AIMS For a better birth...

NICE Guidelines and Appraisals - How we can make a difference

Debbie Chippington Derrick reports on how we can make a difference to the guidelines and appraisals from the National Institute for Health and Clinical Excellence (NICE).

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As the National Institute for Health and Clinical Excellence (previously The National Institute for Clinical Excellence - NICE) marches on with its programme of guidelines and technology appraisals, we continue to have the opportunity to be involved with the consultations. However, if we are going to be able to comment as an organisation on more than the occasional item, we will need the involvement of more of the AIMS membership; we need your time and your experience.

Much of the detail about NICE guidelines and technology appraisals can be found on their website www.nice.org.uk (then click on "clinical excellence"). Downloadable copies of all the versions of all completed guidelines and appraisals are available, as are details of all those in progress and schedules for that work, including the consultation dates. If you donÕt want the expense of printing out a copy, ask NICE to send you a hard copy free of charge.

Completed Appraisals and Guidelines

There is currently only one pregnancy and childbirth completed technology appraisal - "Pregnancy - routine anti- D prophylaxis for rhesus negative women", and there are none currently in development or planned. However, there are quite a few pregnancy and childbirth-related guidelines completed, in process or planned, such as: Antenatal Care; Caesarean Section; Electronic Fetal Monitoring; and Induction of Labour. Others which are not solely childbirth issues but may have childbirth issues included in them, such as Post Traumatic Stress Disorder, are also completed. Currently there are childbirth guidelines in process on Antenatal and Postnatal Mental Health (APMH);

Intrapartum Care; Postnatal care; Diabetes in Pregnancy; and again there are non-childbirth guidelines where childbirth issues should be included such as Urinary Incontinence and Heavy Menstrual Bleeding for example. Full listing of all guidelines and appraisals, complete, in progress or proposed are on the NICE website. So, how can we be involved at the various stages of production of guidelines and Appraisals?

Selection of Topics

"*The Department of Health and the Welsh Assembly Government are responsible for selecting topics for the NICE technology appraisal and clinical guidelines work programmes. Each year they ask NICE to develop around 25 technology appraisals and 10 clinical guidelines.*"

We can make suggestions as an organisation or individually about topics we would like to be considered. NICE says: "You can suggest a topic on the NICE website by clicking the 'suggest a topic' button (in the top menu bar) on the website home page. You will be asked to check whether or not the topic is already being looked at by NICE and, if not, you can submit your suggestion online by filling in a form. The form is also available in hard copy and can be sent in by post." For example we could suggest a technology appraisal on the use of ultrasound in pregnancy or that a guideline may be needed for women with pre-eclampsia. So, if you feel there are topics that should be considered you may like to let both NICE and AIMS know.

The Scope

Once a collection of subjects for guideline and technology appraisal are agreed, organisations are able to register as stakeholders on these guidelines. NICE produces a draft scope which is published on their website; Then the guideline scope is prepared by NICE staff. This is basically a list of what the guideline will cover. This is then made public for comment, for a period of about a month.

Stakeholders

Organisations can register as Stakeholders, these can be national consumer or professional organisations, service provider and statutory organisations, research organisations and companies who produce relevant medicine or devices. Although any individual or organisation can submit comments to NICE on drafts, it is only the stakeholders who will receive replies to their comments.

Guideline Development

Individuals can be nominated to be involved with the guideline de velopment, as a member of the Guideline Development Group (GDG) - this is the group that actually decides what should be written in the guideline, although NICE does retain the editorial say, and most of the text is drafted by NICE researchers. The group will contain health professionals with experience in the field and consumers who have personal experience or are involved with consumer organisations with interests in the topic.

I was put forward by NCT for the Caesarean Section guideline. Although it was a challenging and frustrating process at times, it was also rewarding and I learnt a huge amount about the subject that I would not have otherwise. It does require a considerable commitment, over a period of about 2 years, requiring you to attend 10 - 15 meetings during this time, to read through tabulated reviews of the research that have been found on each topic, and then to read through the draft versions that have been prepared by the NICE researchers. I also felt a need to consult others on specific topics and to find evidence for particular issues. As a consumer member of the group you can be paid an honorarium for

meetings that you attend; and expenses are paid for all members of the group. NHS staff should be able to take paid time off to attend meetings.

Submission of evidence by stakeholders

Stakeholders have the chance to submit evidence to be considered by the GDG on any of the agreed scope. If they have case studies, or research that is relevant they can then submit that. However these would only be considered as evidence to inform the guideline if information was not available at a higher level of evidence, such as a Randomised Control Trial (RCT) or cohort study. For example, a collection of reports by mothers about choices they made or wished to make for the caesarean birth of their baby was taken as it was the only evidence available. This allowed the guideline to include the research recommendation: "More evaluation of interventions such as seeing baby born via a lowered screen; music playing in theatre; silence in theatre so the mother's voice is the first baby hears and lowering the lights in theatre during CS are needed". It may be that you are aware of small studies, sometimes carried out as part of education projects that are not published, that could make a difference to the recommendations made in one of these guidelines.

Consultation on the Drafts

Each guideline is published in draft form and comments can be submitted as they were for the scope, with stakeholders receiving a reply to their comments. In each case a period of just over a month is usually allowed for comments to be made. Again there may be the possibility of submitting evidence at this point, if it is supporting comments that you are making.

Even once a guideline or appraisal is completed it will come up for review again at least every four years.

Our Dilemma

As an organisation we would have plenty to contribute to these guidelines and appraisals. However, the time requirements mean that it is not feasible to be involved unless we can find individuals with interests in particular topics. Below are topics that are due to have their scope commented on, are recruiting GDG membership or due to have the draft published for comment.

So we would like to find volunteers who would be prepared to read through material on a subject that they have an interest in, or personal or other experience of. AIMS can then submit these comments to NICE. This is your chance to help us to help others by addressing issues in NHS guidance. You can do as much or as little as you want; you are not committing yourself by expressing an interest. It would be ideal if we could find small groups that are interested in commenting on a guideline, and even better if one or more of that group felt they would be prepared to put themselves forward for the GDG.

Involvement in the development process can make real differences to what recommendations are made and consequently to practices that follow. Slowly these documents are becoming more consumer orientated, but we need to be in there continuing to make sure that things move in the right direction.

The other advantage of involvement, especially as a GDG member is that it allows us to understand the basis of information given and recommendations made, understand flaws and limitations in some recommendations; in turn allowing us better to provide information and support to parents wishing to make informed choices.

If you are interested, now or in the future, or want just to discuss any of this further then please contact debbie.chippingtonderrick@aims.org.uk. or any other AIMS committee member.