Small Talk
9 June 2005

Focus group discussing nanotechnology with patients or carers of patients

Introduction
The BA organised a focus group on Thursday 9 June 2005, 18.30 – 20.30 at the BA offices in London. The aim was to gather information on people's views about nanotechnology which will feed into the Small Talk project and help shape future events. These views will also be shared with scientists, decision makers and science communicators.

Small Talk is a collaboration that aims to explore the aspirations and concerns of the public and scientists about nanotechnologies, and share the findings with policymakers. (see www.the-ba.net/smalltalk)

Susie Fisher, an independent professional facilitator, was employed for the evening, to direct discussion and gather information.

Participants
Attendees were invited through a number of different avenues including direct emails to contacts at organisations such as the Genetic Interest Group, British Heart Foundation, local hospitals and local support groups. Members of the BA events mailing list were also contacted, and in total over 50 people were interested in attending. Participants were chosen so that the group had a mix of men and women with different diseases or conditions.

Eight people signed up to attend, and 5 turned up on the night. There were 4 women and 1 man; 3 white, 1 Asian and 1 black Afro-Caribbean. One falls within the 18-25 age group, 1 in the 26-35 age group, 1 in the 36-45 age group and 2 in the 46-60 age group. There was one wheelchair user.

Discussion
To start the discussions each of the 5 participants explained the condition they suffer from or care for. They were then asked what they would wish for if they only had one wish. The 5 answers were:

- Attendee with brain tumour wished for new imaging technology and improved method of targeting disease area and repairing tissue
- Attendee who cares for her mother who has had a stroke wished for pain free living for her mum
- Attendee whose son has a skin condition called XP which means her son cannot go out in the daylight wished for invisible protection for her son
- Attendee who suffers from Muscular Dystrophy wished it could be cured within the next 10 years.

- Attendee who suffers from a respiratory condition called Primary Ciliary Dyskinesia wished for her cells to get better

Participants were then given a piece of paper with a target on. They were asked to record their thoughts and feelings on nanotechnology, placing things they were sure of in the centre and things they were unsure of in the outer rings.

Inner ring	Outer rings
Science of very small	Increasingly topical
Touted for multiple applications, but no real delivery yet (except some lasers and sunscreen)	Lots of spin and "me too"
Interesting future research	Necessary, important area of research but early days
New technology	Yes, yes, yes I am all for it
Technology of the future	Particles?
Biotechnology	As a researcher, I am sceptical to new ideas and research phenomena so I would like the idea to be tested.
Atomic, strong	
Very small, smaller than micro (i.e. invisible to naked eye)	
Future science for improving health	
Film – 'Inner Space'	
miniaturisation	Scary, optimistic
Science of working with microscopic robots to use in manufacturing medicine	There seems to be lots of potential, a little wary that developments should be controlled and open

Where did participants obtain these views of nanotechnology?

- Books and films
- Family member studied chemistry

Nick Hillier from the BA then gave a brief introduction to nanotechnology reflecting on what he had learnt from the Small Talk project. A picture board with artists' impressions of nanotechnology was used as an aid to promote discussion. The discussions that followed focused on:

1. Views on nanotechnology
2. Questions and worries about nanotechnology
3. Surprises of nanotechnology

1. Views on nanotechnology

- May help with my genetic condition, but have yet to work out how it's going to work
- Medicine could move towards more selective work
- Nanotechnology could provide more precision and accuracy
- Nanotechnology may have problems, lead to designer humans, too much manipulation, not enough randomness, we need all types of people, need natural selection
- Great for my condition
- It seems nanotechnology is creating a new tool kit
- I'm imagining silver/metallic

2. Questions or worries about nanotechnology

- Depends on how you can programme nanotechnology, it may get too clever
- What powers them? Would they suddenly stop?
- I worry, we rely on technology with no input from humans, I'm frightened
- The tinkering worries me, depends on who controls them
- By-products, may it infect the body, maybe negative effects

3. What surprised or intrigued participants?

- Impossibly small
- Does it actually exist is it just theory?
- Precise nature, how can you track it?
- How do you get rid of it?
- Can you see it with scanners?
- Spooky aspect to it, technology could be delayed by a backlash
- Prince Charles grey goo – that is not helpful

Please reflect on how you feel about nanotechnology?

- Scary but slightly optimistic
- Yes, yes, yes, I'm all for it! I've always been interested in technology
- Lots of potential, bit wary. Suspicious about control and openness. Can't leave, you've got to go there
- You can't stop this
- Needs hypotheses tested, public needs to be confident. Needs rigorous testing
- Very interesting and important area, the way forward but early days. Feel positive
- Nature's tool kit
- How much does it cost, how will it impact on the 3rd world?

Could you tell a friend about nanotechnology?

- Yes, must be very exciting, what happens when we shrink!

Then PhD student Alexis Vlandas from the University of Oxford explained the work he is doing with nanotechnology, explaining how his work was not applied science nor theory based. In his work, he is trying to probe how matter behaves when constrained inside the hollow cavity of a nanotube. He also discussed potential applications further down the line - such as new transistors, solar cells, etc.

Participants had a number of questions which they then raised.

What is your reaction to Alexis' work?

- Playing stage
- Exciting
- Is NASA using nanotechnology?
- I want to see proof
- It's wonderful because it's a way of diagnosing cancer through blood test/urine that you could not do another way
- It's great, pick up problems at early stage
- Economical science, not new materials, using what you already have
- I like the idea of early diagnosis
- Is it all theory? Does it happen in practice though?
- Is it just mathematics?
- Makes our condition a perfect candidate of nanotechnology. Nanotechnology would cure it. Needs to be done for every damaged cell. (XP sufferer)

Alexis then explained that one possible application of nanotechnology is to employ viruses like Ebola or HIV. Normally these viruses attack our body's cells and change the make-up of the cell. However these viruses could be modified so that they correct an abnormal gene. When the cell then replicates the edited version of the gene is copied rather than the mutated form.

Would you use these live viruses to deliver drugs?

- They're certainly active
- Like to see it done on a lot of rats before it's done on me!
- Taking it into our hands, wary of interfering with nature, eventually something happens to our detriment
- I disagree, I think nature is not very nice so technology is great at overcoming disease. Injecting HIV is just the next step, one more than vaccines such as TB, polio etc
- Keep scientists focused
- We interfere in very crude ways

Alexis then explained what scientists are worrying about, namely funding and regulation

- Everyone is different, maybe they would react differently
- Does that mean that the regulatory bodies test it in different ways?
- That's not a problem for nanotechnologists, but a problem for bodies who regulate
- Can get away with more when it's cosmetics than when it's medicine
- It's worrying, what are they doing?

Is there a time when risk is worth taking?

- Yes, but only when you know the risks
- Bit like pollution, we did not think it would cause problems like the ozone hole etc
- Balancing known hazards versus unknown hazards
- It could attach itself to plants, animals etc, get in the water
- Always been frightened, still am

Participants were then asked to comment, based on the discussions that had occurred, on whether their original wish had advanced and how.

How has your wish advanced, if at all?

- Good to see develop sunscreen, good to see if developed further

Advantage to be outside, play football, be a child (XP sufferer)

- Clearing sinus, clear up infections

I don't mind if it goes in, move it out, need to control it. Like a Hoover. (respiratory sufferer)

- Have you scientists sat down and though about what the public or patients want?

We need a forum to match up what people want and what the scientists are doing? Nanotechnology has a lot to offer in regard to medical imaging (brain tumour sufferer)

- Nanotechnology could be a good thing for my mum, get drugs into her

Could drugs be targeted to neurotransmitters as opposed to the muscle where the pain is? (stroke sufferer)

- I feel the same way as before, a cure in 10 years. It's possible they could use nanotechnology, looking into ways to put missing protein back into body

Target certain muscles that are affected (Muscular Dystrophy sufferer)

As with previous Small Talk events, participants were asked two key questions:

1. what would you say to a politician about nanotechnology?
2. what would you say to a scientist?

However, this time participants were given the opportunity to think how the politician and scientist might reply.

Participant	Politician
Introduce nanotechnology without scaring people. Make sure the applications that are possible are ethical and not damaging people and the environment.	Hmm.. I must enforce policies considering the effect it may have - make the policies positive
Make sure that you get value for money out of research in nanotechnology	How much should I spend on nanotechnology?
Please ensure that the necessary safeguards are in place before the results of nanotechnology become common in our everyday life	Thank you, we have listened to what you have said
Give us the money Guv	We will have to see – lobby!
I'd like a commitment that nanotechnology will be controlled and only used for good	I'm sure we all would. The companies in charge are subject to the law of the land blah blah

The above comments are slightly different to the answers provided in previous Small Talk events, the participants seem to be more concerned with the issue of funding as opposed to regulation.

Participant	Scientist
Keep telling us in layman's terms all you discover. We need to keep communicating	Yes I will
Hurry up	Believe me I'm trying
Find us an invisible UV protector for my son's face and hands, that won't leave him with awful side effects	I think this is in our scope; we'll try.
Think about the applications – there are probably some easy wins that can support further research	It's too early for applications. I am interested in the fundamentals.
I hope that this technology can be applied so that it can benefit everyone.	Yes, but this will take time.

The above comments show scientists being responsive to the participants' requests but seem a little dismissive. The participants also seem to accept that scientific research takes time and is quite slow for new medicines to come on the market.

As a trial for a new question, participants were asked what they would like to say to nanotechnology ad how it would reply.

Participant	Nanotechnology

I'm excited about your possibilities – I hope you make it easy for us to discover all aspects of you.	That's up to the ethics and skill of those who use me!
Can't you get any smaller?!	As small as you want
Take care, look at the good and bad, don't let the baddies get hold of you	I'll do my best
What happens next, smaller than nanotechnology?	Nanotechnology goes all the way down!
I hope it can cure, detect and prevent the biggest diseases, illnesses, i.e. breast cancer, genetic disorders.	I'll try!

The comments above show nanotechnology responding positively, suggesting the participants don't view nanotechnology as a monster. This question should be explored further in future Small Talk events.

General points that came out of the discussion

The participants who attended this focus group were a very different audience to those that have previously attended BA Small Talk events, since they came looking for a cure to their disease, or for that of the person for whom they care. They seemed to know more about the topic of nanotechnology than other publics probably due to the fact that they are more aware of new technology/medicine that could benefit them. They came with semi-formulated hopes. To confirm this, it would be interesting to compare their knowledge with that of the people that attend the Democs nanotechnology events.

The mood in the room changed during the event – at the beginning the participants were fairly positive about nanotechnology in terms of what it might be able to do to help them as a patient/carer. They seemed more likely to take greater risks as they have a condition that at present requires new treatment. However, after listening to Alexis and hearing about his work their views were very similar to previous attendees of Small Talk events as they were more concerned with how nanotechnology could affect society and the environment and less about how it could affect them directly. They were less positive about the uses of nanotechnology and voiced their worries about regulation and funding. Their framework of risk moved from personal to societal but then moved back to personal again when the facilitator asked them to think again about their wishes for their condition and nanotechnology.

Alexis has spoken at previous Small Talk events but on this occasion his delivery was quite different – he was more caring and showed more empathy. Although his work is mainly theoretical the participants helped him to relate the work nano scientists do to people rather than just theories. He used some great real examples of where nanotechnology is already in use today, such as in suntan creams and bus exhausts and in using metals to deliver pain relief.

It seemed very important to ask the question 'does nanotechnology actually exist?' as this is something that the participants kept on asking. Is nanotechnology real, is it just theory or is it happening already? Can you touch it or see it? Even after the initial questions and discussion about nanotechnology - how it could help them and their disease - they reverted back to the same basic question – is it real? It is important to revisit that same question throughout the discussion, to spend time explaining the 'does it exist?' question. Allow room to explore people's doubts - what counts as proof?

It would probably be a good idea to have some images or video clips that would help clarify the scale of nanotechnology as the participants struggled to get their head round how small nanotechnology really is! The BA may discuss the possibility of getting a video clip made with one of our contacts.