Patient and public involvement is at the heart of the government’s plans to modernise the health service and seeking patient’s views on care received is a critically important part of any effort to improve the quality of health care services.

Patient and public involvement can occur on a number of levels whether it is regarding decisions about personal care and treatment, volunteering time and expertise to help with the delivery of services at a local level or involvement in service planning and proposals for change through patient forums and working groups.

Decisions about Healthcare

Failures in communication of information about illness and treatment are a frequent source of patient dissatisfaction. A fact echoed by those inpatients surveyed by Picker Institute Europe, 48% of whom reported that they wanted to be more involved in the decisions made about their care and treatment and 21% of whom felt they weren't given enough information.

To help patients make informed choices about care and treatment it is essential for health professionals to:

- Provide full and detailed information
- Elicit patients views and preferences
- Answer questions honestly
- Use written material and visual aids where appropriate
- Allow patients enough time to reflect before and after making a decision
- Give patients the opportunity to discuss issues with their families

Some patients may prefer not to make a choice about their healthcare but they should be offered the option of involvement nonetheless.

An inpatient visit can be a daunting experience so it is extremely important that patients have the opportunity to share any of their fears and uncertainties so that they don’t feel too far removed from the decision making process. However an astonishing 60% of surveyed patients who had concerns could not always find someone to discuss them with. In addition 54% of patients who had anxieties or fears about their condition or treatment were not always able to discuss them with a nurse and almost half were unable to talk about them with a doctor.

**Contributing to service delivery**

Patients and the public have many skills to offer to the delivery of local health care. In a voluntary capacity they can provide a wide variety of services to complement the support provided by professional staff.

Offering a ‘listening ear’, inpatient based befriending and welcome and reception duties are just a few of the areas of work that patients and the public can help with. As well as forging links between hospitals and their local communities volunteering can help to create an involved and informed public.

Patients should be recognised as experts in their own condition. Many can offer the benefit of their experience to those suffering from the same condition or undergoing similar treatment.

Establishing a register of patients willing to discuss their experiences with others is an excellent way of offering a high level of advice and support to patients.

**Service Planning**

Patients and carers should be involved in planning and service development if health care is to become more responsive and accountable to their needs.

Patients must be given the opportunity to provide feedback about their experience and this information should be used in a constructive way. Patient survey results are one excellent way of finding out what matters to patients. Setting up groups with patient and carer representatives to evaluate services, influence decision making and suggest improvements is also an important way of engaging the perspective of service users.

* All figures quoted are based on 80 patient surveys carried out by Picker Institute Europe as part of the NHS Inpatient Survey programme 2001/2. The total number of patients who responded was 44,383.

**Improving Patients’ Experience** is published by Picker Institute Europe, a registered charity (No 1081688) that specialises in measuring patients’ experiences and using this feedback to improve the quality of health care. Picker Institute Europe also runs the advice centre for the NHS patient survey programme. For more information please visit our website at www.pickereurope.org. If you would like to receive this newsletter by email, contact Danielle Swain at: danielle.swain@pickereurope.ac.uk
**Useful Information**

This newsletter only focuses on some of the issues surrounding culturally sensitive patient care. The following may be helpful for more detailed information:

- National Commission for Patient and Public Involvement in Health (CPPIH): www.cppih.org
- Department of Health: www.doh.gov.uk/involving patients/index.htm
- Ridley, J., Jones, L., User and Public Involvement in Health Services: A Literature Review: http://www.show.scot.nhs.uk/involvingpeople/A%20literature%20review.pdf

**Sharing Good Practice**

Please send any examples of good practice within your Trust to:
Danielle Swain
Development Officer
Picker Institute Europe
King’s Mead House
Oxpens Road
OxfordOX1 1RX
Tel: 01865 208108
Fax: 01865 208101
Email: danielle.swain@pickereurope.ac.uk

Please distribute this newsletter throughout your organisation.

**Where It’s Working**

**Ward Sister Development Days**

**Mayday Healthcare NHS Trust**

Development days for ward sisters are held monthly at Mayday Healthcare NHS Trust. This initiative allows discharged patients to discuss their experience of care at the hospital. Patients speak for around 30 minutes to the ward sisters who then develop an action plan around a particular issue. This is then discussed and implemented with their ward teams. Changes are made as a direct result of the feedback received at these events.

Many of the patients involved have found the experience an empowering one as they have the opportunity to talk and be listened to by health care professionals.

Staff also value the scheme as an opportunity to hear the patient’s voice as well as time to reflect on their own practice and the delivery of care in their departments. Staff are also able to recognise the influence they have on the patient experience.

**Volunteer Befrienders Scheme**

**West Suffolk Hospital NHS Trust**

In order to make patients feel more relaxed and less anxious during their operations West Suffolk Hospital NHS Trust has adopted a new approach to day case eye surgery.

The ‘Volunteer Befrienders Scheme’ enables patients undergoing treatments such as cataract operations to have their hand held while the ophthalmic surgeon goes about his work. The volunteers provide reassurance to patients and facilitate communication between the patient and staff. If a patient is concerned for any reason during an operation they can squeeze the hand of their ‘friend’ who will tell staff so that they can try to resolve the issue.

The ‘befrienders’ meet and talk to patients before the operation and stay with them until the procedure is over and they have had a cup of tea. Potential volunteers for the scheme are carefully screened and spend time with the theatre staff before they are taken on. Feedback has been very positive and patients appreciate the service. Volunteers also value the contribution they are making to the patient experience.

Contact: Geraldine Debenham, Voluntary Services Manager, geraldine.debenham@wsh.nhs.uk

**Patient Involvement Experience Group**

**Royal West Sussex NHS Trust**

The Patient Involvement Experience (PIE) group at Royal West Sussex NHS Trust actively looks at how to involve patients. A visually impaired patient used a tape recorder to note his experience of navigating the hospital. He included tips about how the signage and environment could be improved and his comments have been used to implement changes.

PIE also commissioned a video for day surgery patients. “Your guide to St. Richard’s Day Surgery Unit” introduces the team, explains what they do and answers patients’ most frequently asked questions. A volunteer patient and her husband were used in the video and PIE wrote the script. The video is widely available and is often played in the waiting areas of Outpatients and Day Surgery.

Contact: Lyn Robertshaw, Director of Operations and Nursing, Royal West Sussex Hospital, 01243 831494

**Register of Urology Patients**

**Royal Shrewsbury Hospitals NHS Trust**

Royal Shrewsbury Hospital have set up a register of Urology patients who are willing to discuss their condition and treatment with other patients. Establishing a pre-operative assessment clinic highlighted the need for further efforts around the issue of informed consent, particularly for those patients facing major cancer surgery. Nurses could provide a lot of information to patients regarding outcomes and risks but there were still questions they could not answer as they did not have real experience of what patients might face after this life-changing surgery.

After tentative discussions with patients some said they would have welcomed the opportunity to speak to other patients about their surgery. Others were prepared to share and discuss their experiences with others. A register of these patients has now been developed. When nurse specialists see patients listed for certain types of surgery they talk through the procedure with them and give them the option of contacting a patient on the register. If required the nurse specialist facilitates contact between the patients but leaves it up to the patient concerned to get in touch and arrange the first meeting or discussion.

Contact: Carol Browning, Senior Sister, Ward 26-Urology, Royal Shrewsbury Hospital, Mytton Oak Road, Shrewsbury, Shropshire, SY3 8XQ