

The Science Communication Conference 24th - 25th May 2004

Session 5 – Real life tales

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SLIDE 1

Good afternoon. As the last speaker of the day I promise I'm going to keep you awake and I'm not going to let you fall asleep. I think its been interesting to look at a specific example of deliberative democracy, 'Grannies versus Bikers', and then for Richard to take us through a journey about what the Environment Council has learnt about its various sorts of deliberative processes. I want to talk about a new experiment in which we are trying to bring the views of the public alongside the views of health expert: clinicians, health economists, other healthcare professionals, patients and carers. I want to introduce you to NICE's Citizens Council. NICE stands for the National Institute For Clinical Excellence.

SLIDE 2 Why have a Citizens Council

Okay we're supposed to communicate with you guys. Hands up those of you who have heard of NICE. Great. Now, those of you who know what NICE does put your hands up.....considerably fewer. Okay, well, what does NICE do then and why did we want to have a Citizens Council? Well, NICE has three main work programmes: technology appraisals, developing clinical guidelines and thirdly, our newest program is looking at the safety and efficacy of interventional procedures. But when you are talking to the public these are all big words and what do they actually mean?

Under the Technology appraisal programme NICE looks at a range of drugs and treatments and whether or not we should use these on the NHS. We use 2 criteria to judge these, whether they are clinically effective and whether or not they are cost effective. Under the Guidelines programme NICE looks at the best pathways of care patients should get if they have a specific disease or condition. We don't look at all drugs and treatments but a list referred to us by the Department of Health. .

To decide whether or not treatments are clinically and cost effective or whether or not a particular pathway of care should be recommended we draw on a range of experts: clinicians, patients, carers, health economists, industry etc. But what we were missing was a view from the public. And so we decided that in order to understand what some of the social value judgements are that the public apply to decisions about their health and healthcare , we needed to find out what they think, and bring that into the decision making process as well.

NICE established its Citizens Council in November 2002, we're now in 2004 and the question we now have to answer is, does it actually make a difference?

SLIDE 3

So what are we looking for? I said before its an experiment, and it is an experiment in deliberative democracy. We've taken aspects of many techniques that have been used in public involvement, social research and facilitation, and we've adapted them to suite what we want. Guidance and best practice, we've got ideas about those, but there it is important to emphasise that there is no road map. We were able to some extent when planning our model to scan the literature and look at what had gone before but because much of what we were suggesting was new it was difficult to know precisely what would and wouldn't work. So much of our learning has been 'learning by doing.'

Actually discovering what NICE wants out of this Citizens Council has also been part of this journey, and so in a sense since the inception of the advert which said to the general public 'do you want to have your say in the NHS?', we rapidly have come to realise that expectation management is absolutely crucial, because when you say to the public 'do you want to have your say in the NHS?' they want to talk to you about the bed problems they've got in their area, whether or not they can see their GP the day they ring up etc., what they are not quite clear about is what does this organisation called NICE do and how do I, as a member of the public actually affect the decisions that are taken?

The process we've set up is not so much about what the public thinks, but its about why they think it, and that's the beauty often of deliberative democracy. If you want to know what the public thinks you can do different things. You can set up focus groups, you can do surveys, you can do polls etc., but it's why they think it that's absolutely crucial.

The other thing to say about our Citizen's Council is that they are not accountable to anyone and their actual decisions count less than their explanations, but they have to inform those who work in NICE and NICE has to take responsibility for its decisions. And its very important to get this across because if you are talking about expectation management people need to know where their boundaries are, how they are going to influence decision makers, but people also need to know whether or not they are decision makers themselves, and that's quite important.

We've got thirty very different people, drawn from all walks of life. That means thirty different attitudes, life experiences, assumptions, and value systems. They are not representative of any group of any sort of class in society, we did when we recruited them we looked at some sort of demographic specifics, but we are very clear they represent themselves, and

that's what's important. And we need to capture as best we can their thinking, their thoughts and their ideas.

SLIDE 4 So how does it work?

So, how does it work? When NICE decided to set up the Citizens Council we decided that one of the things that was very important was it had to be arm's length from the institute. So we outsourced recruitment and facilitation. We have, a Manchester-based organisation called Vision 21 running the meetings for us, and Vision 21 also undertook the recruitment.

Here's an astonishing fact, you hear a lot in the press about how the public don't want to be involved, the public are disengaged, they are losing faith etc., etc. When we put the advert out on the 17th August 2002, I remember the day well, the telephones went mad at Vision 21. We had over 30,000 requests for application packs, and generated so much mail so much so the postal services in Manchester commented on the amount of mail their sorting office was dealing with. Vision 21 had to put in extra answering machines, and of course the media woke up and said "what's all this about?", and there's something about managing the media as well, and I'll come onto that later.

Of those 30,000, 4,000 turned into actual applications for 30 places. Vision 21 used a mixture of random and selection methods to recruit to the 30 places in line with the demographic profile we had drawn up.

Presently we run three-day residential meetings. We started off with the concept that we bring people together for two meetings over the year. Having 3 day meetings gives people the opportunity to debate and to discuss and reflect on the topic/questions that we put to them.

Yes, we pay our members. One of the things that we are absolutely clear about is that if you want people from all walks of life to get involved you have to make it possible for them to get involved, and so you do have to consider paying people for their contribution. We pay members £150 a day, we also pay for travel and carer expenses when necessary.

So far we've had four meetings.

Well what have we done in these four meetings? At the first meeting NICE decided that we would like to talk to them and ask them about what they thought about issues related to clinical need. A very broad topic. We learned something about setting a question for a group like this! At the first meeting we thought we had the perfect question. The Citizens Council didn't think so. What they couldn't understand was why when for years a bunch of experts hadn't managed to define clinical need NICE thought that the Citizens council would be able to do this in three days. Vision 21 had to do some expert facilitation in realigning NICE's expectations alongside those of the Citizens Council. The Citizens Council when dealing with what they saw as an

impossible task began to ask themselves whether or not they had been set up. There were comments along the lines of, 'If all those gurus having thought about it for years couldn't answer the question, why does NICE think that we're going to be able to do it in three days?' We learnt rapidly about how you set a question for a group like that. Once they had re-defined the question for themselves they made good sense of it and we did get a report at the end of the three days.

The way in which we set the meetings up was we started off modelling the meetings on the citizen's jury process. This based on the legal system of juries relies on evidence being presented by a number of experts, after which jurors make up their minds reaching a majority decision. The Citizens Council is more than just this process, yes it relies on some information being presented by 'experts' but the difference is that members have the opportunity to reach their conclusions not just on expert opinion. Much more important than the assimilation of information is the, internalisation and deliberation that allows them to say why they think what they think. The balance between listening to experts and deliberating has shifted towards more deliberation and that is good.

At the next two meetings we got them to consider issues related to age. So should the age of a person be taken into account when deciding what treatments they receive on the NHS and it took them two meetings to actually talk that through. Between those meetings we also commissioned some survey polls, we also did some work with children and young people and got their views and then the Citizen's Council gave us their views as well.

I've just come back from the fourth meeting of the Citizen's Council where they looked at issues related to informed patient consent in relation to the National Confidential Enquiries. Should we be asking for informed patient consent when we want to use patient data for research within the NHS, and we're awaiting their report.

SLIDE 5 Self Conscious deliberation

I want to focus on the issue that NICE in its spirit of openness and transparency has said that the Citizen's Council meetings will be held in public. So, all the meetings are held in public and the members of the public and the press are invited to attend. This means we are operating in, I think, quite an unusual, and possibly unprecedented environment. Its very, very different from other techniques, not only are individual identities published, but individuals are asked to express their views in public, to float ideas, discuss openly, change their mind, say unpopular things, all in public.

Other forms of consultation, even in deliberative methods tend actually to keep public identities quite quiet. And they can be anonymised by sheer numbers, but we can't in this instance, its all out there in the public domain. The organisation that runs this for us can't write the expert commentary. The report is actually pulled together by the Citizens Council themselves, so that

when Vision 21 write the report, the Citizens Council review it, amend it and it then comes to NICE. What we at NICE have said is that the report doesn't come to us as a draft, it comes to us as a report, we publish it on our website, our Board looks at it and our Board makes a response to it.

We have expectations about the process as well as the results and our expectations have changed over time, as we work on the project. Quite interestingly Richard said it's very important to be able to define your expectations right at the beginning. When we were initially putting together the operating model for a Citizens Council we did quite a lot of research wanting to know what others were doing in this field. Everything we looked at pointed to being clear about one's expectations and being clear about the question one wanted the answers to. We didn't find one example of where somebody had got it absolutely right. I have spoken to a number of people in the international arena who are also considering or have undertaken public consultation exercises, their experience has been the same. The one overriding lesson is that you have to learn to change your expectations and be flexible around the process. The process cannot be set in tablets of stone.

The independent evaluation presents another commentary too. We have commissioned this research through the NHS research and development methodology arm., A team from the Open University, are evaluating the project. There are 3 strands to the evaluation. One is an organisational evaluation, so what does the organisation look like into which the Citizens Council interacts? The second one is a member study. What does the Citizens Council itself think about this whole process? And the third one interestingly is an ethnographic study, which actually looks at how opinion forming and decision making happens in groups and is this the best way to achieve deliberation. The Open University are due to produce their final report to us in November 2004 and publish their work in early 2005.

SLIDE 6 A brave step

Okay, so to conclude. This is a brave step not just for NICE but all those involved. We know that it is an experiment, something that hasn't been done before, and we asked our partners and those involved in it to be brave too. I think we trust the public to a degree that is still highly unusual. In the search for the best model of public involvement, this has allowed us to experiment in methods and allowed us to develop a learning culture. If something doesn't work we don't condemn the whole idea but are happy to try thinking again. It isn't an easy ride, but an exciting one.

So what happens now? Two things. We've got ten new members onto the Council, ten members have been retired, and that's in the interest of not allowing group-think to develop, but to retain and refresh the ideas on the Council.

What we are now doing is beginning to think about whether or not this is the best model and how do we implement what the Citizens Council has said.? So

going back to my initial question which was 'has it actually made a difference?' We're now in the process of taking the findings from the citizen's council, and working within the organisation. We've got 4 workshops set up with our technology appraisals groups and our guideline development groups to actually take the report on clinical need and age and say 'How are you going to implement the social value judgements that the Citizens Council have put forward?'. So watch this space.

For more information, do go to our website www.nice.org.uk or you can contact me at ela.pathak-sen@nice.nhs.uk

Thank you