

# **Liberating the NHS: greater choice and control**

## **Comments from NICE**

### **Introduction**

1. NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE is also responsible for providing Quality Standards for the NHS and for reviewing and developing clinical indicators for the quality and outcomes framework (QOF) for primary care.
2. NHS Evidence is a service provided by NICE designed to give professionals easy access to clinical and non-clinical information about health and social care selected from a wide range of sources. NHS Evidence is responsible for digitising NICE's products, an initiative which will have the potential to make an important contribution to the 'information revolution' and enable greater choice and control for patients.
3. We agree that greater choice and control can be brought about through cultural and structural change – as proposed in the white paper. However a key enabler will be the proposed shift in approach to the management and provision of information – 'An information revolution'. As an authoritative evidence-based information producer of health guidance and standards (and social care from 2012), we recognise that the consultation papers 'Greater choice and control' and 'An information revolution' are intrinsically linked and many of the comments we have made on 'An information revolution' will apply directly and indirectly to this document.
4. Patient involvement in treatment decisions is an important underpinning principle of NICE guidance, so we welcome the opportunity to comment on this consultation document.
5. The following comments relate to the chapters in the consultation document.

## Greater choice and control (chapter 2)

6. We support the principle that people should be able to choose among clinically appropriate and feasible treatments (section 2.47), and the proposal that such treatments should include any clinically appropriate treatment that has been approved by NICE. NICE provides guidance on a range of new treatments, including medicines, interventional procedures, diagnostics, and medical devices. Because of our concern with cost-effectiveness, many of the treatments we recommend are likely to provide better value for money than the alternatives. **We recognise that many clinical and other factors come into play in shared decision-making, but the relative cost-effectiveness of the options available must be an important consideration.**
7. As the consultation document points out, many ‘tried and tested’ treatments have not gone through the NICE approval process. However, the absence of NICE guidance does not mean that evidence is lacking. Professionals will want to be aware of relevant evidence on such treatments, including uncertainties about their effectiveness or even that they should not be offered, or only offered in particular circumstances. They should regard NHS Evidence as an essential additional resource for establishing the clinical appropriateness and feasibility of treatments. It gives access to evidence and guidance from accredited sources, including evidence on treatments that should be discontinued or should not be used routinely – via the database of uncertainties about the effect of treatments (DUETs) and NICE’s database of ‘do not do’ recommendations from NICE guidance.
8. Choice and control may be easier to realise when the focus is on specific treatments than on a pathway of care involving a number of treatments at different stages. **Enhancing choice and control needs to be in the context of commissioning that ensures that the design of care pathways reflects NICE Quality Standards, NICE guidance, or guidance from sources other than NICE which has been accredited by NHS Evidence.**

## Making it happen: information, ‘any willing provider’ and other tools (chapter 4)

9. NICE is contributing to the information revolution for both professionals and patients (sections 4.3–4.6). Information from NICE and through NHS Evidence about available treatments supports choice as well as enabling shared decision-making. We will support the NHS Commissioning Board in its responsibilities for making sure that people are given more choice and control over their healthcare (section 3.7).

10. From the beginning NICE has involved patients in the development of its guidance and has consistently been an advocate for patient participation in decisions about their care. We publish versions of our guidance and Quality Standards that give patients and carers full information about what NICE has recommended to healthcare and other professionals. The aim is to empower patients and carers in asking for or questioning options for treatment in the NHS. We include contact information of key patient and carer organisations to help the patient or carer have access to all the information they may need about their disease or condition.
11. A section of the NICE website on 'NICE guidance for patients and the public' provides quick access to user-focused documents. The website also gives access to our public health guidance, which supports the aim of providing information for healthier lives and the wider health of the population.
12. The digitisation of NICE guidance will be a key enabler for patient choice as access will be improved through wider distribution via third party systems and services as well as directly by NICE and NHS Evidence services.
13. NHS Evidence is primarily designed for NHS and social care professionals, but is also open to patients and other service users, and gives them free access to all the available clinical and non-clinical evidence about health and social care, except for commercially-owned material in paid-for databases and journals. These resources include patient information from a variety of sources that meets The Information Standard.
14. Improvements to NHS Evidence, such as an easier-to-use search function, topic pages for prioritised information, and the inclusion of a section about the topic of the search as an introduction to the search results, will benefit patients as well as professionals.
15. The NICE pathways project will present all that NICE has to say on a given topic by relating it to a coherent and user-friendly visual pathway. This will give commissioners and health and social care professionals access to all NICE guidance (including public health guidance), Quality Standards, and supporting products relevant to particular care pathways, and should also benefit patient users.
16. Professionals are interested in access through NHS Evidence to patient information, including, via the NICE website, lay versions of NICE guidance, which they and their patients can use in discussions

and decision-making about treatment, and in decision aids, which also support shared decision-making.

17. We agree that research is key to improving evidence and achieving better outcomes, and support the proposals for enabling people to participate in clinical trials relevant to their condition (section 4.7–4.8).
18. We agree that personal health budgets must be based on an agreed care plan (section 4.26). As a general rule, they should not be spent on treatments that are not supported by evidence or which provide poor value for money. NICE guidance and evidence and guidance from accredited sources available through NHS Evidence should be the essential reference points for deciding on treatments that can be covered – see also paragraphs 6–7 above. We welcome the pilot programme and the opportunity to examine the risk acknowledged in section 4.27 from the challenge of making personal budgets effective for individuals while ensuring that wider NHS services are not undermined. **We recommend that the pilot programme should examine in particular the extent of risk arising from clinically inappropriate treatment choices.**

### **Safe and sustainable choices (chapter 5)**

19. We welcome the discussion of the financial affordability of choices (section 5.4) and of the need to manage the consequences (section 5.13–5.15), some of which are unpredictable. **We recommend that the policy be carefully evaluated over a long enough period to enable a well-informed assessment of what works well and what may need to be changed.**
20. We agree that treatment options would need to be of proven clinical value, as demonstrated, for example, by a NICE recommendation or support from other high quality evidence or guidance, such as that from sources accredited by NHS Evidence. But, as stated in paragraphs 6–7 above, NICE is also concerned with cost-effectiveness, so NICE-approved treatments are likely also to represent value for money compared with alternatives. **A strategy for mitigating risks around affordability must therefore encourage choice of the most cost-effective option unless there are factors connected with individual cases that indicate otherwise.**
21. We agree that that no-one should be disadvantaged by the way in which choices are offered (section 5.5). **We suggest that HealthWatch and local government should be particularly concerned with ensuring people from lower socioeconomic**

**groups and deprived areas, or who share 'protected characteristics', have the same opportunity to exercise choice as those from higher socioeconomic groups.**

National Institute for Health and Clinical Excellence (NICE)

January 2011