Focus group conversations on clinical possibilities and risks within Parkinson disease : a Swedish case study

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2013

Focus Group Conversations on Clinical Possibilities and Risks within Parkinson Research

A Swedish Case Study

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2013

Part of:

TRANSEURO

http://www.transeuro.org.uk/

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ISBN 978-91-637-4758-8

Lund 2013

Background and Aims

TRANSEURO is the name of a multicenter and mainly biomedical consortium, whose goal is the development of methods for treating patients with Parkinson's disease through transplantation of dopamine-producing cells into the brain. The consortium started in 2010 and includes several partners and sites around Europe: Cambridge University, Lund University, Freiburg University etc. A crucial step in the process of this scientific collaboration will be the recruitment of suitable patients for the clinical trials that are planned and the performance of these trials in a scientifically and ethically acceptable way.

The Swedish focus group study that is to be presented here is part of the TRANSEURO initiative. However, in contrast to TRANSEURO in general the study is based on a cultural-scientific rather than a biomedical method. It has been conducted within the project "Ethical Governance", which is headed by Professor Herbert Gottweis at Life Science Governance Institute in Vienna, Austria, and which is aimed at analyzing differences and similarities regarding patient and public attitudes towards and experiences of, cell transplant research in Germany, England and Sweden. The Swedish study has been led by Professor Susanne Lundin at Department of Arts and Cultural Sciences at Lund University. The focus group interviews have been organized and carried out by associate professor Markus Idvall and PhD student Andréa Wiszmeg in collaboration with the Department of Experimental Science at Skånes University Hospital/Lund University, Sweden.

The aim of the Swedish focus group study was to investigate how three categories of lay individuals – patients, relatives of patients and the public – relate to the ongoing cell transplant research within the field of Parkinsonism. How do they value neurosurgical alternatives, such as fetal and embryonic stem cell transplants, in relation to the pharmacological alternatives offered as treatment in the clinic at present? What do these individuals know about the different research and treatment alternatives? What are the possibilities to develop a strategy for ethical guidance on specific biomedical research? How should the governance of biomedical research on Parkinson's disease be conducted? The Swedish context of the focus groups is included in a transnational comparison where corresponding groups and categories are investigated in England and Germany.

The Project Starts

The Swedish project started in the fall of 2011 when an application for ethical approval of the project was submitted to the regional ethics committee at Lund University.

In the application, the different steps of the project were outlined. The focus group conversations were to be conducted by the use of a topic guide, provided in an English version from Professor Gottweis. This topic guide was translated into Swedish and became part of the application to the regional ethics committee. Also, other documents were produced in order to substantiate the upcoming information, recruitment and informed consent process that was to take place: a combined information and recruitment sheet on the project, a form where the consenting participant could fill in his or her name and sign, and an advertisement text for recruiting potential participants in public and media spaces.

The project was approved by the regional ethics committee in Lund in the fall of 2011.

The Recruiting of Focus Group Participants Begins

The recruitment of focus group participants started in the fall of 2011. In the recruitment process we approached both the public and patients. The recruitment of the public was not successful and after some time we decided to approach people in our own local environment. The first public group, here called Focus Group 1 or FG1, was recruited through our place of work: Department of Arts and Cultural Sciences at Lund University. The second public group, FG2, was recruited through a relative of Idvall. This relative used her neighborhood contacts as a source of recruitment for the focus group. The third public group originated with one person whose name was given to us by a participant in an earlier focus group. With the help of this new contact, we gathered a focus group of affected members of the public, FG6.

The first two patient groups, FG3 and FG4, were recruited in collaboration with the Department of Experimental Science, Lund University Hospital/Lund University. The recruitment and information letter of the project was sent twice to a number of patients through the patient register of the university clinic. Also, through this process, recruitment of focus group participants was slow. The third patient group, FG5, was therefore recruited through a contact person that we found through the website of the national patients' organization, *Parkinsonförbundet*.

The informed consent of the participants was secured through the combined recruitment and information letter disseminated among potential participants. Before the start of every focus group interview, there was also verbal information given by the moderators. At this point, the focus group participants were able to fill in and sign the letter of informed consent.

The Focus Group Method in Hindsight

Six focus groups were conducted from January 2012 to January 2013. Five of these six focus groups were conducted at the Department of Arts and Cultural Sciences in Lund on five separate dates, either in the afternoon or in the evening. The sixth group, FG2, took place in the home of Idvall's relative, where the invited neighbors could interact casually. This group was conducted early in the afternoon in a small village in the northwestern region of Skåne.

Five of the six focus group interviews were each about two hours long. FG1 was, however, special since this focus group was split on two different occasions and all together the conversations of this focus group lasted for almost five hours (appendix #1). FG1 was the pilot focus group interview of the project, and afterwards the topic guide was modified in order to correspond to the time frame of two hours.

Each focus group was directed by one moderator and one co-moderator. The moderator headed the discussions with the participants by using the topic guide. The co-moderator took care of the clock and the timing of each interval, the sheet of papers that were handed out and handed in, etc. Idvall and Wiszmeg switched between these two roles as moderator and co-moderator. All together Idvall and Wiszmeg were moderators and co-moderators three times each, respectively (appendix #1).

The number of participants was between five and eight individuals in the different focus groups.

Each participant filled in a form of biographical data before the focus group started: name, sex, year of birth, place of birth, occupation/title and education. In this report, with respect of the anonymity of the focus group participants, only sex, year of birth and place of birth are included (appendix #2).

The mutual talk of the focus group, which ran according to the topic guide, usually started with an introduction by the moderator. The moderator described what the participants were about to engage in. In connection to this information the co-moderator turned on the digital recording. The first form was distributed; a self-evaluation of how the participants rated their knowledge about the topic. It took some minutes for the form to be filled in (for the result of this step in the investigation, see appendix #3). After this, they were given a task with post-it notes. The participants were asked to write down one positive and one negative thing about a theme relating to the research on Parkinson's disease (appendix #4). In the end of this first part of the focus group, the participants received a ten-page long information sheet on different research and treatment alternatives regarding Parkinson's disease. Here, information was given on the pharmacological treatment of levodopa, fetal VM cell transplantation, embryonic stem cell transplantation, etc. During the reading of the information sheet, participants generally had some coffee or tea together with something to eat. Thereafter, the moderator directed the conversation by guiding the participants from one question or theme to another by the use of a flipchart. Questions such as "How do you appreciate risks and benefits with transplantation of fetal VM cells?", "Under what circumstances would sham surgery be acceptable within the research of Parkinson's disease?" or "Would it make a difference to you if the cells were human embryonic stem cells or fetal ventral mesencephalic (VM) cells?" were discussed. This provided an opportunity for the different contrasting perspectives of participants to be represented. This part of the discussion was planned to be rather long. After this the participants came back to the task of post-it notes where they were supposed to give examples of positive and negative aspects of a certain theme in the context of Parkinson's research (appendix #4). Finally, a form ranking different alternatives of treatment of Parkinson's disease was completed by the participants (appendix #5).

The interaction between moderator and participants ran for the most part, smoothly. The moderator had the role as guide and sometimes even as a teacher. The latter role was in line with how the topic guide was structured.

The interaction between the participants did not run so smoothly all the time. The participants often orientated themselves toward the moderator rather than towards each other. This of course inhibited the internal discussions within the group. In some groups, one or two of the participants dominated the discussion, while the other participants were rather silent.

However, it felt like there was quite a strong consensus in most of the groups. Those small differences that existed were often between two or three individual participants. Usually, the participants avoided focusing too much on the differences.

The Material Emerges

The focus group conversations were all recorded, digitally. The sound files were transcribed by Idvall, Wiszmeg and an external resource.

The sound files were at first transcribed verbatim. However, in order to protect the different focus group participants, the transcribed material was coded and made anonymous.

At the end of the project, the transcribed and coded material was then translated into English by external resources.

Thirty-five individuals, 17 women and 18 men, took part in six separate focus group conversations. FG1 involved four women and two men; FG2 five women and three men; FG3 one woman and four men; FG4 one woman and five men; FG5 four women and one man; and FG6 two women and three men (appendix #1).

The average age of the participants was 64.6 years. The oldest participant was 86 years old and the youngest one was 33 years old. FG2 was the oldest group with an average age of 79 years. FG1 (53.8 years) and FG5 (53.4 years) were relatively young groups. FG4 (63.5 years), FG3 (65.2 years) and FG6 (66.6 years) were all close to the general average age of the investigation (appendix #2).

Of the 35 participants, there were as many as 34 that were born in Sweden. Only one person had a different national background than Swedish (appendix #2).

There was a great variety of occupation and educational background among the focus group participants, from chief executive officer and physiotherapist to self-employed and bus driver.

The 35 participants in the focus group interviews represented three categories: patients, affected public (relatives of patients) and non-affected public. In sum, 17 patients, 8 affected public and 10 non-affected public participated in the focus group interviews. FG1 gathered four non-affected public and two affected public; FG2 six non-affected public, one affected public and one patient; FG3 five patients; FG4 six patients; FG5 five patients; and FG6 five affected public. In the presentation of results below FG1 and FG2 are featured as non-affected public focus groups; FG3, FG4 and FG5 as patient focus groups; and FG6 as an affected public focus group (appendix #1).

Results

Here we will discuss some preliminary results on the basis of the different themes that the topic guide comprised. We will present the themes in the same chronological order as they were discussed in the focus groups. In the presentation we will refer to two different kinds of voices: the collective voices of the focus groups (FG1, FG2, FG3, FG4, FG5 and FG6) and the individual voices of the single participants (P1, P2, P3 etc. up on to the very last participant of P35).

Self-Estimating one's Knowledge of Treatment Alternatives

Each focus group began with a form to be completed by the participants, where they estimated how well informed they were about the topic. The following five statements were put on the form:

1. Neurological diseases such as multiple sclerosis and Alzheimer's disease are becoming more and more common, with the result that the number of patients with Alzheimer's and Parkinson's disease is increasing. Researchers have calculated that the number of cases of Parkinson's disease will even double by 2030.

2. There are no treatments that cure Parkinson's or Alzheimer's disease or that can halt or even slow the progressive degeneration of neural cells. Current treatments primarily consist of reducing the symptoms.

3. Currently, Parkinson's disease is mainly treated with drugs. The therapy targets symptoms of the disease. The reduction of dopamine that is caused by Parkinson's disease is treated with an appropriate drug therapy (dopamine agonists or L-dopa).

4. Did you know that the treatment of Parkinson's disease could also be carried out using neurosurgical approaches? One approach is called deep brain stimulation (DBS), which involves the implantation of a medical device (a small wire) with multiple electrodes into a dysfunctional region of the affected brain.

5. Did you know that the transplantation of cells constitutes another treatment option? This time, via the hole drilled in the skull, fetal cells are implanted into the region of the brain where dopamine normally works but is missing in the case of Parkinson's disease.

Each statement was followed by the question: "To what extent are you already familiar with this information?" The question had four alternatives of answer: "Not at all", "To some extent", "For the most part" and "Completely".

In order to operationalize the answers of the six focus groups, we scale the alternatives from 1 point to 4 points, where "Not at all" equals 1 point, "To some extent" 2 points, "For the most part" 3 points and "Completely" 4 points.

The three patient groups had relatively high scores on the level of self-evaluation of personal knowledge. On average the participants in the patient groups scored 3.1 on each question, which equals the answer "For the most part". The participants in the public groups scored 2.5, which equals the answer "To some extent". However, there was great difference between the two groups of non-affected public and the single group of affected public. The participants in the two groups of non-affected public scored 2.1 or "To some extent", while the participants in the affected public group scored 3.2 or "For the most part" when self-estimating how well informed they felt. The affected public thus scored even higher than the patient groups on the self-evaluation test of information regarding Parkinson's disease and its treatments and scientific progress (appendix #3).

Pros and Cons in the World of Parkinson's Disease

After the self-estimation the participants were given two post-it notes each, one red and one green. They were told to write down one positive and one negative aspect of a certain theme that was presented to them. The positive thing was to be written on the green post-it note and the negative one on the red post-it note. The moderators received the notes after some minutes and put each of them on the billboard. Each contribution was read out loud by one of the moderators (appendix #4). The participants were invited to comment on what was read out loud. The talks that followed became a kind of introduction where the two moderators and the focus group participants learned to know each other and each other's ways of thinking and arguing.

FG1, the first public group, was to deliberate on the themes of Deep Brain Stimulation (DBS) and cell transplants. In the discussion, based on the red and green post-it notes, DBS was distinguished as a routine method that could specifically help against involuntary movements of Parkinson patients. As the treatment is so specific, only a small group of patients is helped, according to P3. One of the post-it notes reminded the discussants that DBS treatment makes the human into a cyborg or a human of spare parts. Whether this is positive or negative can be discussed. A negative side of DBS was, according to P6, that the treatment is effective only against the symptoms and not the cause of the disease. In this scenario, cell transplants can become interesting as a future routine treatment. Here the group was a bit ambivalent. On the post-it notes the group had listed some reasons for looking positively at cell transplants. It was, for example, exciting that new technologies can help patients. Cell transplants could also be a way of creating more long-lasting effects of treatment. However, in the group discussion, the more negative or problematic aspects of cell transplants were highlighted. Cell transplants were for example associated not only with risky surgery treatments in general, but also with extra risky and complicated brain surgery treatment.

When the moderator told the second public focus group, FG2, to write down one positive and one negative aspect of the different treatments that are used for treating Parkinson today, he met only confusion and questions in return. Instead of receiving the post-it notes and initiating a discussion on their basis, the moderator started a less formal and "noteless" discussion with the group of participants who had obviously felt a bit lost in the situation. This discussion concerned different concrete experiences of Parkinson's disease and its treatment within the group. P11 told the group about her only experience of Parkinson's disease: A friend who is suffering from the disease and who was now described as "stiff and tired", but still "in good mood". P7, who had arrived to the public focus group without letting the moderators know about his background, but who then actually turned out to be an individual with Parkinson symptoms, described the problems he had with involuntary movements of his hands. This self-presentation led to a discussion on ineffective medical treatments. P10, who previously in his professional career had worked closely with doctors, had experience of earlier kinds of neurosurgical treatment against Parkinson's disease. He declared that he was skeptical regarding cell transplants. "We need to know a lot more than we do today," was his opinion.

FG6, the focus group with affected public, was on the whole positive to transplantations with fetal VM cells, but they were worried about the access to these cells. P35 also related a problem that researchers have with the stem cell alternative, the fact that one cannot really limit the growth of the stem cells in the recipient body, which, in a way, makes the fetal VM cells alternative even more promising. P33, however, reminded the other focus group participants of the existence of "somebody who has lost their child" in order to supply the cells. Further on in

the conversation it was stressed that interventions, such as brain surgery, demands close follow-up of patients, something that is not always done, according to the participants.

FG3, the first patient group that was interviewed, jumped right into a discussion on the use of the aborted fetus. The group seemed to agree that it was good that a fetus could be used for experimental purposes. P16 argued that it should not be an ethical problem to use a fetus when the decision to kill the fetus has already been made. However, P15 reminded the group that not everyone is of the same opinion. In this discussion P16 mentioned another aspect of this question that highlights the interests of the users rather than the donors: The main problem of the present cell source is not the donor issue but the access issue. In the patient perspective there are not enough fetal cells. In this way the discussion came to be focused more on the situation of the possible recipients of cell transplants. In the group there was an age span of 33 years. P18, a man in his forties, explained that he was not prepared to take great risks as a research subject since he had a family and young children. Next to him were sitting participants in their sixties and seventies and together they could understand this, but concluded that risk-taking is part of life in all ages and what you do is try to make your life longer, even in phases of life where you are relatively old. FG3 also agreed that brain surgery is a particular kind of risk-taking. However, as P15 said, “brain surgeons seem to have steadier hands than certain other surgeons”. Here the conversation moved on to more personal experiences of clinical trials. One of the men had been participating in a clinical trial involving human growth factor and he described how this had been done through a twenty-hour long surgery.

In FG4 the participants, all patients, started their conversation by highlighting the political conditions of the research on Parkinson’s disease. The group could identify political resistance against research involving fetal cells and embryonic stem cells. A symbol for this resistance was, according to FG4, the former U.S. President George W. Bush. The group seemed to reason that during his presidential era between 2001 and 2009, research on Parkinson’s disease had been greatly inhibited in the U.S. as well as worldwide. One of the participants, P24, remembered that he, already in the 1990s had great hopes that researchers were to find a cure against Parkinson’s disease. But, because of the limitations on research that were instigated in the U.S., scientists had not been able to work in a proper way. In relation to this, the group maintained that use of fetal cells for transplantation should not be seen as a problem, since the decision has already been taken that the human being in question is not supposed to live. Here P22 told us that he had been recruited to a planned research project that was about to start soon and that he saw cell transplant research as something exceptional, since it “in some way was to get to the root of the disease”. FG4 also identified the foreign websites that you can visit on the internet, as a negative aspect of current developments. There, cell transplants are advertised as an unproblematic cure against Parkinson’s disease. When P20 asked his doctor at a clinic in Sweden about these foreign websites, he was answered that this was, “only business”. Patients are given false promises that their Parkinson’s disease will be cured by cell transplants.

According to FG5, primarily consisting of female patients, one could not ignore the fact that Parkinson patients, thanks to pharmacological developments, live a much better and longer life today, than only a few years ago. However, the group wanted to see still, even more progress and cell transplants could be part in this. FG5 wanted a final conclusion about the cause of the disease and they longed for a treatment, such as with HIV/AIDS or Multiple Sclerosis, that can slow down or even curb the disease. As individuals with a chronic illness, that are used to long waiting times for different treatments, the FG participants could identify limited access as a possible problem for future cell transplants. Another negative aspect could be the ethical

charges around the aborted fetus. P26 saw a promising development in the fact that research is now conducted on the possibilities of transplanting reversed skin cells to the human, taken from the body of the individuals themselves. In that way, one could move away from the dependence on the aborted fetus. Still, FG5 seemed to agree on the position, why not use the aborted cell material, if it is accessible. The only man in the group, P29, raised the question of ethics. Following this, the group touched on questions about animal experimentation and the clash between different generations regarding what is right and wrong in this context.

Thus, it seems that patient focus groups, in contrast to focus groups with non-affected public, moved more quickly into discussions on different ethical dilemmas concerning treatment and research alternatives. The focus group with affected public was a cultural crossover in this case. These focus group participants did not have the embodied experience of Parkinson's disease, but they could easily relate to the ethical problems regarding treatment and research alternatives.

Different Alternatives of Treatment and Scientific Methods

After the first discussion, the participants were given an information leaflet on different research and treatment alternatives. After reading, the participants were invited to comment on the different methods of treatment. The moderator started this part of the focus group by giving a short summary of what the participants had just read. Gradually, the participants took part in the discussion.

In FG1 one of the two individuals who represented the affected public in the group, P3, started by explaining how medicines are necessary for Parkinson patients, but how these medicines eventually lead to different kinds of complications and side-effects for individuals. In this way, more symptoms are added to the symptoms of just the Parkinson's disease. A large share of this discussion around the information sheet, concerned however, different economic and societal aspects of Parkinson's disease. The varying prices of different treatments were a topic that engaged the interest of FG1. The group debated the valuation of a Parkinson patient in economic terms, in relation to, for example, a road traffic victim. The risk that fetal cells can become part of international trade was discussed as well.

The next public group, FG2, began to discuss the topic of brain surgery. P9 mentioned the drilling of a hole in the patient's skull, as something that sounded both horrid and complicated. Some of the other participants then tried to imagine how they themselves, or more realistically, somebody with Parkinson's disease, would relate to the possibility of being operated on, in the skull. "One agrees to this," as P11 said, "if one thinks that life is not worth living any longer." Following this, the moderator as well as the assistant moderator, took time to explain to the group how cell transplants are performed. Of the eight group members only one of them, P10, seemed to have some kind of pre-knowledge about the topic. This man, quite independently stated, in the middle of the discussion, that researchers know how to produce a cell today yet, they do not know how to generate life into the cell. Still, P10 was confident that science would eventually solve this matter.

In FG6 the discussion revolved around the pharmacological alternative. The group agreed that the medicines were a necessary evil for Parkinson patients today. The patients could not manage their everyday life without medicine. Not even after a DSB surgery, is it possible for the

patients to manage without medicine in the long term. However, there seemed to be divergent expectations about the so-called pharmacological method, in the group. One of the participants, P34, described it as a deadlock, while another one, P35, argued that the final solution of Parkinson's disease might be a medicine of some sort. In the end of this part of the discussion, on different treatments and scientific alternatives, FG6 returned to the question about the importance of following up on all kinds of interventions with patients, irrespective of whether these are pharmacological or surgical in approach.

In FG3, the patients began by reflecting on the pharmacological alternatives. P18, at this very moment of the focus group conversation, was suffering from a characteristic side-effect that the medicines were causing, namely involuntary movements of the body. This was, in a respectful way, called attention to, by one of the other participants. P18, against this background, explained that he had suffered from Parkinsonism since the 1990s and over the years his problems with side-effects of the medication has grown greater and greater. It was now very difficult for him to foresee how the medications would affect him from day to day. He wished he could have a greater regularity in how they affected him. This self-presentation of a group member, led to deliberations on different themes: how regulated food intake can contribute to better health, how treatment of Deep Brain Stimulation can generate problems with the speech, etc.

In FG4, the discourse first circled around the question about what causes or triggers Parkinsonism. The group of patients discussed the possibilities of heredity as well as stress. This question about the original cause of the disease is of course relevant in the scientific context, but from the patients' point of view it was a very personal question, too. P23 explained that all individuals with Parkinson's disease ask themselves why and when they got the disease, trying to create meaning and causality around the events leading up to the illness.

FG5 initially compared pharmacological and neurosurgical alternatives of treatment. P30 described how she, as a Parkinson patient had become a "slave under the medicines". Everybody knows that there is a limit for how much medicine you can take and that you eventually have to choose a different, read: a neurosurgical alternative. However, this participant continued, not everybody is helped by neurosurgery. The other participants continued on this track, describing the medication as something, that is not salvation and surgery as something that you cannot really choose, but rather, as something that becomes necessary in the long run. Following, there was a discussion on how the Swedish Social Insurance Agency (*Försäkringskassan*) is forcing individuals with Parkinsonism to work more, by taking more medicine. FG5 saw this as an expression of complete lack of knowledge about the disease and how medication must be balanced in relation to how its side effects appear or can be postponed.

Summarizing the discussions on the different treatment and scientific alternatives, it is apparent that the pharmacological methods generate great ambivalence in the focus groups of the patients and the affected public. Present medicines are necessary but also greatly insufficient in the treatment of Parkinson's disease. In the two focus groups with mainly non-affected public the discussion on treatment and scientific alternatives was approached in two different ways. In FG1, one of the two representatives of the affected public in the group directed the discussion by initially informing the group about the complications that the medicines cause. In FG2, in contrast, the two participants that represented patient interests in the group never touched on this issue and the discussion was entirely focused on the neurosurgical alternative.

Transplantation of Fetal Ventral Mesencephalic (VM) Cells

After the self-estimation form, the post-it notes and the information sheet, it was now time to introduce the focus group participants to the flipchart. From here on, the focus groups were confronted with a number of straight–on questions, each implicating some kind of hot and controversial topic. The first question concerned transplantation of fetal ventral mesencephalic (VM) cells.

In FG1, dominated by non-affected public, the donor issue appeared immediately as a subject. How donors are approached, was a central question for FG1. The "parents" of the fetus must first give their informed consent about the donation to science. There was a discussion on how specific the information must be. Should the donors know specifically, how the fetus is to be used, or is it just enough if they know that the fetus will be used for science, in general? When FG1 was asked about risks regarding the recipient, the discussion moved to the issue on how the cells may "behave" or function in the body of the recipient. Eventually, the group reflected on the issue of personality transformations of the recipient. P3 explained that she experienced cell transplants as something better than speculations about the "new human" in science fiction movies. FG1 also discussed the question of genetics in this context. The participants concluded that these fetal cells were to be received by elderly who, in contrast to younger individuals, will probably not spread the genes to future generations.

In FG2, where individuals representing the non-affected public were in majority, the first issue to appear was about the risk of the recipient. P11 highlighted the question about heredity and genetics. She was worried that "bad" genetic features would spread through these cell transplants. She concluded, however, that the elderly would not spread the genetic features to the future generations. In accordance to the worries of genetic transformations, FG2 also confirmed the risks of personality transformations for possible recipients of the cell transplants. P10 reminded the group about the risk of untrustworthy doctors, who could in one way or another exploit these kinds of transformative cell transplants. P9 expressed that some personality changes could be acceptable if the recipient gets well after the cell transplant. However, these changes of the personality of the recipient should then be a very minor.

In FG6, with the affected public, the discussion turned at first to the risk scenarios of the recipients of the cells. The group was aware of the risks that patients may take when participating in clinical trials. Some of the focus group participants showed at the same time great confidence in ongoing scientific research. P35 referred to a public lecture where a scientist had explained how the injection of a virus was to stop the development of possible cancer tumors in the recipient's body. Further on in the focus group conversation, specifically regarding the donor issue surrounding the fetal VM cells, FG6 expressed the conviction that the procedure should not be questioned, not in ethical terms at least. If the decision has been taken to perform an abortion, then it should be no problem for the donor of the fetus to "make another human happier", instead of getting rid of the fetus in the trash bin.

In FG3, our first patient focus group, cell transplants were seen as something still very pre-clinical. One of the participants referred to what the famous Swedish pharmacologist and Noble Prize Winner Arvid Carlsson once said about animal trials: There is great difference between the brain of a young mouse and the brain of an old man! The focus group participant related this to his own participation in a clinical trial with human growth factor. The clinical trial had

according to him had no effect on him or any one of the other patients taking part in the project. The only individual change that he experienced was that his ability to smell returned temporarily. As a consequence of discussing this question about how the sensations of smell can return for an individual, FG3 never really went deeply into the question of the pros and cons of fetal VM cells.

In FG4 one of the focus group participants had been recruited as a research subject in an up-coming clinical trial with fetal VM cells. This made him a key person at this part of the discussion. The man explained that he had thought a lot, before he finally said yes to participate in the planned clinical trials. He had asked himself: What will this participation imply? How will it affect my illness? He did not think of the cells in a way where he, so to speak, was "taking" the cells from one or several fetuses. The other participants asked him about what kind of intervention the cell transplant was to be. One of the participants mistook it for the neurosurgical intervention of Deep Brain Stimulation. This misunderstanding led the discussion to the question of DBS. Eventually, when FG4 came back to the question of cell transplants the group concluded that it is easier for an individual who has been ill for a long time, to agree to participation in a clinical trial, than it is for an individual who has been ill for a shorter period of time. However, here it was also emphasized by P24, that it is always difficult to know where the "limit" or the bottom line is for this kind of question.

Also, in FG5 the dialogue started with a patient with some experience with clinical trials. This patient had volunteered as a research subject in a near-term clinical trial. She said that she does not know yet, if she actually will become one of the trial participants, but she hopes that she will. She explicated that she wants to take the chance and that she trusts her decision. The group understood her decision and a couple of the participants talked about "taking all chances" or about the interest they themselves have of taking part in clinical trials. FG5 also reflected on the motives of participating in clinical trials. Of course, there is great motivation by the fact that you, yourself can be cured from Parkinson's disease, but you are also motivated by the fact that you might be able to contribute to a solution of the disease.

In the focus groups of the public, it is then clear that both donor and recipient issues absorbed a lot of attention. In contrast, in the focus groups of patients, the attention was placed, from the very beginning, on recipient issues. In these groups there was also clearly a difference between experienced and non-experienced individuals. Those patients, who had experience of being a recipient or even a possible recipient in clinical trials, were the ones who directed the discussions.

Sham Surgery

The next page of the flipchart had a question about sham surgery within cell transplant research. The moderators introduced the theme by relating how sham surgery had been used previously, by different research groups in the world, but how this approach had also been criticized for being unethical and even unnecessary (in terms of safeguarding the evidence base of the experiments). Here, it was also added that TRANSEURO did not plan on conducting sham trials.

In FG 1, the first reactions toward sham operation trials included laughter and expressions such as these: "Ugh", "That is terrible", "In the stone age you had trepanation". The discussion then continued with an ambition to understand the concept. Critical points of view were, however, clearly dominating this part of the process. While the discussion went on one could sense a

division between those who were clearly against sham surgery and those who were more appreciative of, or willing to understand the concept. The division was particularly evident between two men in the group. P2 was, from the very beginning of the argument, rejecting sham surgeries for the reason that the operation will harm a patient without giving him or her any treatment. P5 was not so outspoken about his own position at first, but eventually took a position by, for example, declaring that it is a good thing to do experiments even though some people must sacrifice in the process. One of the other participants then asked him if he, himself, would take part in a clinical trial as a "placebo patient". With great hesitation, he replied, yes to this question.

Also, in FG2 the rejection of sham operations was quite clear. Some group members took a stand against the concept early on, at this part of the conversation. However, P9 raised the issue that some might be interested in participating in this kind of experimentation where you have both a treatment group and a control group for neurosurgical interventions. She added that younger people and people who are experiencing low life-quality because of their illness are often more willing to take risks. In the following discussion P10 disagreed quite openly that younger people would be more risk-taking while other focus group participants recognized that individuals who are relatively ill might be more willing to take risks. In the reflections, it also appeared that the neurosurgical site raised in itself some worries in the group. It was, as P11 said, the worst place where you can be operated on.

In FG6, arguments both for and against sham surgery were voiced. At first P34 and P35, two of the more loquacious members in the group, declared that they were, in principle, for the use of sham surgery since placebos can have effects in different ways. P33, however, stated that she was against "blind tests" on individuals who are ill and already in bad shape.

In FG3, the patient participants were positive to the use of sham surgery, yet, not completely eager. Sham surgery was characterized as something, which is a necessary evil. Surgery is always a risk for the patient, but the effects of a placebo must be recognized in circumstances that involve Parkinson's disease. P16 explicated that if you, as a Parkinson patient believe in a treatment, that it will help a lot. The opposite is also relevant: If you do not believe in the treatment, it will turn out badly. The group also proposed how sham operations can become more acceptable for everybody. All patients taking part in research where control or placebo groups are used, must be promised that they themselves afterwards, if it turns out that they were included in the control group, will be the first ones in the new trial, to get the effective treatment.

In FG4, there was a greater divide between those who were against and those who were for the use of sham surgery. P21, the only woman in the group, initially called sham operations, sheer madness and she got agreements from other members in the group. However, this was quickly followed by an approving comment by P20. He explained that sham operations are something "one can take" if it is beneficial for the development of the research. In the following discussion on sham operations, the opposition between the two attitudes remained. Most participants stuck to their own opinion, but in one case, the discussion had obviously started a kind of re-thinking process. P25 pronounced that before the focus group event he had always been positive about the use of placebo in science. But now, listening to the discussion, he started to get a different opinion on the topic. Sham operations on the brain was something he could not really approve of. He also suspected that these placebo interventions were there to make research slower and therefore also more expensive.

FG5 was the most hesitant of the patient groups, towards sham surgery. The participants were aware of how all research subjects were to be informed about the structure of the research project; how everybody was to be told about the research group and the control groups, etc. This would possibly be acceptable if it concerned the matter of medical pills, however, it is completely different when it comes to neurosurgical interventions. There is, as it was agreed on, too much at stake in the latter context.

Not surprisingly, the awareness of sham operations was greater in the focus groups of the patients and affected public. This greater awareness was combined with greater ambivalence, in these groups. Evidently, the use of sham surgery spawned mixed feelings among Parkinson patients and their relatives.

Trust in Biomedical Science

Now the moderator turned to the next page of the flipchart, where the topic was about trust in biomedical science in general.

In FG1, the discussion focused on how biomedicine operates in society in different contexts. A recurring theme in this discussion was the problem of the lack of openness of scientists towards society. FG1 agreed that scientists in general, need to become more open about their results, more willing to explain to lay people what kind of outcomes they have achieved. Scientists should stay away from keeping secrets from society and they should talk in an intelligible way and avoid all sorts of academic "mumbo jumbo." Commercialization of science was given as an example of a worrying trend in society. The pharmaceutical industry was described as only interested in developing medicine for big markets. Another trail was how biotechnology in a dystopic way, could create Frankenstein–like beings in a gruesome future.

In FG2, biomedical science in general was characterized as necessary by P13, an individual who was relatively silent during major parts of the conversation. The other participants nodded approvingly in the background. The discussion then turned towards research, as a threatened necessity, in Swedish society at least. Money is lacking, was a message. Another trend, according to P10, is that scientists are leaving the country and research activities are being moved abroad.

The discussion of FG6 was colored by references to an earlier incident when a clinical trial study had to be stopped prematurely, because of lack of money. The focus group agreed that both the institution and the individuals are crucial for how you as patient, experience biomedical research. A team of medical staff, as well as individual contact people can, if they are doing a good job, instill feelings of hope into those who are participating in the clinical trials.

Among the patients in FG3, the question about trust in biomedical science in general brought up the issue of necessary and unnecessary research. When asked about what the latter kind of research could be, P17 replied that she herself, being ill from Parkinsonism, but not from high blood pressure, thinks that it is great when research is conducted on Parkinsonism and not on high blood pressure. This kind of self-orientated reply motivated the moderator to ask what FG3 thought about groups in society which are against Parkinson research for the reason that it involves fetal and embryonic stem cells. Some in the group reflected on the question by referring to whether it is right or wrong to manipulate life, and whether there is a risk that cell transplants may become commodities in countries of the Third World. However, this discussion was abruptly closed when one of the more dominating voices in the group, rather drastically

declared that people are shocked by so many things and that an Indian woman who is producing fetal cells for Parkinson patients in the West, would have a great income.

FG4 started by explicating that science is needed and necessary. However, in their reflections on the question about trust in medical science, the group came up with a number of problematic issues. P23 related how a Swedish evening paper recently revealed news on how the side effects of certain medications for different illnesses have been kept secret. Regarding the possibility of cures against Parkinson's disease, the incitements of the pharmaceutical industry was seen as quite poor. It was perceived that the high competition between scientists, leads to manipulation of research results. FG4 did not see the market forces as productive within science, and wanted transparency within the system.

FG5 too, raised the question whether the pharmaceutical industry actually is interested in finding a neurosurgical cure against Parkinson's disease. At the moment the industry is making a lot of money on the medicine that is sold and distributed to the community of individuals with Parkinson's disease. This source of income would of course be lost if a surgical cure would be discovered by scientists. A crucial question is then who directs the development – the scientists or the market forces? The group, with relatively young participants, saw a new trend that will make Parkinson's disease into a more interesting topic within science, in the future. The disease will become more and more associated with younger people and thereby, it will also become more interesting in the eyes of the doctors and researchers. Parkinsonism will be a distinctive neurological disease, striking both old and relatively young individuals.

In sum, the patient groups, more than the public groups, referred the question about trust in biomedical science to questions about Parkinson's disease, in general.

The Alternative of Human Embryonic Stem Cells

The focus groups now turned to what is the real cutting edge of biomedical science: the transplantation of human embryonic stem cells. In FG1 to begin with, this alternative was promoted as a much better alternative than the fetal VM cells. The embryonic stem cells were seen as a way of getting rid of the problematic donor issue. Still, they are not an ideal solution. The embryo can be subject to trade, and women in poor countries can be exploited when they are forced to sell their eggs as a consequence of their poverty and dependency.

In FG2, the topic of embryonic stem cells did not generate a very passionate discussion. The group seemed a bit puzzled. P10 excused himself by referring to the topic as a "women's field". One of the women, P9, argued that embryonic stem cells is much better than fetal VM cells since you do not need to consider the question of the aborted fetus any longer. She added: A fetus is always a human life, while an embryo is a bunch of cells that you can manipulate with.

FG6 chose not to discuss the human embryonic stem cell alternative; instead the group focused on trials that have been recently conducted on rats with dopamine-producing cells from the body of the recipient. The group seemed to have great expectations in this case, but was also aware that the development of this method can take a long time. In the meantime, FG6 was more positive about transplantation with fetal VM cells than with human embryonic stem cells.

In the discussion of FG3, P16 said in a determined way that "we, as patients, in general, are not so interested in what kinds of cells that are used". "We", he continued, "are more interested in the result of the research". Nobody contradicted him here. Like P16, the other participants did

not seem to be fully convinced that human embryonic stem cells would offer a better alternative than fetal VM cells. Stem cells *might* be better, but this, they reasoned, is not known yet and therefore, the researchers should not give up the fetal VM cells at this moment. Here, the group repeated its positive attitude towards the use of the aborted fetus. P15 explained that it does not matter at what stage one kills a human fetus, if it is to be used as research material. The question of which one of the two applications one decides to use – fetal or embryonic cells – must be settled by which, of the two materials, is most accessible. Here, FG3 also had expectations of the use of the patient's own cells. According to the group, this kind of transplantation where the cell transplant comes from the recipient's own body, would solve the problem of immunological rejections.

FG4 penetrated the issue of the alternative of embryonic stem cells in a different way than expected. Instead of focusing on embryonic stem cells they choose to come back to the other alternative: the fetal VM cells. The group seemed to have its hope in the fetal VM cells. P25 explicated that the research on these cells should be in further progress than the alternative of embryonic stem cells. However, in this context, the question arose of the number of needed aborted fetuses for each cell transplant. In the viewpoint of FG4, this question was as much a question about access to material as it was an ethical issue regarding the donation of the fetal cells. Research material, and in the longer perspective, material for treating patients, must be guaranteed.

In FG5, the patients did not see themselves as very well informed about the alternative of human embryonic stem cells. The participants had heard about the problem about possible developments of cancer in the body of the recipient. The main impression was that this stem cell alternative was something that could possibly evolve in the future. In this context, it was seen as positive that the cell material that is collected from in-vitro fertilizations, may be rather substantial in comparison with the scarcity of fetal VM cells.

The non-affected public was thus positive to the use of human embryonic stem cells, since this approach was expected to solve the ethical dilemma of the donor question. In the focus groups of the patients, the access to material – the cells – was the central question, rather than the donor issue. The patient groups could see the human embryonic stem cells as an alternative in the future, but they felt uncertain about the approach at the moment. This was because the other alternative – fetal VM cells – have been subject to much more research and progress. In a way, the patients put more faith into an alternative that exists within their own lifetime, rather than in an indefinite future. The focus group with affected public had a perspective on the questions that was similar to that of the patients' perspective. However, the affected public saw in a more direct way, that transplants from the patients' own body was the most promising alternative in the future, and the solution to both the ethical dilemma with donation and the access problem.

Returning to the Post-it Notes

Once more, the moderators handed out the green and the red post-it notes and told the participants to choose one positive and one negative aspect of a certain theme. The discussions that were to follow in each focus group became a kind of epilogue for the conversations as a whole (see the written result of this procedure in appendix #4).

In FG1, the participants discussed a reason, for and against participation in a clinical trial with fetal VM cells. In the discourse, the autonomy of the research subject was highlighted in

different ways. The group agreed that certain treatments could be linked with quite many side effects without being questioned, while others should involve no side-effects at all, in order to not lose their credibility. It depends on how serious the disease is and the group compared headache medicines to cancer medicines and how the former should have no side effects while the latter, can have several without being questioned. The question is of course, where in this span are the treatments of Parkinson's disease? How much suffering can a Parkinson patient endure, in order to support science without losing his or her autonomy as an individual? In this context, the group also referred to commercial interests that can dominate over humanistic ones in biomedical research. Individuals might lose their autonomy when they, because of their poverty or their marginal position in society, are paid as research subjects.

FG2 discussed the future of cell transplant research and seemed to be quite confident that some kind of cure against Parkinson's disease will come, ultimately. However, FG2 also identified some ethical problems of this development, regarding the use of research subjects. The group felt ambivalent to the question, but could not really point out the essential matter in the case. Instead, in more general terms, it was referred to how variegated and complex the situation can be for each individual. The man with Parkinson's disease symptoms in the group, P7, said that he had been participating in a research project that was related to his bad hips. But, in spite of this earlier relatively positive experience, he was not interested at all in taking part in research projects on fetal and embryonic cells.

In FG6, the topic of clinical trials was discussed. Here, it was stressed that there must always be a written agreement on how the participants in the trials can use an emergency exit away from the trials, if needed. Again, there were references to the previous project of clinical trials, which were stopped prematurely because of lack of funding. It was also concluded that there would always be individuals who are prepared to take a risk even in those cases when money might be prematurely lacking. In the discussion, there were references to the role of relatives in experimental trials as participants in control groups.

FG3 took on the topic of participation in clinical trials. Here, the patient focus group concentrated on the communication between doctors and researchers on the one hand, and the patients on the other. Some of the participants had experience in taking part in clinical trials and they were disappointed about how the doctors or the researchers had neglected to inform them about the project and its results, after the experimental interventions were finished. As a research subject, you want to know about several things: You want to know about how your own results are, in relation to the results of other subjects; you want to have a summary of the main conclusions; and you may even want to go to the seminars of the researchers. All this might balance, the more negative sides of participating as a research subject; the fact that it takes up your personal time to take part in clinical trials and that it might decrease your quality of life, if the trial in some way fails.

In FG4, the fetal VM cells recurred as a theme for the post-it note discussion. The discussion grew, however, more inclusive than this. Simultaneous to the conducting of FG4, in June 2012, a Presidential campaign was running in the U.S. Consequently, the former President Bush was once more heralded as a threatening example of how biomedical research on cell transplants could be stopped if the "wrong" person was to be elected President in the upcoming election. Another menace that the group could distinguish was the foreign websites where cell transplants were presented as a routine and health-bringing treatment. Individuals who are desperate can easily be manipulated by the messages from these websites. A proposal was made that doctors could take a greater responsibility for the information on the internet, by

setting up alternative websites where the status of research would be presented in a more objective and honest way. P22 saw all these discussions as an expression of the disadvantages of an information society. He could foresee how everything will become even more difficult, successively. As a chronically ill person, he had experienced how hard it could be to learn about one's illness on the internet. Not only does one need to know English very well, one also needs to have basic knowledge about the specific disease.

The post-it note discussion was initiated as a reflection on participation in clinical trials in FG5. However, the participants chose to debate more general conditions for research on Parkinson's disease, instead. P27 concluded that she did not feel that she had any control over or any insights into what kind of research, scientists will be occupied with. Another kind of control issue, regarding what type of research should be performed, was raised by P29, when he commented on his red or negative post-it note about "luxury research". By this, he meant a kind of research, which might be exciting for the scientists themselves, but, on the other hand, would not be so useful for the patient population at large.

Evaluating the Different Treatment Alternatives

At the end of the sessions, the participants completed an additional form where they were to evaluate the three main therapeutic approaches to Parkinson's disease – pharmacological therapy with L-dopa drugs, surgical therapy through Deep Brain Stimulation (DBS), and surgical therapy through transplantation of fetal VM cells – on a scale from one to five.

Four of the six focus groups evaluated L-dopa drugs higher than fetal cell transplants. Of these four pharmacologically optimistic groups, the two focus groups with non-affected public – FG1 and FG2 – were the ones that stressed the L-dopa alternative most thoroughly and, simultaneously, ranked relatively low points for the two surgical alternatives, especially the fetal cell transplant alternative. In the two patient focus groups of FG4 and FG5, the scoring between the three alternatives was more even. Still, the highest score was given to the alternative of L-dopa drugs (appendix #5).

There were thus, two of the six focus groups in the investigation, that distinguished themselves by ranking the surgical alternative of cell transplants higher than the pharmacological alternative of L-dopa drugs. These two were the patient group, FG3, and the focus group with affected public or relatives of Parkinson patients, FG6. FG3 gave high scores on cell transplants, but not so high on Deep Brain Stimulation (DBS), while FG6 gave high points to both of the neurosurgical alternatives, of which the fetal VM cell transplant alternative scored highest.

Conclusion

In this report the different views of patients, affected public and non-affected public on the ongoing cell transplant research within the field of Parkinsonism have been investigated in separate focus group conversations. The patient focus groups expressed great, embodied experiences of the ethical dilemmas of research on Parkinson's disease. These focus groups were keen on discussing the issues of the recipients. The issues concerned everything from access to transplant material to participation in sham surgeries. The focus groups of the non-

affected public, in turn, were more prone to discuss the issues of the donor. The fetal VM cells were a great concern in this context. The non-affected public sees the alternative of human embryonic stem cells as a way out of the ethical dilemmas surrounding the issue of the aborted fetus. Correspondingly, the patients were less confident about the human embryonic stem cells and put more faith into the fetal VM cells, an alternative with more concrete realistic expectations at present time, than stem cells.

The relationship between the patients and the public can be understood in a rather dichotomized way. However, the single focus group with affected public turned out to be a kind of cultural crossover in this context. The members of this focus group did not have the embodied experience of Parkinson's disease, but could easily relate to the ethical problems regarding the different treatment and research alternatives. The affected public's way of mediating between the two polarized positions between non-affected public and the patients was also illustrated in at least one of the two public focus groups where the affected public was in minority, yet still represented.

Understanding the mediating role of the family members of the patients – read: the affected public – appears to be crucial in understanding how treatment and scientific alternatives are negotiated in a societal context and how ethical governance can be performed.

Appendix #1: List of focus groups

Focus Group:	**Place/date:**	**Moderator/** **Co-moderator:**	**Participants:**	**Recording time (hours, minutes, seconds):**
Focus group 1 (non-affected public)	Lund/2012-01-11	Wiszmeg/Idvall	P1: Fem b. 1964 P2: Male b. 1979 P3: Fem b. 1948 P4: Fem b. 1939 P5: Male b. 1964 P6: Fem b. 1955	02:52:49
Focus group 1, continuation (non-affected public)	Lund/2012-02-06	Wiszmeg/Idvall	P1: Fem b. 1964 P2: (absent) P3: Fem b. 1948 P4: (absent) P5: Male b. 1964 P6: Fem b. 1955	01:56:20
Focus group 2 (non-affected public)	North-western Skåne/2012-03-07	Idvall/Wiszmeg	P7: Male b. 1930 P8: Fem b. 1930 P9: Fem b. 1935 P10: Male b. 1926 P11: Fem b. 1941 P12: Fem b. 1932 P13: Male b. 1937 P14: Fem b. 1933	02:14:54
Focus group 3 (patient)	Lund/2012-03-12	Wiszmeg/Idvall	P15: Male b. 1948 P16: Male b. 1946 P17: Fem b. 1934 P18: Male b. 1967 P19: Male b. 1939	02:11:01
Focus group 4	Lund/2012-06-12	Idvall/Wiszmeg	P20: Male b. 1946	02:11:49

(patient)			P21: Fem b. 1940 P22: Male b. 1956 P23: Male b. 1953 P24: Male b. 1942 P25: Male b. 1954	
Focus group 5 (patient)	Lund/2012-11-27	Idvall/Wiszmeg	P26: Fem b. 1959 P27: Fem b. 1968 P28: Fem b. 1965 P29: Male b. 1940 P30: Fem b. 1961	01:48:43
Focus group 6 (affected public)	Lund/2013-01-16	Wiszmeg/Idvall	P31: Male b. 1955 P32: Fem b. 1940 P33: Fem b. 1945 P34: Male b. 1940 P35: Male b. 1952	02:20:48

Appendix #2: List of participants

Participant/focus group:	Sex:	Place of birth:	Year of birth:	Category:
P1/1	Female	Sweden	1964	Non-affected public
P2/1	Male	Sweden	1979	Non-affected public
P3/1	Female	Sweden	1948	Affected public
P4/1	Female	Sweden	1939	Affected public
P5/1	Male	Sweden	1964	Non-affected public
P6/1	Female	Sweden	1955	Non-affected public
P7/2	Male	Sweden	1930	Patient
P8/2	Female	Sweden	1930	Affected public
P9/2	Female	Sweden	1935	Non-affected public
P10/2	Male	Sweden	1926	Non-affected public
P11/2	Female	Sweden	1941	Non-affected public
P12/2	Female	Sweden	1932	Non-affected public
P13/2	Male	Sweden	1937	Non-affected public
P14/2	Female	Sweden	1933	Non-affected

				public
P15/3	Male	Sweden	1948	Patient
P16/3	Male	Country in northern Europe	1946	Patient
P17/3	Female	Sweden	1934	Patient
P18/3	Male	Sweden	1967	Patient
P19/3	Male	Sweden	1939	Patient
P20/4	Male	Sweden	1946	Patient
P21/4	Female	Sweden	1940	Patient
P22/4	Male	Sweden	1956	Patient
P23/4	Male	Sweden	1953	Patient
P24/4	Male	Sweden	1942	Patient
P25/4	Male	Sweden	1954	Patient
P26/5	Female	Sweden	1959	Patient
P27/5	Female	Sweden	1968	Patient
P28/5	Female	Sweden	1965	Patient
P29/5	Male	Sweden	1940	Patient
P30/5	Female	Sweden	1961	Patient
P31/6	Male	Sweden	1955	Affected public
P32/6	Female	Sweden	1940	Affected public
P33/6	Female	Sweden	1945	Affected public
P34/6	Male	Sweden	1940	Affected public
P35/6	Male	Sweden	1952	Affected public

Appendix #3: Result of self-evaluation of knowledge of Parkinson's disease

Participant/ Focus group	Question 1	Question 2	Question 3	Question 4	Question 5	Total
P1/1	1	2	3	2	2	10
P2/1	2	3	3	2	2	12
P3/1	2	4	3	4	3	16
P4/1	3	3	3	3	3	15
P5/1	2	2	2	1	2	9
P6/1	2	3	3	2	1	11
Fg 1 sum:	12	17	17	14	13	73 (12,2)
P7/2	2	2	2	1	1	8
P8/2	2	2	1	1	1	7
P9/2	2	2	1	1	1	7
P10/2	3	2	2	3	2	12
P11/2	2	2	3	1	1	9
P12/2	2	2	1	2	1	8
P13/2	2	4	3	3	1	13
P14/2	2	3	3	1	1	10
Fg 2 sum:	17	19	16	13	9	74 (9,2)
P15/3	2	2	3	3	2	12
P16/3	4	4	4	4	4	20
P17/3	3	4	3	3	3	16
P18/3	3	3	4	4	2	16
P19/3	3	4	4	4	4	19
Fg 3 sum:	15	17	18	18	15	83 (16,6)

P20/4	2	3	4	3	3	15
P21/4	2	3	4	3	2	14
P22/4	4	4	4	4	4	20
P23/4	2	3	3	3	3	14
P24/4	3	3	3	3	3	15
P25/4	2	3	3	3	2	13
Fg 4 sum:	15	19	21	19	17	91 (15,2)
P26/5	4	4	4	3	3	18
P27/5	4	4	4	4	4	20
P28/5	1	4	3	3	2	13
P29/5	4	3	3	3	2	15
P30/5	2	3	3	3	2	13
Fg 5 sum:	15	18	17	16	13	79 (15,8)
P31/6	2	3	4	3	3	15
P32/6	4	3	3	4	2	16
P33/6	2	3	2	2	2	11
P34/6	4	4	4	4	4	20
P35/6	3	4	4	3	4	18
Fg 6 sum:	15	17	17	16	15	80 (16,0)

Appendix #4: Compilation of post-it note replies

Focus group:	Positive	Negative
Focus group 1 (6 participants) 11 January 2012 First turn: Potential treatment alternatives for Parkinson's disease.	Cell transplantations – all methods that contribute to curing or relieving is good	Cell transplantations Possibly a bit uncertain to use fetal cells
	Positive with both treatment forms if it is used for the right individual and with adequate purpose in relation to diagnosis and symptoms	Cell transplant can be negative, as in other contexts unaccustomed treatment can result in negative side-effects/effects
	# Deep brain Stim. # Trans. with cells Essentially positive to both methods	# Tran. with cells: "Organ trafficing" can be a risk
	Deep Brain Stimulation Simpler to take care of Less medicine Improved mobility	Cell therapy can be problematic ethically
	DBS You become a cyborg! and temporarily cured Cell treatment long-lasting effect, hopefully	Deep Brain Stimulation Dangerous operation? Side-effects Cell treatment Where do the cells come from? Is rejection a risk?
	Deep Brain Stimulation – all methods that alleviate for the patient is good	Deep Brain Stimulation – seems to be risky
	Cell therapy Reduces the medication	Deep Brain Stimulation can give problem with the speech and the understanding of the speech
	DBS reduces the symptoms Cell exciting development of technology that maybe can be used in other contexts if that is not the case already	DBS not treatment of cause Cell problematic ethically maybe difficult to control the Pope may possibly
Focus group 1, continuation (4 participants) 6 February 2012 Second turn: Transplantation	To develop the research. Bring it forward. Because it benefits myself or my next.	If it causes unnecessarily much suffering. Excessively commercial purposes.

with fetal VM cells.		
	Help to bringing the research forward	Unethical design of the study with the control group which is operated on but does not get the treatment
	(From a patient's perspective) That it possibly can bring the research forward + that my self-esteem can improve	The risk
	If one has any <u>personal</u> interest which overcomes one's negative view of this research	I agree with the previous speaker.
Focus group 2 (8 participants) 7 March 2012 First turn: None		
Second turn.	The latest medicines are promising but do they cure??	Stem cell research should continue but do not promise anything now without having solved ethical questions
		Feels unethical to do research on both of the types of cells
Focus group 3 (5 participants) 12 March 2012 First turn: Fetal VM cells, for and against.	Hope of cure	Uncertain about cure
	Cell therapy easy treatment by use of stem cells	Can arise ethical problem when using fetal cells
	Terrific to get well	How sure can one be about getting well
	I get cured	The surgeon can cut wrong
	Possibility to cure	Surgical intervention > the risk Contagion Prions?
Second turn: Clinical trials,	Benefit for me preferably cure	Side-effects Risks

negative and positive.		
	Participate in clinical trial. Positive if good communication with doctor	Negatively risk for contagion at hospital
	I am positive to all research that can make me well!	possibly side-effects
	Bring the research forward which in extension can be useful for me	One can be hurt (in different ways). Costs time and effort
	Fastare development with several trials with Parkinson patients	
Focus group 4 (6 participants) 12 June 2012 First turn: Fetal VM cells.	Can cure Parkinson	there are ethical aspects which can limit the procedure
	Treatment that not only reduces symptom but also has the possibility to ”cure” PD	---
	• Has the longest progression • It works! Shown in tests. Where stands Sweden • Is available in Europe (Germany…) • Research – what.	• Difficult to get hold of fetal cells
	Cure the disease. (?)	Ethical aspects of using an aborted fetus (?) as ”spare part”.
	I suppose that it is of advantage to ”curing” of the disease	---
	Can be a great help for certain people pos.	Not an easy surgery..! Neg
Second turn: The use of fetal VM cells.	Same as previously. + Focusing	---
	Positively if it cures. Has progressed the furthest in the	Negative with ethical aspects, that 5-6 fetuses are needed for

	research.	a transplant. Negative that it can cause brain tumours
	Can possibly cure	Limited access to fetus
	My opinion is the same as previously.	The uneasiness about a surgical intervention
	I ”vote” for fetal VW cells	
	---	---
Focus group 5 (5 participants) 27 November 2012 First turn: Fetal nerve cells.	increases the possibility to produce effective therapies that can curb the disease	Ethical indecision about using stem cells
	That it can cure or curb Parkinson	The treatment will not be available for all
	bring the research forward, knowledge about more accessible alternatives	cannot be available for that many
	To find a medicine that can curb PD would be good	People in society react negatively to it being fetal cells
	Fetal nerve cells May open for continuing new possibilities to positive treatment	Fetal nerve cells feels difficult to have to be using so many newly aborted fetuses, which is demanded at each treatment
Second turn: Participation in clinical trials.	New discoveries that will lead to a new perspective and aims and directions of the Parkinson research in the long run	uncertainty about what clinical research will imply to the ill Parkinson individual (Luxury research)
	Pos. What influences participation in clinical trials? Wants to contribute to the research doing progress, not just cure but curbing the impairment of the illness	Neg Demands very well prepared clinical trials – risks with cells that grow without restraint and cause tumors. How can one guarantee the quality of cells/stem cells?
	Bring the development forward, Get own benefit if it works.	Can be hard for the individual, can be worsening the illness.
	To be able to contribute to the research so that it progresses	Can be a risk that one possibly could get worse in one’s illness,

	and one as individual can contribute is very positive	negative result
	Help to contribute to a solution and hopefully positive for oneself	Who stands behind the trials, pharmaceutical manufacturers?
Focus group 6 (5 participants) 16 January 2013 First turn: Fetal nerve cells.	Good if it works viz. helps the patient. Good that it gives the patient hope	Surgical interventions are always a risk.
	All treatment that benefits the affected one is positive	
	May possibly cure PD	May be feeling a bit unpleasant to intervene into the brain and rummage
	Ready – no need of cultivating	Access limited ethical conventions
	Seems positive to them who have received previously	1) Too many fetuses are needed 2) Too few can get this surgery
Second turn: Participation in clinical trials.	Early with possibly positive result	Risk for negative results of the treatment/the trial
	As healthy person – Can be a good reference	Demands active follow-up may not fall because of lack of money
	- Knowledge - Control of other illnesses - To feel that one contributes - Small/simple contribution	- Takes some time
	The chance is that one can get well One can help others in the same situation	There is a risk that one can get worse Can exist side-effects that one does not know about
	Attention Care – I have some <u>value</u>	Risk of getting abandoned after the trial. No follow-up

Appendix #5: Result of evaluation of different treatment alternatives

Participants/ Focus group:	Pharmacological therapy:	Neurosurgical therapy through DBS:	Neurosurgical therapy through transplants with fetal VM cells:	Comments:
P1/1	5	3	[Not filled in] (i)	
P2/1	[Not filled in]	[Not filled in]	[Not filled in]	(ii)
P3/1	5	3	[Not filled in] (iii)	
P4/1	[Not filled in]	[Not filled in]	[Not filled in]	(iv)
P5/1	3	3	4	
P6/1	3	3	4	
Fg 1 sum:	16	12	8	
P7/2	[Not filled in]	[Not filled in]	[Not filled in]	
P8/2	4	2	1	
P9/2	5	3	2	
P10/2	4	3	2	
P11/2	4	2	1	
P12/2	5	2	2	
P13/2	4	2	1	
P14/2	[Not filled in]	[Not filled in]	[Not filled in]	(v)
Fg 2 sum:	26	14	9	
P15/3	3	4	5	
P16/3	3	3	4	
P17/3	2	3	4	
P18/3	3	3	4	
P19/3	3	2	5	
Fg 3 sum:	14	15	22	

P20/4	[Not filled in]	[Not filled in]	[Not filled in]	(vi)
P21/4	4	4 (vii)	5 (viii)	
P22/4	5	2	3	
P23/4	4	4	2	
P24/4	5	2	5	
P25/4	3	4	2	
Fg 4 sum:	21	16	17	
P26/5	5	5	5	
P27/5	5	5	5	
P28/5	5	4	5	
P29/5	4	3	2	
P30/5	4	3	3	
Fg 5 sum:	23	20	20	
P31/6	3	4	4	
P32/6	3	5	3	
P33/6	3	4	5	
P34/6	1	3	5	
P35/6	3	4	5	
	13	20	22	

(i) Written comment by P1/1: ”Impossible to answer since it only exists on research level. No experience of the effects of this.”
(ii) Participant P2/1 was absent when this part of the focus group interview was conducted.
(iii) Written comment by P3/1: ”Do not know at all.”
(iv) Participant P4/1 was absent when this part of the focus group interview was conducted.
(v) Participant P14/2 was absent when this part of the focus group interview was conducted.
(vi) Written comment by participant P20/4: ”Incomplete and without value.”
(vii) Written comment by participant P21/4: ”if one is very ill.”
(viii) Written comment by participant P21/4: ”if it existed.”