



## NanoMed Round Table Patients' Needs Working Group

### Annex 2 – Findings From Patient Interviews

#### i. Introduction

During July 2009, 12 patients and patient representatives from patient groups throughout the UK were interviewed on the emerging field of nanomedicine. The interviewees were selected from the membership of the Genetic Interest Group (GIG), on the basis of their being interested in or affected by condition areas where nanomedicine is taking place. Consequently, the majority of the interviewees were affected by Parkinson's Disease, but because research is taking place into other genetic conditions such as Thalassaemia and Huntington's Disease these are also represented. The main focal point of this research was to gain a broader view of patients' understanding of nanomedicine and if they felt it was something that researchers should continue exploring.

To generate the interview questions, desk research was undertaken into what nanomedicine is and how it is currently being used. This research included an interview with the ethicist Dr Donald Bruce<sup>1</sup>, who specialises in nanomedicine, as well as internet research. From the interview with Dr Bruce a brief presentation was created that highlighted the key areas of current development and potential interest in nanomedicine for the patients, before they were asked questions on the topic. The presentation focused on what nanomedicine is and on some of the research that is currently being conducted. The presentation also showed some of the concerns with the research that ethicists such as Dr Bruce have raised. The presentation also let patients know that nanomedicine is still in the research phase, and that according to ethicists such as Dr. Bruce only lab-on-a-chip<sup>2</sup> and targeted drug release<sup>3</sup> will be in clinical use in the next five to ten years. Dr Richard Moore<sup>4</sup> was also interviewed towards the end of the survey period to confirm and provide

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<sup>1</sup> Ref. Working Group on Ethical and Social Aspects of Nanomedicine.

<sup>2</sup> Lab-on-a-chip is a nano-chip with many applications, including sequencing genes with small amounts of blood. It will be used to determine which disorders patients are genetically susceptible to as well as which medication will be most effective for the patient.

<sup>3</sup> Targeted Drug Release transports medication directly to infected cells by encapsulating small but highly toxic doses of medication in small capsule made from fatty acids and proteins. Embedded within the capsule membrane are protein markers that allow the capsules specifically to target infected cells.

<sup>4</sup> Dr Moore is the Nanomedicine and Life sciences Manager at the Institute of Nanotechnology, Stirling, Scotland. The Institute of Nanotechnology (IoN) was established in January 1997. A registered charity, its core activities are focused on education and training in nanotechnology in the widest sense.

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further details on the information provided by Dr Bruce. The slides that outlined current nanomedicine research are provided at the end of this Annex.

The interview questions were as follows:

- What is your exposure to nanomedicine or nanotechnology?
- Have you heard of nanomedicine being used in your area of interest before?
- Knowing this information do you think that nanomedicine research should be continued in this area?
- Do you have any concerns about the use and safety of this technology?
- Do you think that nanomedicine will be useful in the treatment of your disease?
- What type of information would be useful to you about nanomedicine and where would you go for the information?
- In your opinion is nanomedicine completely different from current medicine, or is it the next step in medical research?

The majority of the interviews were carried out by telephone with the presentation emailed to the interviewee prior to the interview. If there were any questions about the presentation these were answered by email or at the time of the interview. Each telephone interview lasted approximately 15 to 20 minutes. For those interviews that were conducted face-to-face, the presentation was made to the patient before the questions. For the most part the face-to-face meetings garnered more detailed answers, while the phone interviews gave more direct and to the point answers. The majority of the answers were the same for most patients; more in-depth analysis is provided below.

## ii. Analysis of Patient Interviews

### **What is your exposure to nanomedicine or nanotechnology?**

This question gave the most consistent answer. Eight of the patients surveyed had never heard of nanomedicine and four had heard of nanomedicine, but didn't realise that it was nanomedicine. All of the genetic disorder groups interviewed in this survey had the same prior exposure, which was very little to no exposure to nanomedicine.

Participant A had read about the protein sets that are removing the defective genes in Huntington's patients, *"but I had not realised that it was nanomedicine research."* Participant H had heard of both nanomedicine and research into Parkinson's: *"Pretty much I knew of it and knew the implications in Parkinson's, but I thought that the application would be last on the list."*

Participant K also echoed this sentiment: *"Yes I have heard of it, but not as nanomedicine."* Some interviewees had read up on nanomedicine through press articles after hearing about the Nanomed Round Table Project and the patient survey and interviews being carried out, however they only knew what it was and did not know about the research itself. Participant B confirmed this: *"Very little exposure, almost none at all, except that which was covered in the national newspapers."*

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## **Have you heard of nanomedicine being used in your area before?**

The responses to this question revealed a lack of knowledge in nanomedicine amongst patients and their carers. Half of the patients interviewed had never heard of nanomedicine being used in their area, and only four interviewees had heard of it in a general sense.

Participant E, a Parkinson's patient, gave one of the most repeated answers to this question: *"No I haven't, it is not familiar with the treatment that I have been getting and it's not something that has been mentioned in the Parkinson's newsletters or research magazines."*

Participant D, also a Parkinson's patient, had not heard of nanomedicine in Parkinson's but had heard of its use in cancer treatment. Another Parkinson's patient, Participant F, said: *"I am aware of the interest and the general sense of the research, but didn't know that it was nanomedicine."*

Participant B, who deals with research grants into Chronic Granulomatous Disorder research, said that in her condition area: *"very little was said about nanomedicine and there was no request for money for research into nanomedicine."*

This question revealed that many of the patients had not heard of the research being conducted in their interest area. It also showed that some have heard of the research, but did not realise that it was nanomedicine research.

## **Knowing this information do you think that nanomedicine research should be continued?**

All but one of the patients and carers interviewed believed that research into nanomedicine should be continued based on the information presented in the PowerPoint presentation.

Participant J said: *"It sounds as though it has a lot of potential."* Participant G said that he thought that, *"It would be interesting to see which phase the research is currently in,"* while Participant B also supported nanomedicine research but noted that: *"public opinion research needs to be done to get information out on both patient feelings and knowledge of the subject."* Participant I was also more cautious, concluding that: *"it depends on the results of what can be treated with the medicine."*

In general, however, the participants of this patient survey believed that nanomedicine research should continue. Many had concerns about the development of the research, but made a risk judgment and felt that with appropriate regulation nanomedicine was just another avenue of research.

## **Do you have any concerns about the use and safety of this new technology?**

This question elicited a wide array of answers with some patients not having any concerns about nanomedicine, whereas others did.

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Those who were concerned did not have prior knowledge of nanomedicine, but were concerned with technological advances in medicine. For instance, Participant I was not concerned with nanomedicine, but was concerned about scientists manufacturing male sperm in research labs<sup>5</sup>.

Participant G echoed Participant I's concerns: *"Not really, I think that in most cases it will be used as a line of last defence. To some people there may be concerns about the testing that is being done on animals in nanomedicine, but I do not think that there is any harm in that because it allows one to see if the medication is useful for the treatment of that disorder, and if it is safe enough to use in humans."*

Participant J had concerns about the risks to the patient but believed that: *"There are always risks when it comes to testing new technology, but you can't get away from it and you can't let it make you shy away from research."*

Participant B said, *"I have less concerns for this than gene therapy,"* but was nonetheless concerned with *"the public understanding on nanomedicine. I would like for someone to get across what the advantages and disadvantages are to patient groups, and am concerned with the use of the name nanomedicine. Is it too late to change the name?"*

## **Do you think that nanomedicine will be useful in the treatment of your disease or area of interest?**

The majority of patients interviewed thought that nanomedicine would be useful in the treatment of their disease or condition.

Participant H believed that: *"One day, sure, it will be useful, but I suppose that it will be more useful in diagnosis with bio-markers and will be less therapeutic."* Participant D thought that: *"It is impossible to tell really because the underlying cause of Parkinson's is still unknown, so until the cause is discovered I cannot see its possible helpfulness in Parkinson's treatment."*

Participant G, a biochemist and Parkinson's patient, believed that: *"It would be useful in the treatment of most diseases, but a problem could arise when there are multiple genes responsible for a disorder."* Participant E was more sceptical: *"I hope so, but I am not convinced. It would be worth having back to back experiments to truly see if it has the potential to help patients with Parkinson's."*

There was confusion amongst the participants on how nanomedicine could be useful in the treatment of their genetic disorder. This appeared to stem from a lack of lay information on what nanomedicine is (three participants even suggested that it be re-named) and where it is in terms of research development. Participant G commented: *"I think that there is a need for the people working in the area to sell ... their ideas ... so that people can see where the field currently is. Also, for most*

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<sup>5</sup> In July 2009, there was considerable press coverage regarding the development of sperm from stem cells. E.g.

[http://www.timesonline.co.uk/tol/life\\_and\\_style/health/article6661357.ece](http://www.timesonline.co.uk/tol/life_and_style/health/article6661357.ece)

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*people who are not scientists it can be hard to get information that is easy for them to read". Participant A stated: "The information that is released is a bit too technical for patients to really understand."*

## **What type of future information would be useful to you about nanomedicine and where would you go to get the information?**

Over half of the patients interviewed would like to get the information from patient organisations, while one quarter would like to get their information from the internet, and just one patient would like to go to a physician to get the information.

Participant A would like to have the pros and cons made available, as well as general information about nanomedicine in a more lay format than what is currently available. Participant J agreed: *"I suppose if there was some kind of website set up by people acting in the interest of the patients in coordination with clinicians and researchers to provide factual information in lay terms for the patients."*

Participant G would look for information on search engines such as Google and believed that: *"There is a need for the people working in the area to sell and put out their ideas across the spectrum so that people can see where the field currently is."* Participant B would also like *"Updates on where the research is currently at, for instance, I would like to know at what phases in clinical trials research like targeted drug release is in."*

Participant H said: *"I think nanomedicine should from a patient's perspective be communicated to patient organisations' research departments so that they can see the potential of the technology."* He also believed that it was important to communicate science so that collaborations will be made across the field because in his view a cure for Parkinson's will come from a collaborative effort.

Participant L would also like the involvement of patients' groups in the release of information on nanomedicine: *"Something written in a non-technical way, Parkinson's research groups. I have a standard group to see what research is being published on the web, and I haven't seen anything yet on the web."*

When more information is presented on nanomedicine, the participants would prefer to get it from an online source. There was also a desire for the information to be presented in lay format, so that it is easier for the patient to make an informed decision on their treatment plans. However, there was also concern regarding the regulation of what is posted on nanomedicine.

## **In your opinion is nanomedicine completely different from current medicine, or is it the next step in medical research?**

Over half of the patients believed that nanomedicine is the next step in medical research, while patients like participant D believed that it is *"Completely different. It's studying something very small that we still don't know much about and will open new worlds in medicine."* Participant H echoed this: *"No, I think it is something completely different in terms of technology."*

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Other interviewees took a different viewpoint. Participant G believed that *"It is a continuation of medical research; it is somewhat different from current medical research, because it is aimed at specific diseases."* Participant L thought that *"It's a new branch, not a step change like DNA therapy, might be complimentary with other methods, I see it as a good contender at the moment with respect to controlling protein folding in the brain."*

To the participants, nanomedicine is both something new and a continuation of medical research. It is new concerning the size and characteristics that the medicine is exhibiting, but it is a continuation of the research because the tools used in medicine are constantly getting smaller and the scope of treatment is getting more focused on the diseased area.

### iii. Conclusions

In summary, there is very little knowledge about nanomedicine and its research in the patient population. When told about the research patients are very open and willing to learn more about the research, because it is something that they care a great deal about and are willing in some cases to accept higher levels of risk to find a cure or treatment. All the patients interviewed wanted research to continue in not only their field, but in all areas of medicine. They also wanted more information to be presented to them through either their patient organisations or on the internet on nanomedicine, but in a much more lay friendly format, with the pros and cons presented to enable them to make informed decisions on the treatments that they have.

### iv. Powerpoint Presentation

#### SLIDE 1 – What is Nanomedicine?

- Nanomedicine is an emerging field of medicine that is incorporating technologies and instruments developed in nanotechnology research, which is looking into the properties of elements at the nano-scale.
- The nano-scale allows physicians to treat illnesses at the cellular level, instead of the current method that treats the entire body instead of just the infected area.

#### SLIDE 2 – Current Examples of Nanomedicine

- Lab-on-a-chip - Using lab-on-a-chip technology, which is a small chip that is capable of sequencing DNA and running diagnostics physicians are able to use a small drop of blood to generate a patient's genetic sequence diagnose their ailment. Pharmacogenetics is another field where this technology can have wide uses. A physician can prescribe medicine that will be effective for the patient and cause the least amount of side effects. Physicians will also have the ability to see which disorders and medical conditions a patient will be susceptible to based on their DNA sequence and will allow medicine to become a pre-emptive science.

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- Theranostics - This field combines diagnosis and therapy into a small chip that is placed inside a patient. The chip can then move about the body monitoring things like blood/glucose levels in diabetic patients. If the chip notices a drop in the glucose level it can deliver an amount of insulin either directly under the skin or somewhere within the body. Physicians and researchers are, however, moving away from this smart chip and instead pushing for something that can tell the patient that a drop has occurred and allow the patient to control the amount of medication that is released.

## **SLIDE 3 – Current Examples Continued**

- Targeted Drug Delivery - Using fat polymers lined with antibodies specific for cancer cells, or infected cells physicians can administer small doses of medicine directly to those areas of the body that are infected or cancerous. This removes the holistic treatment that current medicine uses, and will also give physicians the opportunity to use medication in smaller doses and medication that on a large scale is harmful but at the nano/cellular scale is very effective.
- Implants - In Parkinson's patients Physicians can now place small electrodes on the VIM (Ventral Intermediate Nucleus), which is the middle region of the thalamus, and extending to the subthalamic nucleus, which is in front of the thalamus. Then applying a high-frequency electrostimulation, physicians can help patients reduce and control the tremors accompanying Parkinson's Disease. This treatment has also been shown to increase the thalamic activity that is diminished by the disease.
- Remote monitoring - Another growing area of research is in developing nano-chips that can monitor a patient's medical status, while at home. This would allow patients to return home after surgery and recover at home, and would free up much needed space in the hospital.

## **SLIDE 4 – Nano-research in Huntington's Disease**

- In the nucleus of a cell there are a set of proteins that when combined together manage the cell's DNA, the replication and repair of DNA, RNA synthesis, and protein translation. Researchers are currently viewing the formation and disassembly of the proteins in the hopes of generating a set of synthetic proteins that can target and correct genetic defects in a patient's DNA sequence.
- Another line of research is using Atomic Force Microscopy to better understand how incorrect protein folding causes genetic disorders like Huntington's disease. They hope that this will allow them to develop a nano-bot that would allow them to control the folding of the proteins within brain cells.

## **SLIDE 5 – Huntington's Continued**

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- A group of researchers at MIT have developed an antibody that binds with Huntington's Disease protein epitopes (which are protein markers on cell surfaces that allow the immune system to recognise the cell) which suppression of protein aggregate forming on HD cell surfaces. In experiments with *Drosophila* the antibody has been shown to increase the amount of flies maturing to adulthood and significantly increased the lifespan of the flies. The antibody also showed slowing in the degenerative effects of Huntington's and slowing in the formation of the protein aggregates.

## SLIDE 6 – Where is it, and where is it going?

- Nanomedicine is still very much in the research phase and will most likely still be in the research phase in the next five to ten years. However, areas such as lab on a chip and targeted drug-release are much closer to fruition.
- There are already working models of lab-on-a-chip available, however, researchers are still trying to get the machinery smaller and applicable to all diseases.
- There are also targeted drug-release medications in circulation; however, most are still either in development or in clinical trials.
- Also, physicians are currently introducing nano-particles of iron oxide into tumors and causing them to vibrate outside of the tumor by applying an alternating magnetic field. This vibration causes the temperature of the tumor to increase, making it more sensitive to radiation or chemotherapy.

## SLIDE 7 – Concerns

- As with all new areas of research some concerns have been raised about nanomedicine.
- In the remote monitoring people believe that it is giving too much control over to the doctors and hospitals. Knowing the location and current medical status of a patient seems to many to be too much information for physicians to have, and in addition people would like to know who would be monitoring them.
- In the lab-on-a-chip many worry that if a physician learns that someone is predisposed to a life-threatening disease, does the physician tell the patient and is that too much information for a patient to process.
- Target Drug-Release also has its concerns because what if the antibody that the capsule is covered with is for the wrong cell type, then a perfectly healthy cell could be targeted with potent medication and the infection could continue spreading while healthy cells are being destroyed by the medication.

## SLIDE 8 – References

- Bruce, Donald. *Human Enhancement? Ethical Reflections on Emerging Nanobio-technologies*. Edinburgh: EdinEthics 2007.

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- Nanomedicine: <http://nanobio-raise.org/>
- Nanobiotechnology: Responsible Action on Issues in Society and Ethics: <http://nanobio-raise.org/>
- Müller, Sabine. *Magnetic Fluid Hyperthermia Therapy for Malignant Brain Tumors-An Ethical Discussion.*