

# CLINICAL GOVERNANCE

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## Bulletin

### Editorial: Patient involvement

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Improving the quality of care has been an NHS priority for many years and many guidance documents have been published, such as the Department of Health's *Patient and Public Involvement in the New NHS*<sup>1</sup> and *Signposts* from NHS Wales, which includes many practical examples of good practice<sup>2</sup>. The Kennedy report following the Bristol inquiry also highlighted the need to ensure that 'the perspective of the patients and the public must be heard and taken into account'<sup>3</sup>. While this is a very complex issue, NHS organisations must nonetheless make patient involvement and public participation a reality; only thus will they be sure that their services meet the needs of the population they serve.

Patients, their carers and the public should be involved not only in shaping their local services but also in monitoring their quality. Greater participation will engender greater trust in the local health services and will improve communications between NHS organisations and the communities they serve.

How can this be achieved? Most organisations have by now developed their patient involvement strategy and have included users on their clinical governance committees, which allows them to use patients' expertise to inform service development. Patient advocacy liaison services and patients' forums are being set up across the NHS in England; it is still early days and their benefits have yet to be fully realised.

Different methods for patient involvement have been described, such as focus groups for patients with specific conditions, patient diaries, opinion surveys, questionnaires, patient involvement in critical incident

reviews and citizens' juries. The NHS Modernisation Agency has published a guide<sup>4</sup> which gives a description of the tools available; so too has NHS Wales, whose guide includes not only a description of the various methods but also their advantages and disadvantages<sup>2</sup>. When choosing a method, however, organisations and clinical teams must be clear about what they are trying to achieve<sup>5</sup>, so that the information they gain is relevant to service improvement.

This issue of the *Bulletin* gives a number of practical examples of patient involvement. Whether public participation can lead to long-term improvement in the outcome of care will require further investigation. Future issues will cover guidelines and clinical networks, and will also revisit topics examined in previous issues. Please continue to send in your contributions so that others can learn from your experience.

#### References

- 1 *Patient and Public Involvement in the New NHS*. NHS Executive, 1999. See [www.doh.gov.uk/involve.htm](http://www.doh.gov.uk/involve.htm)
- 2 *Signposts – A Practical Guide to Public and Patient Involvement in Wales*. Office for Public Management/National Assembly for Wales, 2001. See [www.wales.nhs.uk/publications/signposts-e.pdf](http://www.wales.nhs.uk/publications/signposts-e.pdf)
- 3 Kennedy I. *Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984 – 1995* (CM 5207). July 2001. See [www.bristol-inquiry.org.uk/final\\_report/report/index.htm](http://www.bristol-inquiry.org.uk/final_report/report/index.htm)
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# Clinical incident reporting: capturing patient experience

**Karen L. Robinson**

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- Patients are able to provide information about clinical incidents which is not otherwise reported.
- Patients may be willing to share this information if they are confident that their care will not be compromised as a result.
- Feedback on improvements in care resulting from comments is important to patients.
- Patients have as much need as staff to understand a trust's risk management philosophy.

Patients, more than anyone, gain from the NHS delivering safer clinical care and learning from mistakes. This vested interest supports the development of patient participation in clinical risk management and could provide an additional source of valuable information to trusts.

The present paper reports how a focus group with patients and the public was used to find out what would encourage patients to report incidents.

## Clinical incident reporting

The Trust needs reliable information on clinical incidents in order to detect and respond to the risks inherent in our organisational and management systems. Generally, the reporting of clinical incidents is known to be inconsistent and little improvement is anticipated until the process is made easier for staff and the changes towards the 'just blame' culture are realised. Little attention has been given to the patient's contribution to effective reporting. It was proposed that a patient information leaflet on clinical risk management might empower patients and encourage them to report incidents.

## Focus group

The focus group confirmed that clinical incidents in the Trust were being under-reported and established that many patients do recognise incidents and near misses. However,

## Results from the focus group: two themes

### *Difficulty for patients of recognising a problem*

- While many patients would recognise a problem, some would not because of disability or illness.
- Patients may receive reassurance and disregard their doubts because they trust health-care staff not to make mistakes.
- From a reporting perspective, patients are not clear what constitutes a 'clinical incident'.

### *Not saying anything after recognition*

- Patients feel vulnerable from the moment they are admitted.
- Patients do not want to get staff into trouble.
- There is no 'right' time to speak or 'right' person to speak to.
- Patients worry that their care may be compromised if they speak up.
- Patients make excuses for problems, such as there being too few staff.
- Patients do not think reporting a problem will make any difference.

patients did not feel empowered to raise their concerns; while they felt written information would be helpful, they were also able to offer additional useful suggestions.

## Patient experience

Currently, patients can share their negative experiences only through the complaints or claims route, and evidence shows that these negative experiences have not usually been recorded by staff as incidents. Since quality assurance theory suggests that there are numerous dissatisfied customers for each one who complains, we can assume that there are many patients who do not share useful information with the Trust.

We wanted to understand the conditions that would make a patient willing and able to increase our knowledge about clinical incidents, errors and near misses. Facilitated by the patient advocacy liaison officer and clinical risk manager, the focus group explored this proposition using scenario analysis. Two themes emerged from the focus group (see Box 1): recognising a problem; and not saying anything about the problem once it was recognised.

## Relationships

It appeared that patients were willing to suffer ill effects from a clinical

error rather than question their care. A powerful influence on this behaviour was the relationship between the health professional and the patient. The patients participating in the focus group clearly did not feel they were true partners in their care.

## Empowerment

The participants in the focus group presented some suggestions for how to overcome some of the barriers that prevent patients from speaking about their experiences and questioning their care.

- a patient-focused orientation or induction at the point of admission;
- staff with customer-care skills who can listen and respond positively to questioning;
- information for the patient on the need to identify clinical incidents;
- information for patients on the Trust's philosophy and response to incidents;
- feedback on changes made as a result of incident reporting.

## Conclusion

Patients have information that the Trust needs to make its management of clinical incidents more effective but they may not be willing to share this information until the conditions are more favourable.

# Engaging service providers, users and carers in clinical governance: a qualitative study gathering evidence about a service and taking action

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- Ownership of the clinical governance process is encouraged by getting front-line practitioners to take part in gathering evidence about a service.
- Focus groups are a quick way of getting a range of views from practitioners who work for different agencies and across a range of disciplines, as well as from users and carers.
- Service users and carers told us (by feedback questionnaire after the study) that they liked focus groups as a way of getting their views across.
- Listening to the stories of practitioners, service users and carers gives a real-life snapshot of a service. This is a good practical basis for change.
- Focus groups seem to be a good vehicle to engage everyone in clinical governance.

A study was undertaken by the Clinical Governance Team of the South Hams and West Devon Primary Care Trust (PCT). It had two main aims:

- We wanted to help people who provide services to learn from each other and from the experiences of service users and carers.
- We wanted to involve those same people in acting upon the results.

## Background to the study

For this project, we looked at the use of short-term 'intermediate care' beds in two localities:

- Locality A, where the PCT has an arrangement with a private nursing home for the provision of short-term rehabilitation beds for patients before their return to the community;

- Locality B, where the community hospital provides a similar service.

The striking thing was how similar the messages were from the two localities.

We wanted to find out:

- What works.
- What could be done better regarding intermediate care services at the hospital and the nursing home.

## The process

The project team met with managers, practitioners, representatives of the voluntary sector and other major stakeholders in both localities. We called these the 'Big Voices', as they have the authority to take decisions and make changes.

The Big Voices met in their locality groups and decided, along with the project team, how the evidence for the study should be gathered. Focus groups were chosen because they generate wide-ranging discussion and are cost-effective<sup>1</sup>.

Focus groups were therefore held with four groups of people in each locality:

- former patients
- carers/relatives
- staff from the hospital and nursing home
- people who work in the community (e.g. community nurses, social services personnel and general practitioners) but who come into contact with people using the two services

Participants in the focus groups were called the 'Smaller Voices' because they are not heard so easily. Their contribution to our understanding of how the services worked was vital.

## Key findings

The focus groups generated a lot of data, which took time to analyse. This analysis highlighted a consensus among the practitioners, service users and carers on five main themes:

- *The facilities have to provide care for patients who have different needs and expectations.* This means that there is sometimes a mismatch between what patients and carers expect and what they get.
- *Building better links.* There were several examples of good communication, but better links were sometimes clearly needed between the community and the acute hospital. Service users and carers seemed to lack the information they needed to find their way around 'the system'.
- *Resource constraints.* There were noticeable staff shortages at times at both units. There were particular skill shortages when patients had higher or more intense needs. At both facilities, it was felt that more reablement staff were needed.
- *Length of stay.* The nursing home had a contract with the PCT for patients to stay two weeks only (there was no specific time limit at the hospital). This influenced

## Topics for future issues

- Guidelines
- Clinical networks

Please share your practical examples with us, and email them to: [mlugon@compuserve.com](mailto:mlugon@compuserve.com) (see page 4 for guidance on the submission of contributions).

both who was admitted and the care they received.

- *The built environment.* The community hospital building was a Victorian conversion. The nursing home was purpose built. Advantages and disadvantages were identified both for single rooms and for 'Nightingale wards'. Single rooms could be lonely, whereas confused patients caused distress to others in open wards. Daily routines and the timing of meals and choice of food were identified by patients as important for their wellbeing.

## Action plan

The Big Voices met together to discuss the findings. Half a day's intensive work resulted in a list of short-, medium- and longer-term goals. The Big Voices said that the process had given them an insight into what it was like to use and provide these services. This helped them decide upon practical actions that could be taken to make improvements.

The short-term solutions were implemented within four weeks of the meeting. These included:

- Photographs of staff at the two facilities on a board at the entrance to help patients and carers identify them.

- A leaflet for both facilities, designed with patients and carers to give the kind of information that they wanted.
- The drawing up of admissions criteria for the community hospital.
- Giving the nursing home patients a letter on admission outlining their care plan.

Medium- and longer-term aims were presented to and approved by the PCT executive and board. A longer-term action plan was agreed, which covered the following points:

- a review of the intermediate care pathways to be undertaken by the PCT;
- information to be collected from patients and carers about how well the service works;
- closer working with the acute hospital regarding discharges to the facilities, with consideration of nurses having more control;
- joint training with social services, particularly on the care of confused patients.

## Conclusions

The Commission for Health Improvement identifies three main questions for clinical governance<sup>2</sup>:

- What is it like to be a patient?
- How good are the trust's systems for safeguarding and improving the quality of care?
- What is the capacity in the organisation for improving the patient's experience?

This study addressed all three questions and provided some answers:

- The PCT and the wider health community were able to hear patients' voices directly.
- It was these voices that told us where gaps and weak points existed in the system. Essentially, these occurred between acute and primary care, and between health and social services.
- In terms of capacity, staff shortages in reablement and nursing were identified, as well as other skill shortages at certain times.

This process has given us a model that can be used both to evaluate and to plan services. One of the advantages of this model is that it seems to inspire ownership by all those involved at different levels of the organisation. We are hoping it will be a real aid to improved clinical governance.

## References

- 1 Kreuger RA, Casey MA. *Focus Groups: A Practical Guide for Applied Research*. London: Sage, 2000
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## Contributions

The audience is predominantly practising clinicians and managers, so please make your article as practical and relevant to everyday practice as possible.

**Length:** 500–800 words plus a maximum of five references in Vancouver (numerical) style.

**Illustrations:** where appropriate, use tables, charts, summary boxes etc. to present information, and to break up the text.

**Web links:** where possible, provide web and/or email addresses for further information – e.g. Department of Health reports or circulars, publications, societies, etc.

**Presentation and submission:** On the first page include the article title and author names and addresses (including email addresses); please also indicate which author is responsible for correspondence about the article and proofs. Start the article with three to five brief bullet points summarising the key lessons learned. Use plain, unjustified text throughout, with subheadings in bold upper and lower case.

Please send your contribution, by email (or by post with floppy disk), to:

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# Involving patients and the public in clinical governance: a practical approach

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- The NHS exists to look after patients. They are the primary stakeholders.
- If the system does not work for an individual patient, it does not work for anybody.
- Do not involve patients unless you mean to act upon their input.
- Be prepared to listen to their views.
- Look at the patient as a resource, not a problem.
- Ask people what they need to do the job you are asking them to do.
- Give patients the resources and training to participate in the process.

Rising patient and public expectations are becoming a key stimulus to improving quality in the NHS. People – particularly those under 45 years – are less ready than in the past to accept a paternalistic style of service ... as well as good quality clinical care, they want fast and convenient services, tailored to their individual needs.

Liam Donaldson<sup>1</sup>

Clinical governance aims to improve the patient's experience of health-care; it is therefore important to include patients in the process from the outset.

## A patient-centred development programme

The NHS Clinical Governance Support Team (CGST) supports multi-disciplinary clinical teams through the Clinical Governance Development Programme (CGDP), which inspires and enables frontline teams to understand and apply clinical governance through a patient-centred programme of facilitated change<sup>2</sup>. Fundamentally, patient involvement in the CGDP aims to create a more interdependent culture, in which patients and health-care professionals are prepared to work and learn together, to share their experiences and to make a difference together.

Patient involvement requires investment. The CGDP uses a systematic process (RAID – Review, Agree, Implement, Demonstrate) to encourage involvement, from information giving to full collaboration<sup>3</sup>. The four phases of this process are outlined below.

### Review phase

During the review phase, clinical teams capture patients' experience of their service and use multiple methodologies to develop a comprehensive understanding of their service as seen by patients and their carers.

Learning to listen actively to patients in a range of settings, either formally or informally, is a key component of this review. Listening to patients and hearing their stories provide a wealth of knowledge and initiate a continuous dialogue between patients and professionals. Much can be learnt from sitting and listening to patients in a waiting area or talking to a community group and taking their views seriously. This listening exercise is part of a wider review of collecting information and building relationships to create a culture of ownership to enable continuous quality improvement. The information that the Patient Advice and Liaison Service (PALS) officers collect, National Patient Survey data and information from patient groups are also key sources that add to the richness of the review.

### Methods for capturing information

What is the best method for capturing information from patients and the public? The answer is not straightforward: the method should be fit for purpose. A variety of methods may be employed (see Further sources, at the end of this paper). Discerning which method to use will depend on who you are wanting to involve, what problem needs to be solved and thinking through how best to engage, motivate and empower those people.

In addition, from an ethical standpoint, it is important to be sensitive to the patient's needs.

### Agreement phase

The agreement phase of RAID is an important part of agreeing the priorities and quick wins that will be taken forward as different projects. Feedback to patients and involving them in making the changes happen create the next step in the ladder, involvement. Methods used have included: workshops jointly with patients and staff, large group interventions with patients and staff working together to define the priorities, newsletters and the use of existing communication channels, such as forums and meetings.

### Implementation

The implementation phase is when patients and health-care professionals work together to plan and shape service improvements. Health professionals can ask themselves, 'How would I like to be treated in this situation?' Practical considerations of remuneration, venue, access issues, time, personal needs and administrative support need to be built into the process of patient involvement and there must be a genuine desire to create change as a result of this involvement.

At this stage, involvement is the beginning of embedding patients as an integral part of clinical governance. Examples include patients actively involved:

- on interview panels
- in audit
- in research
- in training
- in critical incident analysis
- in dealing with complaints
- on project groups
- in process mapping
- in designing patient information material (see page 7 of this issue)

## Demonstration

The demonstration phase often elicits a sense of 'not knowing any way other than involving patients'. Capturing the tangible improvements in the patient's experience is achieved through clinical teams describing their service changes<sup>4</sup>. The CGDP also demonstrates partnership working, as patients are active teachers on the programme: patients deliver differing components of the programme, describe their own personal experiences and advise on how best to involve patients and the public.

## Conclusions

Patient involvement gives rigour to the clinical governance process and improves the potential for learning. If patients are to be central to this process, with care shaped around their convenience and concerns<sup>5</sup>, it is important to think about including them as full partners from the outset, and systematically involving them in the design and implementation of change.

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- 2 For further details of the CGDP see [www.cgsupport.org](http://www.cgsupport.org)
- 3 Nicholls S, Cullen R, Halligan A. NHS Clinical Governance Support Team – facilitating cultural change. *Clinical Governance Bulletin* 2001;2(1):2–4
- 4 Examples are available as 'Eurekas' and case studies in the resources section of the CGST website. See [www.cgsupport.org](http://www.cgsupport.org)
- 5 Department of Health. *The NHS Plan*. London: Stationery Office, July 2000: section 10:8

## Further sources

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# Implementing users' ideas to change mental health services

Debbie Wall<sup>1</sup>, Val Parker<sup>2</sup>, Sarah Squire<sup>3</sup> and Aidan Halligan<sup>4</sup>

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■ Valuing users' perspectives of their care has enabled service improvements.

■ One-to-one interviews with users and carers resulted in their suggestions being put into practice, including 'welcome' information booklets for new users and the introduction of a 'crisis card', carried by users, that gives contact details of key workers.

Increasingly patients are being involved in helping to define quality of services, in participating in decisions about their care and in

planning and improving services for future patients.

Liam Donaldson<sup>1</sup>

'Active' patient involvement in the Clinical Governance Support Team's Development Programme (CGDP) varies and depends to some extent on the focus of the delegate teams' service reviews. However, some improvement stories (which are often a part of more extensive programmes of change) show that if users' and carers' views are actively sought and listened to, their ideas and suggestions can be the basis for

improvements in service delivery and can lay the foundation for further patient involvement.

## Involving mental health service users

Although mental health services have often led the way for active user involvement<sup>2</sup>, there is evidence to suggest that these users do not always feel involved in their care<sup>3</sup>. The involvement of users who may be socially excluded and who may have difficulty relating to formal structures poses particular challenges

to health professionals<sup>4</sup>. A patient-centred NHS means including the 'voice' of all patients and not excluding particular groups because they are hard to reach. According to Rose<sup>5</sup>:

Mental health users not only have something to say about the services they receive but what they say is sound, rational and can be taken on its own merits.

The following case studies support this view and take it one step further, in that mental health teams have implemented ideas for change which have come directly from service users.

### Case study 1. Users' information booklet

As part of a service review, a CGDP delegate team that worked in a mental health unit conducted one-to-one interviews lasting 20–30 minutes with users and their carers, as key stakeholders. They listened to their thoughts, ideas and suggestions. Among the ideas put forward was a 'welcome' information booklet for new users admitted to the ward, and a photograph gallery of staff. Both suggestions were fed back into a multidisciplinary workshop attended by staff and patient advocates. It was agreed to implement these ideas.

Action on the gallery was agreed and photographs of *all* staff – nursing, medical, clerical, domestic, occupational therapist and psychologist – were put up in the main corridor.

During the interviews, users said that they lacked the basic information they needed when they arrived on the ward; they needed help with immediate queries they had about their stay. This prompted their idea for the booklet, which was produced early in 2002. It provides concise information, is written in simple, clear language and avoids technical terms. The content includes an introduction to the range of therapeutic activities on the ward (a structured activity programme for about 30 groups run by doctors, nurses and psychologists – another result of the team's clinical governance review); reassurances about medication; the daily routines and visiting times on the unit; and an explanation of the patient advice service, with contact details. A user played an active role by volunteering to be a part of the team on the project subgroup and by

taking a lead role in decisions about what content to include in the booklet (Box 1).

All mental health service users have this information booklet in their bedroom on the ward when they arrive, so they can read it at leisure. Informal feedback confirms the value of the booklets and many users take them home when they leave. Structured monitoring of responses to the booklet is underway, using a ward patient satisfaction questionnaire. Word has spread and most remaining hospital wards have information booklets or leaflets for patients and users. Although it is a simple change, the information booklet enables users to know whom to ask and whom to go to to have their views and opinions heard.

#### What's the difference for users?

- Users know that their views are taken seriously.
- 'Staff treat me as an equal.'
- There is better access to information for users about their care.
- There is more user ownership of improvements on the ward.
- There is improved communication between staff and users.
- There are systems in place for continued user and carer involvement.

### Case study 2. Creating a 'crisis card'

Another mental health team on the CGDP, comprising a clinical manager, locality director and consultant psychologist, took on board a user's suggestion to improve information for users: this time the information was to support users who were discharged from the inpatient unit. During an interview (which was part of the team's service review), a user suggested the idea of a credit-card-sized 'crisis card' to provide contact

names and numbers of the care coordinator, GP, social services department and telephone helplines.

A regional inpatient collaborative review had previously shown that users and carers were dissatisfied with discharge procedures. As things stood, arrangements for discharge from hospital lacked planning and coordination, and communication between the ward and community teams was poor. Users and carers received no written information and only 50% knew their care coordinator's name before they arrived on their doorstep to introduce themselves. In times of crisis, users were confused about who was looking after them and they had difficulty remembering contact telephone numbers.

The crisis card, with key contact numbers, was developed for mental health service users by users. They were involved in the design, content and final decisions about the card. The card did *not* have a mental health service logo. It was tailored to meet individual needs. The main cost was £50 for the laminating machine. The bespoke crisis card gives details of the named care coordinator and other services for each patient.

All staff in hospital and community services were told when the card would be introduced and now every user is given one when discharged from the inpatient unit. The ward and community teams now meet to discuss plans for patients' discharges.

#### What's the difference for users?

- The path to care is smoother, quicker and less traumatic.
- Users and carers are more confident, especially in times of crisis.
- Other mental health units have started to adopt the idea of crisis cards.

#### Box 1. Excerpts from the 'Welcome' booklet

.... It is our intention to work with you, to treat you as an individual and to listen and take note of your views and opinions and whenever possible, allow you to be fully involved in your treatment and care.

One of the most important things for us is to know that you are happy with our delivery of care to you. For this reason we have a community group on the unit. Here you can express your concerns relating to the day to day running of the unit, quality of meals, cleanliness, suggest new ideas etc. We welcome your views, and you can make a difference.

- Work is in hand, supported by the local service users network, to extend the idea of crisis cards across the whole service – not just inpatient discharges.
- An audit carried out in summer 2002 showed 90% of users knew the name of their care coordinator.

## Conclusions

By listening to and acting on mental health service users' ideas and suggestions for change and by involving them in planning and implementation, service improvements have been delivered.

These case studies from teams who have been through the CGDP help demonstrate tangible improvements in users' experiences through their involvement as partners in service reviews and project implementation.

One of the CGDP mental health teams, talking about the process of conducting a service review, has said, 'It really is about involving absolutely everyone'.

As these case studies show, actively engaging users with their service may lead to new ideas about how care can be improved and provides users with opportunities to put their own ideas for change into practice. Such involvement lays the foundation for continued partnership through clinical governance.

## Acknowledgements

The case study material was provided by CGDP mental health teams from North East London Mental Health Trust and South Tees Hospital NHS Trust.

## References

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- 3 Rose D. *Users' Voices: The Perspective of Mental Health Service Users on Community and Hospital Care*. London: Sainsbury Centre for Mental Health, 2001. See [www.scmh.org.uk](http://www.scmh.org.uk)
- 4 *Signposts – A Practical Guide to Public and Patient Involvement in Wales*. Office for Public Management/National Assembly for Wales, 2001. See [www.wales.nhs.uk/publications/signposts-e.pdf](http://www.wales.nhs.uk/publications/signposts-e.pdf)
- 5 Rose D (op. cit. ref. 3): 4

# Top tips for effective user involvement

## Marcia Kelson

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- Identify clear aims and objectives for individual initiatives. What do you want to achieve?
- Earmark a budget for user involvement activities. Do you have the time and resources to involve users effectively?
- Involve users appropriate to the aims and objectives of your initiative. Are you involving people with direct experience of the topic you are focusing on, and involving a range of people likely to be affected by the outcome?
- Involve people using methods appropriate to their needs and preferences. Are users able and willing to participate in the activities you have planned?
- Provide explicit terms of reference for a given initiative and the anticipated role of users. Is everyone clear what the purpose of the exercise is, and their role in it?
- Provide staff training. Do staff have the skills, confidence and credibility to work effectively with users?
- Provide training to and support for users. Do users have access to an induction programme and ongoing advice to support their involvement throughout?
- Provide feedback on what has been achieved as a result of people's involvement. What happened as a result of all their efforts and what changes, if any, have been made?
- Evaluate the impact of user involvement on the process and outcome of an initiative. What did both users and staff think worked well or badly? Did they feel that involving users made any difference?
- Involve users in all of the above!

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# WhoWhatWhere?

## Patient involvement on the web

NHS Scotland  
[www.show.scot.nhs.uk/achb/reports](http://www.show.scot.nhs.uk/achb/reports)  
A strategy for involving people.

*Signposts – A Practical Guide to Public and Patient Involvement in Wales*  
[www.wales.nhs.uk/publications/signposts-e.pdf](http://www.wales.nhs.uk/publications/signposts-e.pdf)

Patient Involvement in Guideline Development  
[www.sign.ac.uk/patients/](http://www.sign.ac.uk/patients/)

The London Modernisation Board, NHS London  
[www.london.nhs.uk/modernising/london-p&pi.htm](http://www.london.nhs.uk/modernising/london-p&pi.htm)

A practical guide from the London Quality Taskforce.

Clinical Governance Support Team  
[http://www.cgsupport.org/Patient\\_Involvement/default.asp](http://www.cgsupport.org/Patient_Involvement/default.asp)  
Patient involvement page.

College of Health  
<http://www.collegeofhealth.org.uk/main.html>

The College of Health's Patient Involvement Unit for the National Institute for Clinical Excellence.

Royal College of Obstetricians and Gynaecologists  
<http://www.rcog.org.uk/mainpages.asp?PageID=319>

Patient involvement in enhancing service provision. Clinical Governance Advice No. 4.

## The Editor's Choice

The NHS Modernisation Agency's improvement guide on patient and carer involvement.

[www.modern.nhs.uk/improvementguides/patients](http://www.modern.nhs.uk/improvementguides/patients)

There are a number of useful other guides at:  
[www.modern.nhs.uk/improvementguides/patients/global\\_home.htm](http://www.modern.nhs.uk/improvementguides/patients/global_home.htm).

# Clinical governance in end-of-life services

## Revd Tony Brookes and Lyn Ford

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- An end-of-life policy needs to address not only how to deal with the dying and the deceased but also how to care for the bereaved.
- The development of such a policy can become a powerful tool for the education and training of staff.
- The development of an end-of-life policy can help to ensure that bereavement services are given some attention and as such address the recommendations of the Chief Medical Officer.
- The approach taken in this work has supported the spread of clinical governance across a range of other aspects of care delivery, such as consent to postmortem.
- A monitoring plan is necessary to ensure the policy is implemented across the trust.

Events surrounding the Royal Liverpool Hospital/Alder Hey<sup>1</sup> and Bristol Royal Infirmary<sup>2</sup> initially served to heighten public perception of the need for a proper process for obtaining informed consent to postmortem.

Subsequent guidance from the Chief Medical Officer<sup>3</sup>, the Retained Organs Commission<sup>4</sup> and the Royal College of Pathologists<sup>5</sup> identified in addition the need for significant improvement in the provision and delivery of bereavement support services to relatives of patients who die in hospital.

This article focuses on work at the North Staffordshire Hospital Trust over a period of 18 months to develop an end-of-life policy. The work drew on local research as well as national policy and guidelines.

## Method

Initially the Trust undertook a mapping exercise to identify the 'pathway' for deceased patients – from death to the point of release of the body to an undertaker – to clarify the process and to identify any associated guidance documents. Each of the relevant policies was then reviewed with the appropriate professionals and where necessary revised to reflect current national policy.

Simultaneously, the Trust's consent forms in relation to postmortem were revised in line with national policies, after consultation with service users through the use of focus groups.

Finally, the information was integrated into a comprehensive end-of-life policy and guidance document, which outlined best practice. The document drew on a variety of sources, including an earlier empirical study into bereavement care undertaken by the Trust. Wide consultation took place within the organisation and with external stakeholders.

## The end-of-life policy

The policy has four sections:

- *Introduction.* This describes the background, the principles underpinning the policy, and the scope of the document
- *Care of the dying.* This section gives guidance on: communication, education and training needs of staff; patients making a will in hospital; emergency marriages/

baptisms; advance directives – relating to ‘resuscitation’ and ‘do not attempt resuscitation’; verification of expected death; respect for the privacy, dignity and religious and cultural values of patients.

- *Care of the deceased.* This section covers: ‘moving on’; patients’ possessions; disposal of fetal tissue; disposal of organs and tissue retained at postmortem, and retention of organs and tissue after postmortem; transfer of the deceased to the mortuary; reporting death when either the deceased or the next of kin is unknown; releasing the deceased to a funeral director (or elsewhere).
- *Care of the bereaved.* This gives the bereaved guidance on the provision of ongoing support for and follow-up to relatives, consent, the coroner, the patient’s property, financial instructions, registering a death, respect for privacy and dignity.

Care has been taken to identify best practice and develop an integrated document to enhance the delivery of care to patients and their families at the end of life. In addition, this comprehensive policy document, which combines current policies and national guidelines and draws on both local and national evidence, provides a single reference point for practitioners at ward level. As clear guidance is offered across a range of issues related to end-of-life care, the document will enable staff at all levels to act appropriately under very difficult circumstances. It also provides a Trust-wide standard of care to the dying patient and bereaved relatives, and reflects best practice identified from local research and national sources, against which performance and outcomes in the provision of bereavement care services throughout the Trust can be measured and audited.

## Benefits

It is planned to use the components of the policy as training and education resources for staff at all levels. Also, it will be important that appropriate mechanisms can be devised to integrate the quality assurance of bereavement care into the Trust’s existing systems and processes for

evaluating and maintaining clinical governance.

The completion of this work provides a good example of clinical governance in action:

- Initially, it was seen that an area of practice needed to improve.
- Then, the key issues and blocks to development were identified.
- Staff and service users were then engaged in defining the necessary change, and this was crucial to establishing ownership and commitment to the project.
- Completion of this phase of the project provided a framework for the policy and helped to identify the information requirements of staff and service users.
- Both local and national guidance was utilised to ensure best practice was incorporated into the policy.
- A programme of consultation both within and outside the Trust was undertaken to validate the approach and engage the widest possible audience.
- The Trust also embarked on a programme of multidisciplinary education, focusing on breaking bad news and the implementation of the end-of-life policy.
- Finally, the development and ratification of the policy have led to further developments in Trust bereavement services, the management of consent for postmortem, and tissue and organ retention and return, so spreading and sharing best practice across a range of other aspects of care delivery.

Plans to monitor the effectiveness of implementing the policy are to be agreed and the document will be printed in such a way as to allow easy update and refreshing of guidance published.

## Conclusion

The development of this policy demonstrates one element of the Trust’s commitment to the provision of high-quality bereavement support services. Such services have become an important quality assurance issue, which is likely to feature on the clinical governance agenda of all trusts in future.

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# A simple traffic light monitoring system to measure progress in clinical governance: practical implications and the lessons learnt

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- Practical experience of using a traffic light system to monitor progress in the implementation of clinical governance in a large, complex organisation has shown it to be simple, effective and easily understood.
- The use of the system has in some cases been over-simplistic and it can recognise only when a standard has been fully met.
- Standards need to be explicit and their origin clarified to gain the commitment of all staff.
- We have learnt some valuable lessons from the adoption of this approach to monitoring clinical governance.

In the August 2001 edition of the *Clinical Governance Bulletin*, Lees and Fenton<sup>1</sup> described the approach the Southampton University Hospitals NHS Trust has taken to monitor the implementation of clinical governance. This approach involved:

- the development of a number of 'key performance standards' for each pillar of clinical governance;
- the identification of corporate leads for each pillar to support directorates in taking action across each area;
- the identification of two directorate leads to pursue achievement of the key performance standards at a local level;
- the monitoring of all directorates using a traffic light system to show performance in relation to the standards.

The traffic light system provides a very simple method of demonstrating progress made against the identified internal clinical governance priorities. However, a number of limitations with the current system have come to light, which have all been addressed. The purpose of this paper is to report the limitations we experienced when implementing this system, for the

benefit of those considering adopting a similar approach (a more detailed report has been presented elsewhere<sup>2</sup>). These limitations can be classified into three broad categories:

- simplicity of the traffic light system
- the development of standards
- clinical governance leads

## Simplicity of the traffic light system

Progress in meeting standards is assessed using a traffic light system: red signifies there has been no development, amber signifies development is under way, and green signifies that the standard has been met and is fully operational. While this has provided a structured approach to clinical governance, it does have faults.

While the traffic light system is simple and easy to follow, it has proved in some instances to be over-simplistic. The frustration for directorates occurs when standards assessed as 'amber' have been continually worked on for some time but are not quite fully operational. The traffic light system has no way of recognising that work has been undertaken; unless the standard has been met in full the assessment remains at amber.

To address this limitation we have added a fourth colour to the spectrum to account for the large gaps between the previous three assessments. In addition, a monitoring tool has been devised to give clearer, more objective guidance on what needs to be done to reach each different level, rather than the previous recording merely of 'Standard achieved' or 'Standard not achieved', which relied to a certain degree on individual interpretation.

## Development of standards

Historically, the corporate leads had drafted and devised the standards,

which raised anxiety within the directorates. Not being fully involved or aware of where the standards had originated from caused us some difficulty in achieving full commitment to the method.

In order to address this problem, the standards for 2002/3 have been clearly based upon a number of areas of work the Trust needs to consider, including actions required to achieve Clinical Negligence Scheme for Trusts (CNST) Level 2, actions required to meet the recommendations of the Kennedy report<sup>3</sup>, and action still outstanding from our review by the Commission for Health Improvement (CHI) and from common themes emerging from other organisations' CHI reviews. This appears to have led to a greater appreciation of the purpose of the standards and how their achievement will support a number of agendas that we are pursuing simultaneously.

## Clinical governance leads

The final limitation that we have experienced relates to the identification of two leads to pursue achievement across all standards. Soon after implementing the system it transpired that this was clearly unachievable; assessments being made were often subjective and unsubstantiated as a result. There was a danger that this element of the approach would be seen as merely a 'job creation programme'.

To address this issue, and further strengthen the Trust's clinical governance arrangements, directorates have identified a lead individual (or more than one where appropriate) for the seven pillars of clinical governance, to mirror the corporate arrangements. After a review of the roles and responsibilities of staff working within each directorate, it became clear that the majority of directorates

**Table 1.** Matrix of clinical governance arrangements within Southampton University Hospitals NHS Trust: corporate and directorate leads are identified for each cell within the matrix (i.e. for each component of clinical governance)

Directorate	Components of clinical governance						
	Risk management	Staffing and staff management	Patient involvement	Clinical effectiveness	Research and development	Using information	Education/training
Child Health							
Cancer Care							
Obstetrics and Gynaecology							
Trauma and Orthopaedics							
Cardiology							
Critical Care							
Ophthalmology							
Surgery							
Medicine/Elderly							
Head and Neck							
Pathology							
Radiology							
Neurosciences							
Clinical Support							

already had staff working on the different components of clinical governance. For example, the issues outlined by CHI for the staffing and staff management component are predominantly already addressed by the role of the clinical service manager. What has been lacking to date is a formal mechanism by which these individuals can regularly meet and contribute to an integrated programme of quality improvement for their directorate.

All clinical directorates are now able to integrate the work that has previously been ongoing within their area into one coherent programme of quality improvement; they are also better able to pursue more actively and monitor more accurately implementation of the Trust's key performance standards.

Not only does this further support the development of clinical governance at directorate level, but it also consolidates arrangements at a corporate level. Drawing on the resource of

designated directorate leads for each component, corporate leads are able to chair Trust-wide working groups for every component, and this facilitates communication in a vertical and horizontal direction throughout the organisation, for all elements of clinical governance (Table 1). The framework also allows for the integration of the separate supporting strategies adopted for the different components of clinical governance.

### Conclusion

The same conclusion to be drawn in 2002 from using this method of demonstrating performance in clinical governance is held as previously reported by Lees and Fenton<sup>1</sup> – that it is very simple, effective and helpful in managing both the clinical governance process and the process of biennial directorate business plan reviews.

Although a number of areas were in need of improvement, the refined

method has remained useful to assure the Trust Board, directorate teams and ourselves that progress is being made to improve the quality of services we provide.

One challenge that remains, however, is to ensure that 'green lights', once achieved, are sustained year on year. Having addressed a number of the other key issues, this is the next area to be tackled in the continuous development of our clinical governance programme.

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