sex and to some extent ethnic background.

The media can consult the public at large, too: last year a local newspaper conducted a survey of citizens’ views on how health care problems in their city were caused and should be tackled¹. The views of the public can be elicited through user, support, participation or voluntary groups. For example, Jones *et al.*² interviewed carers of patients who died from cancer at home and showed that many did not know how to access sources of financial help or gain assistance from the many charities concerned. During the early 1990s, patient participation groups flourished within many single general practices while, more recently, community health councils were widely consulted for their views on service planning by the primary care commissioning pilots³. Citizens’ juries, developed initially to research political issues in the USA and Germany, are now increasingly used in debates about health care services. Here, groups of citizens discuss complex health care problems using written and verbal evidence from experts before issuing a report. Citizens’ juries can be expensive – up to £30,000 a time – and problems with this method have not been completely cleared up⁴.

A recent study based in the south-west of England showed that citizens, when consulted about the Health of the Nation (HoN) project, contributed ideas that matched those of an expert panel convened as part of the HoN project, and went beyond the panel’s contribution by offering further practical suggestions about achieving the HoN targets⁵. An excellent review of the research around public involvement has recently been published by Ruth Chambers⁶.

But the public is simply the collective term for a number of

individual, unique persons. At the centre of the patient experience is the individual narrative, the personal account of the destructive effects of illness on what Eric Cassell⁷ calls the individual’s personhood, and the description of the acute sense of alienation that accompanies being sick. In order to gain access to these stories, to establish their trustworthiness and to begin to learn from them, the health care professional has to tread carefully into the relatively uncharted waters of postmodernism⁸. The pursuit of this knowledge involves a paradigm shift and, because people’s views, beliefs and experiences are being sought, a qualitative approach. Despite a growing acceptance of this approach, and increasingly rigorous attempts to refine methodology, the enquirer will still find many doctors, nurses and managers hesitating, educated as they are in the positivist tradition of the biomedical sciences. ‘Narrative-based medicine’ is the term now used to describe this approach to understanding the illness experience⁹. Patients’ stories – or any story for that matter – are important because they assume the teller and the listener (a refreshing recasting of the patient and doctor) are connected in the pursuit of shared understanding, and because they emphasise authenticity, uniqueness and above all context.

Engaging with the public in the form of the individual patient is an exacting task, requiring finely tuned interpersonal skills, which can now be robustly evaluated by the public using the Doctors’ Interpersonal Skills Questionnaire (DISQ). Developed from a database of 30,000

patients’ assessments of 600 doctors, the DISQ has high content, construct and criterion validity¹⁰. It is increasingly being used throughout the UK as part of the drive to engage the public using primary care.

Consulting the public in individual consultations is not just the esoteric pursuit of the health services researcher: stories are told to doctors and nurses every day of the week in routine consultations. If we really want to engage the public, then there is no better place to start.

References

- 1 Chambers R, Jacobs B, Schrijver E. *Stoke-on-Trent City Population Survey*. School of Health, Staffordshire University, Stafford, 1991
- 2 Jones RVH, Hansford J, Fiske J. Death from cancer at home: the carers’ perspective. *British Medical Journal* 1993; **306**:249–51
- 3 Popay J, Williams G, eds. *Researching the People’s Health*. London: Routledge, 1998
- 4 McIver S. *Healthy Debate? An Independent Evaluation of Citizens’ Juries in Health Settings*. London: King’s Fund, 1998
- 5 Bradley N, Sweeney KG, Waterfield M. The health of their nation: how would citizens develop England’s health strategy? *British Journal of General Practice* 1999; **49**: 801–5
- 6 Chambers R. *Involving Patients and the Public*. Oxford: Radcliffe Medical Press, 2000
- 7 Cassell E. *The Nature of Suffering and the Goals of Medicine*. New York: Oxford University Press, 1991
- 8 Muir Gray JA. Postmodern medicine. *Lancet* 1999; **354**:1550–3
- 9 Greco M, Cavanagh M, Brownlea A, McGovern J. The Doctors’ Interpersonal Skills Questionnaire (DISQ). *Education for General Practice* 1999; **10**:256–64
- 10 Greenhalgh T, Hurwitz B. *Narrative Based Medicine*. London: BMJ Books, 1998

Editorial Committee

Editors

- **Myriam Lugon**, Medical Director, Forest Healthcare NHS Trust, London
- **Gabriel Scally**, Regional Director of Public Health, NHS Executive South West, Bristol

Other members

- **Aidan Halligan**, Director of Clinical Governance for the NHS, Leicester
- **Rosemary Hittinger**, Clinical Governance Manager, St Mary’s Hospital, London
- **Susanna Nicholls**, Researcher, NHS Clinical Governance Support Team, Leicester
- **Steve O’Neill**, Communications Manager, NHS Clinical Governance Support Team, Leicester
- **Jonathan Secker-Walker**, Senior Lecturer, Department of Clinical Governance, University of Wales College of Medicine, Cardiff
- **Kieran Sweeney**, Lecturer in General Practice, University of Exeter

Assessing patient experience in partnership with a community health council

Anne Wadey

Patient Affairs Coordinator, Patient and GP Bureau, St Mary's NHS Trust, Praed Street, London W2 1NY

- It is valuable to engage in cooperative working with external agencies to access users' views.
- Patients' needs for information should be assessed individually.
- Trusts should confirm whether their assessments of problem areas match those identified by users.

St Mary's NHS Trust provides health care to a local community in central and west London of approximately 338,000 residents and tertiary services to a much wider area. Twenty-three per cent of the local population are black or from other ethnic minorities.

The trust has a strong tradition of user involvement, headed up by its Patient and GP Bureau, which has won a Chartermark. Recently a study of users' views of breast care services at St Mary's was commissioned in partnership with the Kensington, Chelsea and Westminster Community Health Council. The study was carried out by the College of Health, a London-based charitable body founded in 1983 to represent the interests of patients and to promote patient-centred care. It actively develops research techniques to elicit users' views of health services, known as consumer audit.

St Mary's has two surgical consultants providing specialist breast care services, including one-stop clinics. Oncology consultants can provide on-site chemotherapy, but the trust works with the Hammersmith and the Middlesex Hospitals for the provision of radiotherapy. A specialist breast care nurse supports the clinics together with a dedicated clinic coordinator.

The study involved a focus group of eight women with a diagnosis of malignant breast disease and a telephone interview of a further eight patients who had benign breast problems. All patients had received treatment within the last three years and most came from higher socio-economic groups. Only one of the malignant group was of non-white ethnic origin whereas 25% of the

benign group were from black ethnic groups.

The researchers' findings are summarised under separate headings, below.

Communication

Overall, the report¹ was positive about the breast care service itself, with concerns voiced more about general aspects of the hospital's care. It was particularly encouraging to find consultants praised for their communication skills in terms of ability to put patients at their ease, answer questions accurately and honestly, and give people the time they needed to take on board the information given. In general, participants thought that the whole breast care service was efficient and well organised. An audit of waiting times for first appointments was recommended – this is already being carried out. The system of notifying patients of benign test results is also being revised, as patients frequently did not telephone on the times and dates they were requested to do so.

Not all patients felt they had been given all the written information they needed and it was felt there was a greater need to tailor the information given to the expressed needs of individual patients. Some had found information on breast cancer too much to cope with immediately after diagnosis, but some patients would have appreciated more information about what to expect earlier in the process, for example at the time of referral by their general practitioner. Most patients felt they had been given enough information to enable them to make informed choices.

Choice

Most patients were given adequate time to make choices between treatment options, although patients with benign disease were less likely to be given a choice. Reconstructive surgery was offered at the same time as mastectomy and this was thought

to be an appropriate time. However, patients who declined the recommended course of treatment reported more ambivalent reactions to them from staff.

Support

Patients expressed appreciation of the policy of encouraging them to bring a relative or friend to the consultation. It increased the effectiveness of the consultation to have someone else who could ask questions at a time when the patient might be too shocked to do so. Those who had not brought someone with them regretted being alone. This was less of an issue for the group with benign disease.

The majority of patients who had contact with the breast care nurse were highly appreciative of her support in clinics, during admission and after discharge. This included emotional and practical support. Because there is currently only one breast care nurse, her efforts are concentrated on the patients with a diagnosis of cancer.

Patients in both groups would have appreciated contact with other patients with a similar diagnosis to themselves. There is a support group for breast cancer patients but not for those with benign disease.

Concerns

Patients did express a number of concerns, mainly relating to inpatient stays. Shortages of beds and nurses were seen as being the cause of a number of problems, such as accessing analgesia when needed or assistance with personal hygiene. Concerns expressed about discharge arrangements should be alleviated in the very near future with the appointment of discharge liaison nurses for the wards.

Response to the report

A formal response to the study was yet to be given at the time of writing.

A question mark remains over more controversial aspects, such as how much information it is appropriate for an NHS trust to give about unproven alternative therapies.

Such problems as were found are generally already known to the trust and being formally addressed, such as written information for patients with

benign breast disease, and standards of ward hygiene provided by the contracted service.

Reference

- 1 Kennelly C, Bradburn J. *Patient Views of Breast Care Services at St Mary's NHS Hospital Trust*. College of Health (St Margaret's House, 21 Old Ford, London E2 9PL), 2000

Cost-effective quality service – dementia care support

Jane Winter

Planning and Service Development Manager, Social Services Department, London Borough of Waltham Forest, 313 Billet Road, Walthamstow, London E17 5PX, email JaneWinter@breathemail.net

- The design of a service must include carers if their needs are to be met.
- Carers and users, where possible, should be involved in the matching of support workers to them.
- Continuity of support worker is necessary to build effective relationships with the carer, the user, and their family and friends.
- Supervision of the support worker should facilitate the development of this 'special relationship', which goes beyond normal boundaries.
- The provision of a flexible, person-centred service can help carers to continue caring for longer and delay institutionalisation.

Why was the service developed?

In 1990 the Health Advisory Service and the Social Services Inspectorate conducted a joint review of services for mentally ill people and elderly people in the health district. The final report contained highly critical comments from 'support organisations', which described 'an appalling lack of support both for sufferers and carers. Carers were trapped in the house for very long periods of time with inadequate community support'¹.

In response, the health authority invited MIND, Crossroads and the Alzheimer's Disease Society to meet with practitioners and design a service that would continue to care for relatives. Carers wanted short breaks during the day, uninterrupted sleep once or twice a week and some of the caring tasks shared.

This partnership became a steering group to set up the service and then to oversee its management.

How does the service meet users' and carers' needs?

The carers emphasised throughout the importance of continuity of support worker and involvement in the initial 'matching process' of the support worker to the user. The carer discussed the kind of person that would be most acceptable, with the service manager, as part of the assessment process.

The service ran as a two-year project initially, which was evaluated by the health authority's psychology department. The steering group also helped design this evaluation².

The main findings of the study clearly indicated that families in receipt of the dementia support service were able to support their dependent relative with dementia for a significantly longer than other 'matched case controls', who received traditional domiciliary services (home care, home help and meals-on-wheels).

Support workers provide up to 15 hours weekly to carers and in that time, apart from providing help with personal and practical tasks, they also work hard to establish and maintain relationships, provide stimulation to maximise patients' skills and abilities, draw up individualised, person-centred programmes using reminiscence and reality-orientation programmes, and validation as means of communica-

tion and offer 'after service' support to carers following bereavement or admission to residential care.

The head of psychology prepared training materials based on the work of David Brandon and Wolf Wolfensberger to prepare the support workers for their new role initially, and this training has been repeated as the service expanded and was brought up to date from literature searches, including by the support workers themselves.

Carers are surveyed for satisfaction every two years and 90–95% record that they are satisfied. The particular value for black and ethnic minority families is the one-to-one style and matched support workers, so that real needs can be met. Carers comment on how the service has made a significant difference to the person with dementia. The stimulation and companionship were highly valued. One carer said 'the service brings happiness to my mother ... she is taken out, talks, laughs and has friendship'.

Over 300 referrals were received in two years. Seventy-nine carers currently receive a service for people aged 45–95. Personal histories are very important and support workers recognise this, basing their approach on getting to know the person with dementia and adjusting their care as they go, rather than having set expectations.

The ongoing influence of users and carers

- People are involved in decisions that affect them.
- Staff receive ongoing support and training to equip them with the skills to negotiate.
- Staff have small caseloads to ensure quality and flexibility are offered to carers.
- From the relationship established, difficult days can be eased with resolution therapy and validation, and the person should be settled far quicker than would be the case with a less familiar support worker.
- Such techniques are taught to other involved staff and carers so that the reassurance is consistent and when a person becomes distressed, tried and tested ways can be used to defuse the situation.
- Advocacy is used where appropriate (e.g. when attending GP appointments and reviews), using entrusted information to

assist the user to have the very best services available and to empower users to prolong their social skills and make decisions for themselves.

- The service is being developed, for example with the appointment of a carer support and development worker, providing an advice and information service mainly by telephone and letter, running workshops for carers, and holding carers' drop-in meetings.
- Users and carers have representation on the Care Planning Group for Older People

and its subgroup considering the elderly mentally ill, where regular reports on activity are monitored and gaps in services debated, leading to service developments. These groups have input to the Joint Investment Plans, contributing 'objectives' to ensure the users' and carers' voices are heard.

What has not worked well?

- It is difficult to sustain the level of involvement from carers and their organisations after the service has been established.

- The involvement of carers in the matching of staff could have been formalised, with participation in the recruitment process.

References

- 1 National Health Service Health Advisory Service, Department of Health Social Services Inspectorate. *Report on Services for Mentally Ill People and Elderly People in the Waltham Forest Health District*. HAS/SSI(90)MIE.5. June 1990
- 2 Riordan JM, Bennett AV. An evaluation of an augmented domiciliary service to older people with dementia and their carers. *Aging and Mental Health* 1998;2: 137-43

Harnessing patient involvement – the challenges in determining patient satisfaction

Judi Davis

Nurse Director, NHS Direct – Anglia (Olde Cow Cottage, South Lopham, Diss, Norfolk IP22 2HW, email judi.davis9@virgin.net)

- **User involvement is required at the outset of planning.**
- **It is important to identify what is important to patients rather than to professionals.**
- **Professional 'jargon' must be avoided.**

In achieving the government's wide-ranging modernisation agenda¹, user involvement and participation are key factors in ensuring that NHS services are appropriate and accessible to the patients they serve.

One common approach to evaluating patient satisfaction and obtaining patients' views is the use of audit questionnaires. The difficulty of developing a reliable and valid audit tool is commonly reported. Traditionally, many satisfaction audits have been 'producer rather than consumer-led'². However, a 'must-do' is the involvement of patients and clients at an early stage of development. Without this the data collected will be superficial at best and meaningless at worst.

During the various stages of developing a nursing quality assurance framework³ in a previous trust (West Suffolk Hospitals) the group assigned to this task seemingly took many steps back before getting it 'right'. Determining the pertinent standards to be audited and what

patients expected from their nursing care was a lengthy exercise, with much time and thought being required.

A survey was undertaken to obtain a clearer understanding of what was actually 'important to the patients in our care'. This elicited some interesting findings, with many of the concerns identified by the nursing profession (i.e. named nurse, involvement in care planning) not seemingly being a key concern to the patients. Being treated as an individual, with warmth and respect, being kept informed, with nursing staff being kind, caring and approachable and having the time to talk, listen and provide prompt care were the main issues cited. These interpersonal processes and the social art of care delivery are often ignored in quality care assessment⁴.

Another problematic area to be overcome was the inadvertent use of 'nursing jargon', with patients not always understanding the terms used³. The use of phrases such as 'Were you involved in the planning of your care?', which the profession perhaps takes for granted, caused immense problems in compiling a meaningful and reliable audit tool. The above survey also helped confirm patient understanding and, being undertaken on a one-to-one

basis, many a blank expression was produced when such seemingly innocent and routine questions were asked. Any audit tool had to address those issues identified and be grounded in what truly matters to patients, being 'patient led'. So that the professionals could also evaluate how they were meeting their own standards, the patient-led issues were combined with the audit of 'un-jargonistic' professional standards.

A local patient satisfaction audit tool was successfully developed, but the involvement of patients and users at the outset may have permitted much time and pain and many dilemmas to be avoided or addressed at an earlier stage. Their involvement is recommended to all would-be designers of patient satisfaction audit tools.

References

- 1 Department of Health. *The New NHS: Modern, Dependable*. London: TSO, 1997
- 2 Hart M. Incorporating outpatient perceptions into definitions of quality. *Journal of Advanced Nursing* 1996;24:1234-40
- 3 Davis J, et al. Taking the measure of patient satisfaction. *Nursing Times* 1999;95(24): 52-3
- 4 Donabedian A. The quality of care. How can it be assessed? *Journal of the American Medical Association* 1998;260:1743-8

WhoWhatWhere?

Clinical governance on the web

The Editors' Choice

The Wisdom Centre:
<http://www.shef.ac.uk/uni/projects/wrp/clingov.html>

An extremely useful site listing a wide range of resources and reference material, and also providing discussion lists and 'virtual conferences'.

Oxford City PCG – Clinical Governance Group website
http://www.oxfordcity-pcg.nhs.uk/clinical_governance.htm
Last updated May 2000

Northern and Yorkshire Clinical Governance homepage
<http://www.doh.gov.uk/nyro/clingov/cghome.htm>
Last updated March 1999

South Manchester PCG – Clinical Governance Group
<http://www.smanpcg.com/Subgroups/CLINICAL%20GOVERNANCE/clingov.htm>
Last updated August 1999

National sites

Clinical Governance Research and Development Unit (CGRDU)
<http://www.le.ac.uk/cgrdu>

Primary Care Resource Unit – Clinical Governance Group website
http://163.1.123.60/pcgru/clinical_governance_framework.htm

Royal College of Surgeons of England Clinical Effectiveness Unit
<http://www.rcseng.ac.uk/public/ceu/clinieff.htm>

Healthcare Events
<http://www.healthcare-events.co.uk>
Healthcare Events organises conferences on the subjects of clinical governance, clinical risk and clinical effectiveness

Regional sites

Clinical Governance in the London Region – NHS Executive website
<http://www.doh.gov.uk/ntr0/cgov.htm>
Last updated February 1999

West Midlands Clinical Governance homepage
<http://www.hsrg.org.uk/links/wmro/cgov/>
Last updated April 2000

Clinical Governance Resource Centre for Dorset (Primary Care Groups)
<http://www.clingov.org.uk>

Central Southampton Primary Care Group – 'Clinical Governance Group'
<http://www.cspcg.co.uk/cggroup.htm>
Last updated April 2000

Why not email us your suggestions?

If you know of any useful websites that you would like us to mention in the *Clinical Governance Bulletin* please email kirsty.orriss@roysocmed.ac.uk. In the next issue, we will be listing the websites of relevant health care organisations and government websites and in subsequent issues the URLs of relevant publications and discussion lists.

Involving patients – an opportunity for the whole organisation

Ros Levenson

Independent consultant involved in research, policy development and training for the NHS and for the voluntary sector, and a non-executive director of Forest Healthcare NHS Trust, Whipps Cross Road, Leytonstone, London E11 1NR

- Patients' experiences should be integral to clinical governance in all NHS organisations.
- Patients and the wider community are interested in clinical governance, but the term 'clinical governance' means little outside the NHS itself.
- In order to put patient experiences at the centre of clinical governance, strong leadership and support are needed at the top of the organisation, supported by 'champions' throughout the organisation.
- There is a wealth of readily available material to support clinicians and managers in obtaining and valuing patients' experiences.
- Small initiatives can often have a large effect.

Although both clinical governance and involving service users in the NHS are current priorities, they are all too often seen as being in separate boxes. However, clinical governance systems and processes cannot be assumed to be robust unless the views of actual and potential patients are sought and taken into account. Equally, the experiences of service

users must be integrated into all aspects of quality improvement, including clinical matters, in order to justify the efforts made by service users and voluntary organisations in giving their views, as well as the efforts made by NHS staff in seeking them.

There is a great deal of interest in clinical governance among patients. However, the language employed by the NHS is a long way from that used by patients themselves. Probably few people outside the NHS could even guess the meaning of the term 'clinical governance'. However, discussions with people who use NHS services invariably indicate a sophisticated grasp of what clinical governance is about. For example, focus groups with people in Bromley who had attended or been invited to attend a cardiac rehabilitation programme demonstrated a clear grasp of clinical quality issues, including systems that would benefit patients other than themselves. Another group of people with physical disabilities and sensory impairments has highlighted both good and bad practice in health and other public services. Similarly, a workshop held by Age Concern London for black and minority ethnic elders revealed a long list of patient experiences of the NHS, particularly highlighting the gulf between policy and practice¹.

In another recent example, South Downs Health NHS Trust held a successful workshop for patients, carers and staff on the theme of communication. Each group was able to share experiences and learn from the others in a positive manner, and the views of patients, as well as the views of others, are being used to look at improvements to both clinical and non-clinical quality issues.

In order to put patients' experiences at the top of the agenda, several things are required. First, commitment and leadership from the top of the organisation are essential. Obtaining patients' views is often seen as the responsibility of relatively junior staff, or else it is dispersed among those who happen to have a

Subscriptions and enquiries

Clinical Governance Bulletin (ISSN 1470-9023) is published bi-monthly by The Royal Society of Medicine Press Limited, London, and is available free to health care professionals working in the NHS.

Subscription prices for non-NHS in 2000 (three issues), including postage, are:

Institutional: Europe £25, USA \$48, Elsewhere £28

Individual: Europe £15, USA \$32, Elsewhere £18

Please address all orders and enquiries to Publications Subscription Department, The Royal Society of Medicine Press Limited, PO Box 9002, London W1A 0ZA, UK

tel. +44 (0)20 7290 2927/8

fax +44 (0)20 7290 2929

email rsmjournals@roysocmed.ac.uk

Full text online: www.clinical-governance.com

particular interest, and is uncoordinated within an organisation. However, that is unlikely to lead to sustained interest or cumulative expertise in seeking and using patient experiences. In addition to leadership, it is also important to have champions throughout the organisation to encourage, support and advocate the sustained involvement of users. Both executives and non-executives have an important role to play in keeping the momentum going in involving lay people in clinical governance.

Although NHS staff sometimes feel unconfident and under-informed about techniques for learning about patients' experiences, there is no shortage of helpful material. Many local voluntary organisations, as well as community health councils, have a wealth of experience to share, and constructive relationships with local organisations that are close to patients will yield great benefits. In addition, there is a great deal of published material that includes very practical advice on methods of user involvement, with discussions on the applicability of the various methods²⁻⁴.

It is important for all those involved in clinical governance to realise that fairly small, local initiatives involving listening to

patients and the wider community can be of great value, particularly if lessons are shared throughout the organisation and beyond into the wider health economy. Some clinicians and managers are rendered inactive by a fear that their attempts to listen to patients' experiences will be inadequate, incomplete or unrepresentative. Inexplicably, this leads some to do nothing rather than encouraging them to make a start in what is inevitably an ongoing task. Listening to the experiences of patients is a process, not an event, and it is most important to ensure that it is at the centre of clinical governance, and not at the periphery.

References

- 1 Levenson R. *Elders' Health: The Voice of Experience – A Contribution to the Debate of the Age*. London: Age Concern, 2000
- 2 Barker J, et al. *Reference Manual for Public Involvement*. 2nd edn. London: South Bank University, 1999
- 3 Kelson M. *Consumer Involvement Initiatives in Clinical Audit and Outcomes*. London: College of Health, 1995
- 4 NHS Executive. *An Organisational Development Resource for Primary Care Groups*. London: NHS Executive, 1998: section 9, pp. 53–61, and Appendix 3, pp. 68–72