



Patient Views and Understanding of Nano-medicine

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Patients Views and Understanding of Nano-medicine

This report forms part of the Patient Working Party input into the Nanomed Round Table Project.

Introduction

During July 2009, patients and patient representatives from patient groups throughout the UK have been interviewed on the emerging field of nano-medicine. Nano-medicine is the “development of nano-particles and nanostructured surfaces as well as nano-analytical techniques for molecular diagnostics, treatment, follow-up, and therapy of diseases.¹” In simpler terms nano-medicine is treating a patient at the cellular level with technology that has been manufactured at the billionth of a meter scale, or nano-scale. The main focal point of this research was to gain a broader understanding of patients understanding of nano-medicine and if they felt it was something that researchers should continue exploring. We focused mainly on patients affected by Parkinson’s Disease, as this is a condition where nano-medicine research is active however as research is taking place into other genetic disorders like Thalassaemia and Huntington’s disease these are also represented.

To generate the questions for the survey research GIG carried out desktop research into what nano-medicine is and how it is currently being used. This research involved an interview with ethicist Dr. Donald Bruce, who specializes in nano-medicine, and reading articles on nano-medical research on the internet. From the interview with Dr. Bruce a small presentation was created that highlighted the key areas of current development and potential interest in nano-medicine for the patients, before they were asked questions on the topic. This presentation focused on what nano-medicine is and on some of the research that is currently being conducted. The presentation also showed some of the concerns that ethicists like Dr. Bruce have brought up with the research. The presentation also let patients know that nano-medicine is still in the research phase, and that according to ethicists, such as Dr. Bruce only lab on a chip² and targeted drug release³ will be in clinical use in the next five to ten years. Dr. Richard

1 Ferrari, M et al. Nanomedicine –Challenges and Perspectives. 2009 Wiley-VCH Verlag GmbH & Co.

2 Lab on a chip is a nano-chip capable of sequencing the human genome with small amounts of blood. Will be used to determine which disorders patients are genetically susceptible to as well as which medication will be most effective for the patient.

3 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 to specifically target infected cells.

Moore was also interviewed towards the end of the survey period to confirm and provide further details on the information provided by Donald Bruce. The slides that outlined the current research into nano-medicine can be found in Appendix 2 on page 9:

From our initial desktop research and interview with Dr Bruce as well as a previous survey that the Nanomed Round Table Patient Working Group had already generated, a set of questions were produced that asked general questions on exposure to the topic and the current views on nano-medicine. The questions asked were as follows:

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

In order for the interviewer to be able to speak to as many patients as possible in the limited period of time the majority of the interviews were carried out over the telephone with the presentation emailed to the patient or interested party prior to the interview. If there were any questions about the presentation they were answered by email or at the time of the interview. Each telephone interview lasted about fifteen to twenty minutes. For those interviews that were conducted face to face, which consisted of four, the presentation was made to the patient before the questions. This generally took 30 to 40 minutes depending on the amount of questions during the presentation with the fifteen minute interview at the end of the presentation. 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 with more in depth analysis below.

Analysis of Patient Interviews

1. what is your exposure to nano-medicine or nanotechnology,

Question one, gave the most consistent answer. 77% of the patients surveyed had never heard of nano-medicine and 33% of the participants had heard of nano-medicine, but didn't realise that it was nano-medicine. All of the genetic disorder groups interviewed in this survey had the same prior exposure, which was very little to no exposure to nano-medicine. 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 nano-medicine 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 furthered this sentiment, *"Yes I have heard of it, but not as nano-medicine."* Some interviewees had read up on nano-medicine 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 furthered this with her comments, *"Very little exposure, almost none at all, except that which was covered in the national newspapers."*

These answers show that there is very little knowledge in patient groups about nano-medicine and its uses. This could stem from the lack of evidence that is being provided by researchers who are looking into nano-medicine applications in diseases like Parkinson's.

2. have you heard of nano-medicine being used in your area before,

Question two, also provided answers that showed a lack of knowledge in nano-medicine amongst patients and their carers. . 55% of patients interviewed had never heard of nano-medicine 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 nano-medicine 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 nano-medicine."* Participant B, who deals with research grants into Chronic Granulomatous Disorder research said this about nano-medicine in Chronic Granulomatous Disorder, *"No, very little was said about nano-medicine and there was no request money for research into nano-medicine."*

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 nano-medical research.

3. Knowing this information do you think that nano-medicine research should be continued?

88% of the patients and carers interviewed believed that research into nano-medicine should be continued based on the information presented in the PowerPoint presentation. Participant J of the Thalassaemia patient group 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 I was more cautious saying, *“it depends on the results of what can be treated with the medicine.”* Participant B continued the support of nano-medicine research but also brought up another area of research that needs to be looked at, *“Of course, I honestly believe that public opinion research needs to be done to get information out on both patient feelings and knowledge of the subject.”*

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

4. Do you have any concerns about the use and safety of this new technology?

This question offered a wide array of answers with some patients not having any concerns about nano-medicine, to some who are concerned. Those that were concerned with nano-medicine did not have prior knowledge of nano-medicine, but were concerned with technological advances in medicine. For instance, Participant I is not concerned with nano-medicine, but is concerned about scientists manufacturing male sperm in research labs⁴. Participant G also echoed Participant I's concerns in his answer, *“Not really, I think that in most cases it will be used as a line of last defense. To some people there may be concerns about the testing that is being done on animals in nano-medicine, 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 does have concerns about the risks to

⁴ http://www.timesonline.co.uk/tol/life_and_style/health/article6661357.ece

<http://www.dailymail.co.uk/health/article-1198132/Ethical-storm-flares-British-scientists-create-artificial-sperm-human-stem-cells.html>

July 2009, there was considerable press coverage regarding the development of sperm from stem cells.

the patient but believes that, *“There is 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 she is concerned with, *“the public understanding on nano-medicine. 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 nano-medicine. Is it too late to change the name?”*

5. Do you think that nano-medicine will be useful in the treatment of your disease or area of interest?

The majority of patients surveyed thought that nano-medicine would be useful in the treatment of their disease or condition. Participant H believes 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 believes, *“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 believes, *“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 shows some skepticism in his response, *“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 is a confusion amongst the participants on how nano-medicine could be useful in the treatment of their genetic disorder. This confusion stems from the lack of evidence provided in support of the claims researchers are making, and in the term “nano-medicine” itself. Many of the participants like Participant B said, *“I am concerned with the use of the name nano-medicine, is it too late to change the name?”*

6. What type of future information would be useful to you about nano-medicine and where would you go to get the information?

58% of the patients interviewed would like to get the information from patient organisations, while three would like to get their information from the internet, and 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 the general information about nano-medicine in a more lay format than what is currently available. Participant J said this on the topic, *“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 he believes 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 H speaking as a patient said, *“I think nano-medicine should from a patient’s perspective be communicated to patient organisation’s research departments so that they can see the potential of the technology.”* Participant H also believes that it is important to communicate science so that collaborations will be made across the field because to him a cure for Parkinson’s will come from a collaborative effort. Participant L would also like the involvement of patient’s groups in the release of information on nano-medicine, *“Something written in a nontechnical way, Parkinson’s research groups. I haven’t seen it, 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.* Participant B would 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.”*

Should more information be presented on nano-medicine, the participants would prefer to get their information from an online source. There is 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. There was also a concern amongst the patients on the regulation of what is posted on nano-medicine.

7. In your opinion is nano-medicine completely different from current medicine, or is it the next step in medical research?

55% of the patients believed that nano-medicine is the next step in medical research, while patients like participant D believe 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 also echoed this when he said, *“No, I think it is something completely different in terms of technology.”* Participant G believes, *“It is a continuation of medical research, it is somewhat different from current medical research, because it is aimed at specific diseases.”* Participant L believes that, *“Its 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 nano-medicine 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.

Conclusions

In summary, there is very little knowledge about nano-medicine and its research in the patient populations. 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 to look at all avenues in order to find a cure or treatment for their disease. All the patients interviewed wanted research to continue in not only their field, but in all areas of medicine. The patients also wanted more information to be presented to them through either their patient organisations or on the internet on nano-medicine, but in a much more lay friendly format with the pros and cons of the medicine presented so that they can make informed decisions on the treatments that they take.

Appendix I

Participant List and Key:

- Participant A- Huntington's Care Advisor, interviewed June 30th, 2009.
- Participant B- Chronic Granulomatous Disorder carer, interviewed July 6th, 2009.
- Participant C- Parkinson's Patient, interviewed July 13th, 2009.
- Participant D- Parkinson's Patient, interviewed July 6th, 2009.
- Participant E- Parkinson's Patient, interviewed July 7th, 2009.
- Participant F- Parkinson's Patient, interviewed July 7th, 2009.
- Participant G- Parkinson's Patient, interviewed July 8th, 2009.
- Participant H- Parkinson's Patient, interviewed July 14th, 2009.
- Participant I- Parkinson's Patient, interviewed July 13th, 2009.
- Participant J- Thalassaemia Patient Carer, interviewed July 8th, 2009.
- Participant K- Parkinson's Patient, interviewed July 21st, 2009.
- Participant L- Parkinson's Patient, interviewed July 22nd, 2009.

Appendix 2- PowerPoint Presentation

Slide 2

What is Nano-medicine?

Nano-medicine 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.

Current Examples of Nano-medicine

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 preemptive science.

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.

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.

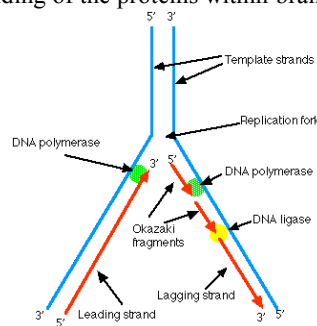
Implants- In Parkinson's patients Physicians can now place small electrodes on the VIM (Ventral Intermediate Nucleus), which is the middle region of the thalamus, and extending to the sub-thalamic nucleus, which is in front of the thalamus. Then applying a high-frequency electrostimulation, physicians 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.

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.

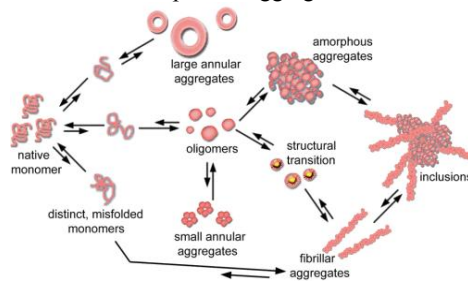
Another line of research is using Atomic Force Microscopy to better understanding how incorrect protein folding causes genetic disorders like Huntington's disease. They hope that this will allow them to develop a nano-bot that would allow them to control the folding of the proteins within brain cells.



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 recognize the cell) which suppression of protein aggregate forming on HD cell surfaces. In experiments with HD *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.



Where is it, and where is it going?

Nano-medicine 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.

Concerns

As with all new areas of research some concerns have been raised about nano-medicine.

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.

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