

○ Improving Patients' Experience Sharing Good Practice

NO 14 SERVICE PLEDGE TOOLS: MAKING PATIENT ENGAGEMENT A REALITY

Patient engagement is a much-used term describing an essential healthcare concept. But what is it, why do it and how in reality can you deliver it effectively? A service pledge tool developed by Breakthrough Breast Cancer offers a tried and tested model.

What is patient engagement and why do it?

Research by the Picker Institute confirms that delivering genuine patient engagement holds the key to more rewarding interactions for patients and healthcare professionals alike. More importantly, involving patients in their treatment and care is known to improve healthcare quality and experiences.

We know that "most patients want to play an active role in their own healthcare...when they are ill they want information about the treatment options and likely outcomes; and, in addition to seeking fast effective health advice and care when they need it, most people also want to know what they can do to help themselves."¹

The sharing of information is proven to improve patients' knowledge, decision-making and ability to self-care. A report written by the Picker Institute, on strategies for improving patients' experience of cancer found that "patient decision aids...lead to more appropriate use of tests and treatments...Support for self-care should be a very important priority now that patients are living longer with cancer...increasing their sense of self-efficacy and encouraging the adoption of healthier lifestyles. In some cases this [leads] to a reduction in consultation and admission rates with resultant cost

savings. Self-management education appears to work best when it is fully integrated into clinical care and when patients' learning is supported and reinforced by health professionals at every opportunity."²

Delivering patient engagement

Effective patient engagement involves tailoring practice according to the needs of both specific conditions and to the needs of individual patients. So how do you devise and deliver such practice?

Robust examples of effective practice exist that can be adapted by others to suit a variety of patients, settings and service needs. Breakthrough Breast Cancer (Breakthrough) has developed a Service Pledge tool for breast cancer units across the country

offering a tried and tested route to implementing patient engagement.

Developing a Service Pledge for Breast Cancer

The **Service Pledge for Breast Cancer** is a tool designed to make service improvements in breast units and encourage and enable patient involvement in the process. To date, fifteen breast units have worked with Breakthrough including those at Pilgrim Hospital, The Royal Surrey County Hospital and Norfolk and Norwich University Hospital. Each produced local Service Pledges, based on a template developed by Breakthrough. A Breast Care Nurse 'Pledge Lead' championed the project in each case and patient representatives were involved throughout.



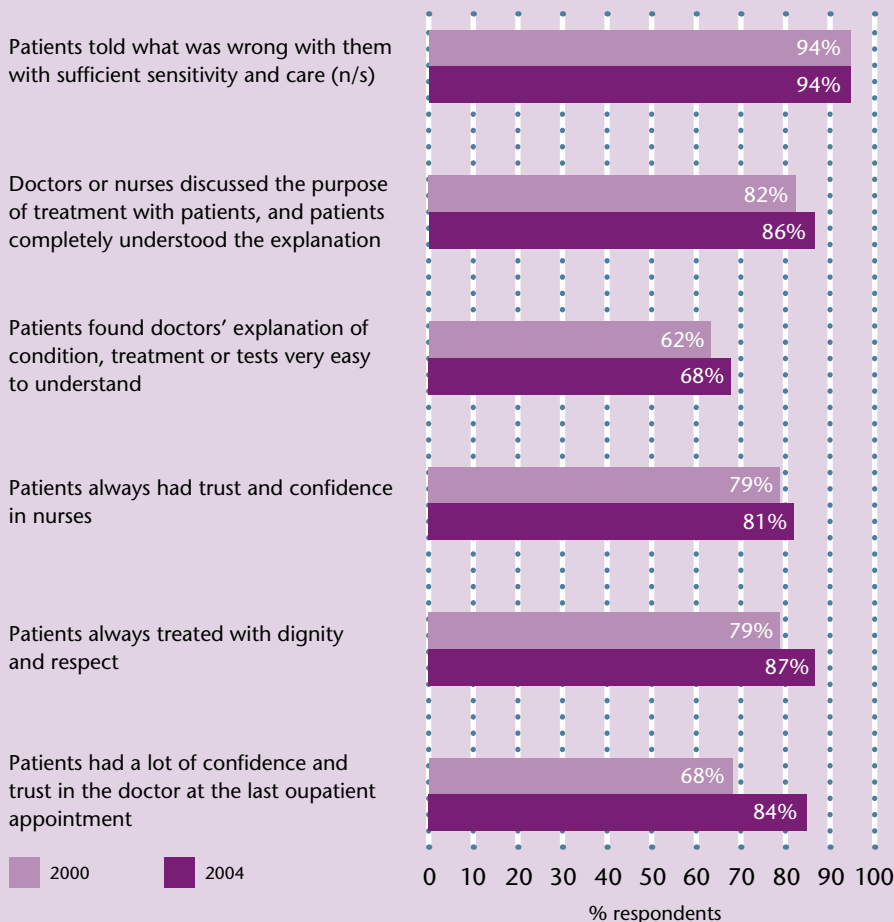
1 Engaging patients in their healthcare: how is the UK doing relative to other countries? A Coulter, Picker Institute Europe 2006

2 Evidence on the effectiveness of strategies to improve patients' experience of cancer care, A Coulter, Picker Institute Europe 2007

What national patient surveys tell us about cancer services

National patient surveys carried out by the Picker Institute on behalf of the National Audit Office* illustrate patient-reported improvements that have been made to cancer services. Such improvements can, in part, be attributed to policy initiatives such as the National Service Framework for Cancer which advocate patient engagement.

Key items from surveys of cancer patients' experience of treatment and care: comparison between 2000 and 2004



NOTES

1 Items are drawn from representative questions for each "theme" within the 2004 NAO Cancer Patient Survey

2 For the items marked (n/s) the year-on-year change is not statistically significant

* Tackling Cancer: Improving the Patient Journey, National Audit Office, 2005



How the Service Pledge works

At every Service Pledge (SP) site, Breakthrough carries out both an in-depth patient survey and face-to-face interviews – a patient audit – to determine to what extent standards of care are being met. Using the results from this patient audit the breast unit develops a local Service Pledge and commits to implement improvements as recommended by patients. These can range from small, no-cost changes to more ambitious longer-term goals.

One task of the Pledge Lead and patient representative, who is recruited via the questionnaire, is to identify improvement goals that are both feasible and likely to make a difference to a significant number of patients. This involves negotiation and compromise, balancing the audit data against such challenges as budgetary and clinical constraints.

The end result is a local SP committing to a minimum of three improvements, usually with at least one short-term, one medium-term and one longer-term goal, that may require financial investment.

"It has been empowering and satisfying to work on the goals of our local Service Pledge as it helps us to focus on what patients tell us they want from us rather than what they get from us."

*Doreen Macaskill-Refaat,
Breast Care Nurse and Pledge Lead,
United Lincolnshire Hospitals NHS Trust*

A dedicated breast cancer bay at Lincoln County Hospital

Undergoing breast surgery can mean leaving a unit where all staff and resources are dedicated to treating breast cancer, for a place where staff are not specialists in the condition and cater for a variety of patients. Feedback from Breakthrough's audits suggests that placing breast cancer patients together fosters a sense of mutual support and camaraderie and helps address the isolation experienced when on general medical wards.

As a result of their audit, the Pledge Leads at Lincoln County Hospital decided to establish a dedicated breast cancer bay in the general ward to ensure that patients were given a bed in an area where they could feel supported and more at ease.



A drop-in clinic at the Friarage Hospital, North Yorkshire

The two Clinical Nurse Specialists Pledge Leads had anecdotal evidence that women living in this large rural area of North Yorkshire found it difficult to access the hospital's drop-in clinic.

Further research confirmed the need for community based clinics for a wide range of reasons, including seeking advice about prostheses and getting reassurance about general health concerns. The feedback also highlighted the poor public transport links which prevented women travelling to the main hospital site.

As a result, a community drop-in clinic 11 miles from the hospital was piloted and has received high praise from the current Secretary of State for Health, Alan Johnson.

Breakthrough's Service Pledge template

Breakthrough's template lists the standards of care and involvement that breast cancer patients can reasonably expect from their hospital during the course of their treatment. In addition it outlines the contribution a patient can make towards a successful partnership with healthcare professionals. It includes such topics as the giving and receiving of information, the opportunity to discuss concerns, and being offered a choice of treatment.

Example standards from Breakthrough's template include:

What the patient can expect...

- to be treated with dignity and respect throughout your care and treatment.
- to receive your test results no more than five working days following your tests.
- for your diagnosis to be clearly and sensitively explained so you can understand as much about your condition as possible.
- to decide how involved you want to be in making decisions on your care and treatment.
- to receive information about local services offering psychological, social, spiritual and cultural support.

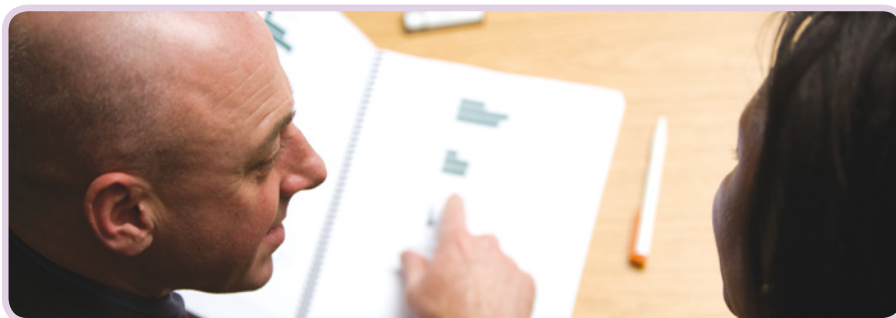
What the patient is asked to contribute...

- accept that your initial diagnosis is not always straightforward and may be revised, but the reasons for any revisions will be explained.
- read the information we provide or ask your Breast Care Nurse Specialist to explain it to you. If you would like any additional information please ask your Breast Care Nurse Specialist.
- keep all appointments or, if you have to cancel, tell us as soon as possible so we can give the appointment to someone else.

"The Service Pledge helps to explain what to expect from the hospital at different stages to enable the journey to run smoothly. I wish I had had access to this wealth of information when I was a patient."

*Helen Howard,
Patient Representative for
Norfolk and Norwich University
Hospital Service Pledge*

Suggestions for making change happen



- **Use patient feedback.** Decision makers need evidence that your issue is important to a reasonable number of patients. Demonstrating that the demand for an improvement exists will put you in a stronger position to secure funding.
- **Refer to Department of Health guidance.** Section 242 of the *NHS Act 2006*, as amended by the *Local Government and Public Involvement in Health Act 2007* places a duty on trusts to involve patients and the public in the planning and development of health services. *The Cancer Services Manual* used in the peer review of cancer services, for instance, states that breast

multi-disciplinary teams must survey patients and implement at least one action point as a result.

- **Demonstrate how you will evaluate the success of your improvement.** Gathering further patient feedback will enable you to assess the impact of your improvement.
- **Identify the clinical case for change.** Work with colleagues in your multi-disciplinary team to establish how your proposals might also improve such things as patient anxiety or pain control. Use any documented evidence in medical literature to back up your claims.

For a copy of the 'Service Pledge for Breast Cancer' and other information visit the campaigning section at www.breakthrough.org.uk or contact Madeleine Davies, at Breakthrough at madeleined@breakthrough.org.uk

breakthrough
breast cancer



For copies of all the Picker Institute's reports, further information on patient engagement and more examples of good practice visit our website at www.pickereurope.org

picker
INSTITUTE

making patients' views count

What patients want: breast cancer patients highlight common concerns

Breakthrough patient audits have produced a wide range of improvement suggestions. Many apply to patients with other conditions or in different settings. They include:

- providing a separate exit or private room nearby to the consultation room to enable distressed patients to leave with dignity
- updating patients on the estimated length of delay for clinic appointments, the cause of the delay and whether it is possible to reschedule their appointment or wait outside the unit
- pairing patients with a "buddy" – a patient who has undergone similar treatment and is happy to describe their experience
- supplying a list of websites that are safe and reliable sources of information
- including enough chairs in waiting rooms to accommodate a friend or family member accompanying patients
- providing clear information about who to contact outside working hours – such as the GP or district nurse – particularly during holiday periods
- not calling patients into the consulting room until the healthcare professional is ready
- keeping GPs fully up to date on patients' treatment and progress.

Sharing good practice

If you would like to receive *Improving Patients' Experience* or you would like to share examples of good practice please contact:

Danielle Swain, Quality Improvement Manager
Picker Institute Europe, King's Mead House
Oxpens Road, Oxford, OX1 1RX

Tel: 01865 208100

Email: danielle.swain@pickereurope.ac.uk

For more information please visit our website at www.pickereurope.org

Improving Patients' Experience is published by Picker Institute Europe
Issue 14: May 2008

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count.

Charity Registration No 1081688. Company Registration No 3908160.

Please distribute throughout your organisation