



# Patient-centred Healthcare

## What should it really look like?

As a child in the late 1940's I spent several months in bed with rheumatic fever and pericarditis. It was a serious illness for which there was then no effective treatment. I have never forgotten my mother's devoted nursing care or the kindly paediatrician who always made me feel as though I was the only patient who really mattered to him. For them, care was all because there was nothing else they could do. Now fast-forward to 2009, and contrast their attitude to care with the outlook of a nursing team leader – also a conscientious woman – who shocked me recently when she said that she 'didn't need to care to do her job properly'. She sees herself as a technician, but is she really patient-centred?

These two anecdotes illustrate the challenge to modern health care. In the intervening 70 years healthcare in the Western world, and societies themselves, have changed out of all recognition. We all know the story. Dominating everything, we have seen, and celebrated, the wonderful, relentless onward march of medical science and discovery which has made it possible for health professionals to diagnose, treat and cure or alleviate the clinical effects of illness as never before. Inevitably, given the relative powerlessness of patients, an all pervasive medical and health policy culture has evolved primarily around doctors' clinical and scientific interests and priorities, which are not always exactly the same as patients'. At the same time the increasing complexity of much care, and pressures of demand, have made it more difficult for health professionals and patients to establish and sustain the relationships essential to the building of trust.

New science and new ways of organising care, welcome in themselves, nevertheless come at a price we have only recently acknowledged. For some health professionals, their professional organisations and the institutions in which they work, the so-called 'soft' parts of healthcare, basically about attitudes, relationships and communications have tended to be seen as less important, less interesting and less relevant than the hard science of clinical outcomes and clinical effectiveness. One result is that patients report wide variations in their experience of care. Even in the same episode of illness such experience can range from excellent to unacceptable. Actually patients have always wanted the best of science and the best of care – for them they are not alternatives. They tolerated the dichotomy because, until recently, they have never had sufficient influence or power to do much about it.

A big step forward came in the early 1980's when the late Harvey Picker, an American scientist and philanthropist, and his wife Jean who suffered from a serious, relapsing infection, decided to try to adjust the

balance. From their own experience they could see that, whilst the US healthcare system was strong on medical science, it nevertheless left much to be desired in terms of its humanity and ability to be responsive to the experience of illness as seen "through the patient's eyes". So, to raise the profile of what they called 'patient-centred healthcare,' they decided to enlist the aid of science.

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They endowed the Picker-Commonwealth Program for Patient-Centred Care, from which the Picker Institutes evolved. Located at Boston's Beth Israel Hospital and Harvard Medical School, the programme's main thrust was to devise new instruments and new scientific methods for measuring, assessing and comparing patient experience

[Article continues onto the next page >](#)



against seven carefully developed dimensions of patient-centred care in the hospital setting. The results of this basic research provided ammunition for the emerging patient-centred care movement and has underpinned our understanding of and ability to measure patient experience in the NHS today.

In the last ten years the policy argument for regarding patients' expectations and experiences as fundamental elements of health care quality has been won on both sides of the Atlantic. Now the focus is on delivery, the subject of the Conference on Quality, Governance and Experience to be held on 17th December 2009 in London.

**What will it really be like?**

My expectation is that patient-centred care in the NHS and private sector will include the following:

1. Full acceptance of the fact and the practical implications of patient autonomy by Parliament and all providers. The patient becomes the active focus of a partnership in care, not a passive recipient. That means their full involvement in decisions about their care – "no decisions about me without me" as Harvey Picker was often heard to say.
2. A thorough understanding of what constitutes patient-centred care at any point in time which is based on solid, well – publicised evidence gained from patients and the public as well as health professionals and policy makers. Health professionals and institutions will have a clear idea of the standards of care expected of them, and the public will be equally clear about what patients are entitled to expect.
3. That understanding will be absorbed fully into the culture of individual health care professions, their educational organisations and their regulators, and into the governance of every hospital and general practice.
4. Since patients do not choose to be ill, and medical investigations and treatment can often be painful, frightening and distressing, it will become a given that the process of care - which is largely in the hands of providers – should be exemplary, and never of itself become a cause for worry and concern to patients or their relatives.
5. Measures of patient experience will therefore be accepted as valid expressions of quality in their own right, not conditional on establishing a relationship with clinical indicators or a business case.
6. Patients and the public will have direct access to a comprehensive range of generic and specialty- specific metrics of clinical performance at the team and where possible individual clinician level, with an emphasis on clinical outcomes and patient experience.
7. In terms specifically of experience data,

near real-time feedback at the level of clinical teams and individual clinicians will replace point in time surveys very quickly. If used imaginatively there is huge new scope for quality improvement.

8. More generally, all concerned with health care will make far more extensive use of the Internet as data on the performance of individual clinicians and clinical teams becomes available, enabling them to benchmark against national and international peers.
9. That will give patients, potentially, much more scope for deciding whom to choose for their care in future. Equally, it will challenge providers who are bound to become more concerned to protect and enhance their reputation as their performance is laid out for all to see.

**Best possible outcome in clinical terms into an approach that is truly patient-centered**

Marrying the imperative to constrain costs with the necessity for the best possible outcome in clinical terms into an approach that is truly patient-centred is likely to be one of the most significant but fundamentally important challenges facing healthcare organisations over the coming years but the rewards of achieving it are priceless. So there is the challenge!

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Chairman, Picker Institute Europe, Former President of the General Medical Council



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