

Essential quality updates

Patients and public trust: a NICE approach?

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Trust is a funny thing – our response to the words ‘trust me’ can often hide a complex range of experiences, relationships, history and environment. Imagine a situation, outside the world of health services, where a brand new public body is established by the government to make national decisions about the way the service you and your family experience is provided.

You have no idea who the players are, some of the stakeholder groups don’t welcome the intrusion in their affairs and have been lobbying against it; the press and political welcome has been mixed, and as it’s a new organisation its processes and methods are still being established.

It says to you and your family – ‘trust us, we want to do the right thing, we want to work with those whose lives will be affected by our decisions’. OK, be honest; what’s your initial response?

How about ‘I’ll believe it when I see it’?

This was exactly the challenge the National Institute for Clinical Excellence (NICE) faced when it was established in 1999. Conceived as one part of a strategy to enhance the quality of care for NHS patients and to eradicate inappropriate variations in clinical performance, the Institute’s remit was to provide national guidance on treatments and care for people using the NHS in England and Wales.

As a Special Health Authority and a part of the NHS we faced the challenges that all NHS transitions faced, engaging patients and their carers in the decisions we make and trying to do it in the full gaze of national and international media.

From the outset NICE was realistic about the challenges it faced. We recognised that the external pressures and scrutiny would be significant, lobbying was likely and the opportunity for mischief makers would be too great for them to ignore. We also understood that with a planned staff of less than 25, and inherited budgets that covered existing contracts our resources to engage in or manage the environment were severely limited.

Against this background we decided to focus on three key areas. Firstly a real commitment to transparency: NICE invested in a website that would put information about our processes, development and guidance in the hands of the NHS, professionals,

the media and importantly the public, all at the same time. We concluded that, in the long term, those who sought to judge NICE, use its guidance or comment on its decisions would want access to the same information as those who made the decisions.

Secondly NICE committed to engage and publicly consult with all stakeholder groups – including patients and carers – and to provide them with an equal voice. Patient and carer organisations are routinely engaged in the Institute’s governance and in the development of its guidance.

The board includes two non-executive directors with substantial experience of patient and carer advocacy and from the outset the board has met in public, moving the board meetings to different towns and cities throughout England and Wales, giving NHS staff and the public outside London, the opportunity to get involved.

The agenda and papers for the meetings are published on the Institute’s website and members of the audience are given an opportunity to comment or ask questions between each agenda item.

One-quarter of the membership of the Institute’s Partners Council (which advises NICE on strategy and business development) represents patient and carer interests. All the Institute’s independent advisory committees and guideline development groups include individuals with experience of patient or carer advocacy; and the Institute created a Patient Involvement Unit (PIU), based at the College of Health, which supports representatives of patient and carer organisations in contributing effectively to the development of NICE guidance.

It is not enough to have patients and carers involved; the Institute wants them to have an equal opportunity to engage.

The PIU also supports NICE in continuously developing its approach to user and carer involvement. NICE recognised it was a new and developing organisation and by really listening to the voices of patients and carers, alongside those of the NHS and professionals we could develop appropriate and rigorous approaches (see Box 1).

Finally we recognised we were in this for the long game – NICE acknowledged that it should be judged by the quality of its ‘products’ and the robustness of

Box 1 Patient/carer and professional involvement in NICE

- Board of NICE
- Developing and reviewing processes and methodology
- Partners Council
- Topic identification (topics are selected by the Department of Health and the Welsh Assembly Government)
- Developing scopes for the work to be covered
- Members of independent advisory committees, collaborating centres guideline development groups, guidelines review panels, appeal committees
- Submission of their own evidence and unique perspectives
- Nominating experts
- Genuine and public consultation
- Appeals (technology appraisals)
- Communication/dissemination of guidance
- Implementation
- Reviewing guidance and guidelines

its advice and methodology. There are three key components to this:

- technology appraisals – which focus on the clinical and cost-effectiveness of medicines and treatments within the NHS in England and Wales
- clinical guidelines – which also consider clinical and cost-effectiveness when identifying the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales
- interventional procedures – which consider whether procedures such as radiotherapy or surgical interventions that are used for diagnosis or treatment are safe enough and work well enough for routine use. The most recent of the NICE work programmes, it was launched in February 2003 and the first guidance was published in July 2003.

Technology appraisal is the more established programme. The Institute published its first appraisal guidance (routine removal of wisdom teeth) in March 2000; between then and June 2003, NICE has published 62 technology appraisal guidance documents covering more than 207 researchable subjects. As this programme has developed, so has the methodology and the way we engage patients and carers. Along with NHS professionals they have the opportunity to engage at all stages in the development of appraisal guidance and are involved in the current review of methodology.

Increasingly as experience of the Institute's work has widened, so has public trust in NICE. Indicative are recent position statements from national groups – typified by a quote from the National Obesity Forum (May 2003): 'NICE has helped end confusion by providing a single national focus for treatment and best practice, and has issued timely and authoritative advice . . .'.¹ In addition, we are seeing further independent support that, 'generally, where NICE recommends the use of a technology it will lead to faster and more uniform access to these technologies' rather than to a denial of access.²

During 2002–2003, NICE has been investigating ways of obtaining a broader perspective on patients' and carers' views and experience of a health technology, particularly with regard to information about quality of life. The Institute has commissioned an independent team at Birmingham University to develop the idea of assessing the impact of a particular medicine or medical device on patients during the technology appraisal process. NICE intends to consult on the team's proposals later this year.

Clinical guidelines is a newer programme; early guidelines published by NICE formed a part of its inherited work programme. The first clinical guideline to be fully commissioned by NICE and developed to the NICE guideline development process was *Core Interventions in the Treatment and Management of Schizophrenia*, published in December 2002.³ Since then guidelines on head injury, infection control and pre-operative testing have followed and with more than 20 due for publication over the next two years this is a rapidly expanding programme.

To support the development of the Institute's clinical guidelines programme, NICE established seven multidisciplinary National Collaborating Centres (NCCs). These centres bring together groups of healthcare professionals, patient/carer representatives and academics to develop clinical guidelines and audit advice for the NHS in England and Wales. The seven centres cover acute care, cancer, chronic disease, nursing and supportive care, mental health, primary care, and women and children's health. Each centre follows the same international standards of guideline development, which include appropriate user and carer involvement and public consultation.

For each guideline, they establish a development group consisting of service users and carers, health professionals and academics. This group reviews the worldwide data alongside current clinical practice, the experience of service users and the feedback they receive from two rounds of widespread consultation.

The NCC for primary care currently has five guidelines under development on epilepsy, generalised anxiety, diabetes footcare, familial breast cancer and referral guidance for suspected cancer. The NCC

will shortly be starting work on guidelines on obesity and postnatal care. More information about all these guidelines can be found on the NICE website at www.nice.org.uk.

And so to public engagement, championed in the Kennedy Report following the Bristol Enquiry.

In 2002 the Institute established a Citizens Council to ensure that the judgements that underpin its evaluation of clinical and cost-effectiveness reflect, more clearly, the values held by people living in England and Wales. Over 35 000 application forms to take part in this groundbreaking initiative were downloaded by members of the public from the NICE website. Around 4400 people applied to join the council.

Drawn from people living in England and Wales who neither work for, nor supply, the NHS, the Citizens Council's views inform the deliberations of the board and its advisory committees.

The Council has held two formal meetings to date, in December 2002 (to discuss 'What should NICE take into account when making decisions about clinical need?') and in May 2003 (to discuss 'Are there circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the NHS?').

Trust is hard won, but easily lost. The Citizens Council and other exciting developments (plans to transfer borderline substances and screening to NICE are under consideration) will ensure that NICE is never far from the headlines over the coming years.

NICE is clear that it aims to keep winning trust and to do so patients and carers will, alongside health professionals, continue to play a welcome, vital and central role in the Institute's work.

To find out more about the work of NICE, to follow the progress of specific pieces of guidance or to see how you or your organisation can get involved, visit the website at www.nice.org.uk. Copies of completed NICE guidance can be obtained from the website or by phoning the NHS Response Line on +44 (0)870 1555 444.

REFERENCES

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