

Patient perspectives

Involving patients and the public in health services: the role of nurses

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Nurses, wherever they are located, have always recognised that one of their most important tasks has been to act as advocates on behalf of their patients and their carers. Undertaking that task has not always been easy, particularly with the many changes that have taken place in organisations, as well as in the roles and responsibilities of the profession. However, over the last few years there have been many policy initiatives and projects to enable patients and their carers to have a louder and more meaningful voice in their NHS. Nurses are often ideally placed to take the lead in ensuring they are implemented to the benefit of patients. For example the relevant section of the Health and Social Care Act 2001 has recently been strengthened,¹ and places an even stronger duty on NHS trusts, primary care trusts and strategic health authorities to make arrangements to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes.

Patient and public involvement has been discussed at various levels in many forums, but working out how to innovatively and creatively place patients and their carers at the centre of decision making and service delivery has been much harder amid the pressures of front-line work. Organisational change, together with the pressure of competing priorities, has slowed adoption, and frequent changes to the patient and public involvement organisations themselves have damaged the good will and commitment of health professionals who wanted to listen to their patients and actively involve them in decision making.

I believe there are two developments that will ensure significant involvement of patients and the public and have the potential to make a difference, and that will mark a watershed in enabling both health and social services to provide much better-co-ordinated services for patients, particularly those with complex health and social care needs.

The first landmark development is now taking place and that is the creation of LINKs. These are local

involvement networks, which will replace patients' forums and the Commission for Patient and Public Involvement in Health, which will cease operations in March 2008 when LINKs should be set up. This recognised that vulnerable people and those with long-term conditions, often groups that have a complex mix of health and social care needs, can be missed by undue concentration on the purely clinical issues. Articulating these needs requires strong input from patients, while successfully meeting them requires a wide range of providers extending well beyond the health service. Ensuring that this care is both available and seamless requires better partnership working and guidance for health services and local authorities, which now increasingly emphasises the importance of joint working and joint service provision. The role of nurses in managing this process will be key to much of its success.

LINKs will therefore be a network of local people, organisations and groups that want to make care services better. They are due to be established by April 2008, so at the end of 2007 and early 2008 local authorities who have been charged with the responsibility to procure the host organisations are busy undertaking that process. The involvement of local authorities is important as there will be a LINK in every local authority that has social services responsibility.

LINKs will encourage and support local people to be involved in how local care services are planned and run. They will listen to local people about their needs and about their experiences of services. LINKs will look at all health and social care services that are funded by taxpayers, and it will not matter whether they are provided by the NHS, a local authority, a private company, a social enterprise or a charity.

LINKs will feed this information to the people responsible for commissioning, providing, managing and checking up on health and social care services, so that things can change for the better.

The really important thing for the LINKs to do will be to bring together local people and organisations from across the whole community, so providing a much broader base than the patient and public forums which they replace. LINKs should include patient groups, patient transport groups, local business groups, older people's forums, self-advocacy groups, support groups for specific service users, faith groups, minority ethnic groups, tenants' groups, foundation trust governors, individuals, youth councils, neighbourhood renewal networks, carer networks and any other groups active in the community.

Their knowledge and insights about their local communities will provide a way for users to feedback the information and intelligence about health needs that commissioners so sorely need. This may be a difficult process for health and social care professionals to deal with, but as more services move out into the community, and as we cope with rapidly changing demographics so the way that services are commissioned and delivered must reflect the experience of users.

So, increasingly, health professionals working in primary care and community settings will be involved in developing partnerships for service delivery, especially where patients and carers have complex health and social care needs. Hopefully LINKs will provide a good first point of contact for finding groups, organisations or individuals who can contribute to the process of commissioning and delivering good-quality services that really will meet the needs of patients and their carers. Specialist community public health nurses have traditionally taken the lead in providing a whole range of these services, and it is encouraging that their work will be enhanced by an early involvement in LINKs. This will be made easier by the commitment in the NHS Operating Framework for 2008/2009, which states that primary care trusts have to work with local authorities and other partners (LINKs) to focus on ill-health prevention and on promoting good health; on helping people to live healthier lives and to take more control of their own health; and on ensuring that health inequalities are reduced. This includes tackling lifestyle issues such as obesity and alcohol abuse, teenage pregnancy, sexual health problems and other areas where inequalities exist. The LINKs legislation is loosely written and encouraging of local people and organisations, building on what already exists in communities. This provides an ideal environment for specialist community public health nurses and others working in the community to engage with them for the benefits of residents, patients and their carers.

LINKs will no doubt make a significant contribution in identifying needs and representing the views of the local community, and should enable the views of the least-well represented to be heard. But how do you listen to what individuals say about the reality of their care and experiences? The methods used by the NHS –

surveys and questionnaires – are a very blunt instrument to get the complexity of the whole experience, particularly the care, thought and respect for individuals which are so important to patients, but which can be missed in a busy clinical setting.

The web provides the second major area of change in how patients can influence service provision. Until the last few years it was hard for anyone to get their views heard in public, but now anyone can blog or post a video clip of the dirty toilet on Ward 16 to YouTube. With the cost of having a public voice now close to zero, a new set of web-based services is springing up, including Patient Opinion (www.patientopinion.org.uk), Rate MDs.com (www.ratemds.com), NHS Choices (www.nhs.uk/Pages/homepage.aspx) and Nurses Recommend Doctors (www.nursesrecommendoctors.com). The rest of this article uses the experience of Patient Opinion to show how these new web-based ways of working can help busy nurses improve services by using patient feedback.

Patient Opinion provides an independent, not-for-profit platform where patients and carers tell their stories emphasising what is important to them and what made the difference – good or bad. Patient Opinion is free to patients, easy to use and carries no advertising. More than 50 NHS organisations currently subscribe and this enables them to direct postings from patients to 'just the right person' in their organisations using RSS feeds. For example the matron responsible for women's services at a trust can receive all relevant postings as a weekly email digest. If she wishes she can also post a reply explaining the situation or telling the public how the trust has improved services.

This helps busy, hard-pressed nurses to access systematic information and feedback about just their services. Interestingly, over half of all stories are positive and many emphasise how much good nursing care is valued.

Patient Opinion is a not-for-profit social enterprise with a website that uses the latest Web 2 technology so that patients and their carers can share their hospital experiences in their own words and in their own time.

It is a simple and easy-to-use site, and it is totally safe and confidential. Patient Opinion is dedicated to improving the NHS by enabling trusts to listen to patients and to respond to their concerns. Trusts who subscribe to Patient Opinion are sent anonymous copies of comments about their services and can respond via the site so that patients and their carers know whether or not their thanks have been passed on or their suggestions for improvements have been implemented.

Patient Opinion has already collected numerous stories of trusts making changes as a result of comments made on the site (see www.myNHS.org.uk/impact).

Patient Opinion has also built strong links with many of the patient groups working in the field of

long-term disease. These groups use the site to monitor what is happening to their disease area across England, and to post their own responses to patient stories. Patient Opinion is now exploring further developments of these relationships to provide a significant opportunity for patient groups to influence the commissioning process locally.

There is a lot of official information about the NHS available on the internet, and it is to be welcomed, but what people often want to know is what other patients think of local services. Patient Opinion provides the interface for these local conversations to take place and for *nurses and managers* to have real-time feedback about what is happening in their wards and clinics, almost on a day-to-day basis. By providing the forum for patients and carers to tell their stories in their own words and in a time that is convenient to them, it is easy to highlight what is important to them and is much more sensitive to what matters to the patients than would ever be possible through surveys or questionnaires.

Patient Opinion is already expanding into mental health, with a pilot under way in the north west. During this year it will also expand its coverage from all acute hospitals in England to all hospitals in the UK.

The potential to provide patient stories and experiences through Patient Opinion is endless, and the more postings there are about particular services the more difficult it will be for service providers to ignore the site. So for the nursing profession committed to improving the quality of health care, promoting this site to your patients and regularly reviewing the stories on the site will be a significant learning opportunity.

Go to www.patientopinion.org.uk, telephone the freephone number 0845 113 0012 or ask for a freepost form if patients do not have internet access.

CONFLICTS OF INTEREST

Christina Funnell has worked for nearly 30 years in the voluntary and public sector as Chief Executive of the National Eczema Society and the Skin Care Campaign, as a lay member of the Nursing and Midwifery Council (until Summer 2006 although she still chairs investigation committees), as a lay member of the Richard Neale Inquiry, as Patient Public Involvement Manager with the Clinical Governance Support Team of the NHS Modernisation Agency and as PPI Manager with the North East Yorkshire and North Lincs Strategic Health Authority. Dr Paul Hodgkin is Chief Executive of Patient Opinion and a Sheffield general practitioner.

REFERENCE

- 1 Department of Health. *Strengthening Accountability – Involving Patients and the Public*. London: Department of Health, 2007.

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Received 9 December 2007

Accepted 7 January 2008