DECIDE Survey on public awareness of NICE clinical guidelines and their implementation

Executive Summary for respondents

1 Introduction
The National Institute for Health and Clinical Excellence (NICE) was set up on 1 April 1999 to ensure everyone has equal access to medical treatments and high quality care from the NHS regardless of where they live in England and Wales. NICE provides guidance and sets quality standards and indicators with the aim of improving people’s health and preventing and treating ill health. A range of clinical guideline documents are published including the full guideline document (detailed description of how the recommendations were developed from the available evidence), the NICE guideline (summary of the recommendations), and Understanding NICE Guidance (summary of the guideline prepared especially for patients, carers and members of the public). Details of NICE guidance may also be published in newspapers and magazines as well as web articles.

NICE is a partner in DECIDE, which is a five-year (started January 2011) collaborative project funded by the European Commission’s 7th Framework Programme and is designed to research and improve the way healthcare evidence and guidance are presented in clinical guidelines.

2 Purpose of survey
NICE conducted a survey in order to gain an understanding of the extent of public awareness of NICE clinical guidelines and their application, to inform the DECIDE project.

3 Methods
The survey questions were initially developed by Voluntary Health Scotland for a survey in Scotland and were then adapted by NICE to suit England and Wales. The survey was available to respondents through Survey Monkey™ (an online survey tool) on the NICE website and was open to responses from 6 July 2011 to 28 October 2011. The survey was advertised to potential responders through emails to patient and carer groups, third sector organisations and previous Guideline Development Group (GDG) members. A news item was placed on the home page of the NICE website and the survey link was shared through social networking sites and organisations were encouraged to post the survey link to a blog or news feed on their website.

4 Results
4.1 Characteristics of respondents
A total of 1675 responses were received. Most survey respondents were female (70%), aged 30 to 74 years (84%) and white British (85%). Responses were received from across England and Wales with a few responses from Scotland and Northern Ireland.

Most responses were received from patients currently receiving treatment from the NHS (48%) or interested members of the public (18%) whilst some responses were also received from health/social care professionals (17%). Many respondents highlighted that they were members of support groups/networks.

More than half of survey respondents indicated that they have a specific condition or disability (61%). Musculoskeletal (19%), cardiovascular (17%) and neurological (11%) conditions were the most common conditions with further responses from...
people suffering from fibromyalgia, cancer, diabetes, endometriosis, arthritis, Chronic Fatigue Syndrome/Myalgic Ecephalomyelitis (CFS/ME), asthma and depression.

4 Awareness of NICE guidelines

Most survey respondents (83%) stated that they had heard of or were aware of NICE clinical guidelines and other NICE guidance. When these results were separated into responses from health/social care professionals and patients/carers/members of the public/others the response rates were 98% and 79% respectively, confirming good awareness among those responding to the survey. We asked whether they understood the purpose of NICE guidelines with responses including guidance/advice for professionals (21%), best practice (11%), cost-effectiveness (11%) and evidence (8%) being the most common replies. Overall, there was a positive attitude towards NICE but many responses did not accurately reflect NICE’s work. For example, many respondents felt that NICE has a role in approving medicines (6%) or care (2%) in a regulatory role or setting and approving professional standards (5%).

Most respondents had heard about or found NICE guidance via the internet (34%) or through national media (22%). Other common means of becoming aware of NICE guidance were through work and support groups/networks. Generally respondents viewed the guidelines in an electronic format (74%) or printed leaflet (25%) although accessing NICE guidelines through media reports and verbal sharing of information were also indicated.

Approximately one-third of respondents (34%) had seen the healthcare professional version of the guideline, 28% had seen the version for patients and the public whilst 36% could not remember which version of the guideline they had seen. Interestingly many respondents indicated that they actually utilise both versions of the guideline. In particular, some patients mentioned that they viewed the version of the guideline for healthcare professionals in order to get more in depth information about their illness. The main types of guidelines that had been viewed by respondents were cancer (6%), mental health (6%) and cardiovascular (5%) guidelines.

4.3 Awareness of the application and use of individual guidelines for specific conditions

A total of 37% of respondents were aware that a NICE guideline was being followed in their care and treatment. In particular, respondents highlighted that they were aware that NICE guidelines had been used in their care and treatment including cancer (15%), diabetes (7%), atrial fibrillation (5%), CFS/ME (5%), arthritis (3%), eating disorders (3%), depression (3%) and dementia (2%). However, some negative responses were received, in particular relating to the NICE CFS/ME guideline where some survey respondents stated that they disagreed with the recommended interventions.

Respondents highlighted that their doctor (55%) or nurse (22%) had applied the guideline recommendations during their care and treatment although allied health professionals were also mentioned. Generally the guidelines had been used in hospitals (52%) or GP surgeries (30%) but also in a variety of other settings including the home, dental surgeries and Child and Adolescent Mental Health Services. Most respondents (89%) were not given a copy of the guideline during their treatment.

4.4 Developing partnerships between clinicians and patients through NICE guidelines

Just under half of survey respondents (45%) felt greater confidence in their own or a relative’s care and treatment for a particular condition as a result of the relevant guideline being applied. Similarly, 50% of respondents were able to tell other people
experiencing the same condition as them or a relative about the application of the relevant guideline to their care and treatment. This was generally through support groups (31%), sharing informally with friends and family (37%) and online via forums (25%).

Few survey respondents (18%) have suggested to a healthcare professional that their care should be delivered according to a NICE guideline. For those that had made a suggestion to a healthcare professional, 39% had received a positive response whereas 61% had received a negative response:

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<tr>
<th>Positive response</th>
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<tr>
<td>‘The psychiatrist was very reluctant to refer my husband for psychological therapies as he felt he was “pharmacologically well controlled”. We were able to use NICE guidelines to argue his case for talking therapies which have really helped him’</td>
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<tr>
<th>Negative response</th>
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<tr>
<td>‘Doctors don’t like patients suggesting anything’</td>
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<tr>
<td>‘Not very responsive’</td>
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Most survey respondents felt that NICE guidelines have made some difference (55%) or a great deal of difference (30%) to the development of care and treatment of a wide range of conditions. Conversely, 15% of respondents felt that NICE guidelines had made no difference:

<table>
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<tbody>
<tr>
<td>‘Guidelines definitely result in healthcare of higher quality’</td>
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<td>‘Have proved useful tool to know what treatment Dad should be getting…’</td>
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<table>
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<tr>
<th>Negative response</th>
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<tr>
<td>‘It depends whether various professionals follow them or not. Some medical staff seem to ignore guidelines. On the whole it’s difficult to tell as you are not often informed as to whether protocols are being use or not’</td>
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<tr>
<td>‘I, and a number of people I have spoken too, have not been treated in accordance with NICE guideline on Rheumatoid Arthritis, particularly with regard to speed of referral to specialists and commencement of treatment’</td>
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5 Discussion

In general, most survey respondents indicated that they are aware of NICE clinical guidelines and other NICE guidance, and felt that they had made a great deal of difference or some difference to the development of care and treatment of a wide range of conditions. However, there are several limitations to the information derived from the survey. Because of the methods we used to advertise the survey (email to patient groups and GDG members and news items on the NICE website), it is likely that responses to the survey gained through these routes would yield a higher awareness of NICE guidelines than would be expected from the general population. In addition, as most survey respondents were white British, this may limit the generalisability of the results. Furthermore, a few survey questions were misinterpreted, the survey was long and response numbers started to decline towards the end. However, we were reluctant to make too many changes to the content as we needed to maintain the option of combining and comparing results with
those from Voluntary Health Scotland so we could use them as background data for DECIDE.

6 Implications for guideline developers/users

Our survey demonstrated that there is a demand for guidance on healthcare among members of the public. People are interested in using clinical guidelines in their care and treatment. In addition, it is clear that the public become aware of this guidance through a range of methods including internet, national media, work and support groups/networks. The results will provide background information which will feed into the DECIDE project which aims to develop and evaluate strategies for communicating evidence-based guidance to patients and the general public. The results from DECIDE will influence how NICE presents its clinical guidelines in the future.

In addition, through the survey responses it is apparent that there is room to improve understanding about the role of NICE in healthcare. One of the themes from the survey responses was that patients and the general public do not necessarily have a full understanding of the various type of NICE guidance produced (for example, clinical guidelines, technology appraisals, interventional procedures and public health guidance) with a tendency to focus on drug treatments as opposed to the full clinical pathway. As such, NICE needs to review how the organisation communicates with the public in the future.

Thank you very much for taking part in this survey. Your comments are much appreciated and will be considered in detail when we are reviewing our procedures and products.

For information about how NICE involves patients and the public in developing NICE guidance please see the Patient and Public Involvement Programme’s web pages: http://www.nice.org.uk/getinvolved/patientsandpublic/patientandpublichome.jsp

For general enquiries please email nice@nice.org.uk or phone 0845 003 7780