

The ethical tool of informed consent

How mutual trust is co-produced through
entanglements and disentanglements of the body

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I [doctor's name] have explained the plan and the aim of the study to [patient's name].

I [patient's name] have been verbally informed about the study described above, have received the attached written information, and have had the opportunity to discuss its contents with the responsible doctor. I agree to participate in the study and I feel that my participation is wholly voluntary. I can at any time and without explanation stop my participation without this having any effect on my future care.

These statements are taken from a copy of an informed consent form that was used in a clinical trial, which a few years ago explored cell transplantation as a possible treatment for patients with Parkinson's disease. I received an unused electronic copy of the document from one of the researchers I interviewed as an example of how his research team had enrolled research subjects in the trial. The informed consent form was several pages long, its primary goal being to make individual patients consider whether to accept the possibility of undergoing a neurosurgical operation. Besides information about the different steps of the cell transplant research, the

document comprised detailed information about risks and discomfort associated with the various tests and interventions. An MRI test, it was explained, can be experienced as strenuous because the subject has to be held still in a space which is confined and noisy. Implantation in the brain entails several risks, such as the spread of contaminants, but the surgery itself is associated with a risk for cerebral haemorrhage. Positive effects were also mentioned in the information sheet. Some patients who had undergone similar surgery earlier had been able to cut down on their anti-Parkinson's medication after the implantation. The paragraphs quoted above came on the last page of the consent sheet, and served as a transition into the part of the form where the doctor (the researcher) and the patient (the research subject) were to sign. The passage spelt out what the two sides were agreeing to: the doctor/researcher stated that they had 'explained the plan and the aim of the study', while the patient/research subject declared that they had been 'verbally informed about the study', had 'received the attached written information', and had had 'the opportunity to discuss' it.

Obviously, this was some kind of pledge that the two partners verbalized relative to each other. But what else is at stake in these few lines? What does it mean to give or obtain consent to participation in a research project in this way? What role does information or knowledge play in this context? In this chapter I will problematize how informed consent is practised in the everyday situations of a biomedical research process. In the analysis the focus will not be on the national legislation per se that exists as a foundation for how research subjects are informed about research participation, but rather the co-productive practices that constitute the informed consent procedures between research subjects and researchers. Informed consent, in a cultural analysis, is not only a signed document with legal connotations, but primarily an ethical tool for realizing research, and, as a consequence, a social process whereby the actors face each other under different circumstances. I will thus explore the constitution of the social process of informed consent, which researchers and research subjects and their respective

allies—research nurses and family members—are engaged in, and thus learn more about informed consent as a co-production of mutual engagement and responsibility in the participating networks of the two negotiating sides.

Co-production and embodied entanglements

Informed consent, in its physical and non-physical forms, will thus be seen as a form of ethical tool that the two sides apply in relation to each other while simultaneously realizing clinical science. Informed consent is here closely linked to ‘co-production’, which is Sheila Jasanoff’s term for how science, technology, and society operate together in the production of knowledge. In *States of Knowledge*, Jasanoff and colleagues (2004) enlarge on this perspective in a number of different kinds of contexts: climate science, science policy, genetic science, and so on. Central for my own work is Vololona Rabeharisoa and Michel Callon’s chapter, ‘Patients and scientists in French muscular dystrophy research’, which develops an understanding of how lay interventions into biomedical research change the conditions for how scientists work. Rabeharisoa and Callon, who look at a patients’ association’s role in relation to science, focus on various aspects of a lay model of support for research. One of these aspects concerns ‘the tools’ applied by the patients’ association for ‘the orientation, the steering and the evaluation’ of how it supports research (Rabeharisoa & Callon 2004, 144). My focus will be on how informed consent—just like the films, photographs, books, and testimonies in Rabeharisoa and Callon’s examples—operates as a tool for the orientation, steering, and evaluation for how scientists and patients collaborate in order to make clinical research ethical and thus feasible.

Thus I draw on both Jasanoff’s and Rabeharisoa and Callon’s discussions of co-production to distinguish that the knowledge that was co-produced in the cell transplant research information procedures was not the type of new biomedical knowledge that eventually changes people’s treatments, or even their ways of being

cured. Rather, what was co-produced in this process was a sort of shared information about the other side, which in the long run may in part be beneficial for how the other type of knowledge, the findings, may be achieved, but which in the process of the trial was essentially about establishing co-productive trust between the two sides. Informed trust, rather than consent, is in this way co-produced through what Rabeharisoa and Callon call 'mutual learning' (2004, 144) (see also Hansson & Irwin in this volume). Scientists learn about the participants by securing individual patients for the research project, and simultaneously listening to the questions and concerns that these participants have. The participants in their turn learn about the research by seeking answers to their own questions in the information process and by listening strategically to the scientists. Therefore, unlike Rabeharisoa and Callon, I focus on individuals in action rather than on a model of an organization. On the pathway of the informed consent procedure, along which information circulates between the two sides and also transforms the positions of the two sides into networks of participating actors, a platform for new biomedical knowledge (and technologies) is co-produced.

In the midst of this co-production is a form of mutual, ethical labour based on the specific tool of informed consent, which centres on the human body in that particular situation, and where the objective is not only to entangle the body in the action, but also to disentangle it from the context that eventually may appear. In *Tissue Economies*, Catherine Waldby and Robert Mitchell (2006, 60) write of one type of economic entanglement and disentanglement as 'analytical categories ... to explore how embryos move from the human body to clinics, laboratory, and stem cell banks'. A stem cell bank, according to Waldby and Mitchell, 'performs a complex double role' when it manages its 'complex regimes of ontological, ethical, therapeutic, and commercial value' (60).

On the one hand, it [the stem cell bank] assists in the technical work of disentangling tissues by facilitating the donation, stand-

ardization, and global circulation of stem cells. Yet on the other hand, it performs ethical work that involves a certain re-entanglement, for by placing certain limits on the marketing of cell lines and the commercialization of research, it attempts to divert the epistemological value of research into the categories of the public good and the national health. (Waldby & Mitchell 2006, 60)

In the case of the informed consent procedure studied here, the process of how the human body is made useful to research goes from entanglements of the human body to disentanglements—something which will be clarified below in a discussion of the move from teaching consent to de/signing (of which more later), documenting and, finally, reporting consent.

Material and method

Before I turn to the question of informed consent, I want to say a few words about fieldwork. Parkinson's disease, the disorder on which I concentrated in my fieldwork, is a neurodegenerative disease that was first designated by the British doctor James Parkinson (1755–1824) in the early nineteenth century. The cause of the disease, however, is still unknown. The disease is elicited by the continuous death of a certain type of cell in the brain: dopamine cells. With the loss of these cells specific symptoms arise: rigidity, shaking, problems with balance, and loss of the power of voluntary movement. Non-motor symptoms such as tiredness, sleeping problems, anxiety, depression, and dementia can also develop. Different pharmaceutical treatments, including levodopa, have an effect on the symptoms, but cannot cure the disease itself. Moreover, these treatments function well only in the beginning; ultimately the positive effects are reduced and instead side effects develop, for example dyskinesias (impairment of voluntary movements) (Hagell 2004, 78 ff.). Parkinsonism is therefore the target of many clinical trials in the world today. The scientists use different kinds of approaches in order to understand the disease better and to find

new treatments for the condition. The research focus shifts between neuroprotective strategies, the role of physical exercise, genetic disposition, cell transplantations, and so on (Palfreman 2015). For some years (2012–18) I had the opportunity to learn more about this research when I conducted fieldwork at a university clinic that specializes in research on Parkinson's disease. I happened to focus on cell transplantation research, but I also encountered other types of biomedical research, for example the mapping of genetic heritage and the implantation of human growth factor. My fieldwork was conducted at intervals and included various methods: observations, focus-group interviews, individual interviews, etc. (Idvall et al. 2013; Idvall 2017a–b). Here I will examine the individual interviews and how this part of the fieldwork, conducted between 2015 and 2018, revealed a form of split collaboration between researchers and research subjects regarding how the two relate to clinical trials and informed consent.

The interviewed researchers were a relatively homogeneous professional staff of five doctors and five research nurses. Two out of the five doctors specialized in cell transplantations. The research subjects who I interviewed were a more heterogeneous category, with individuals with Parkinson's disease as well as relatives of some of those affected. Nine individuals with Parkinson's disease were interviewed individually, while seven individuals were interviewed together with a family member. Only three individuals had first-hand experience of cell transplantation research; however, several individuals had experience of taking part in medical research, and those few who did not were able to talk about science and clinical trials from a perspective that included their personal experience of living with the illness.

In the individual interviews I took an ethnographic approach to learn more about the cultural encounters between researchers and research subjects (Idvall 2005). I tried to map how the co-production of informed consent was realized between researchers and research subjects. Doctors and research nurses were asked how they went about obtaining informed consent from potential

participants in the clinical trials, and we discussed how they as scientific staff retained consent during the trials and what role consent played afterwards. In interviewing the research subjects, I likewise charted their experiences of the process of informed consent in a clinical trial. Individuals with Parkinson's disease and, where relevant, their family members were asked how they had consented, their experiences of taking part in a research project, their understanding of the information given by the medical staff, and the extent to which they felt themselves to be autonomous in their decisions. Those interviewees who did not have personal experience of taking part in a clinical trial discussed the topic on the basis of their illness experience.

Teaching consent

In the event, my analysis of co-productive practices as the realization of mutual consent was sparked by an observation rather than an interview. That moment came at the beginning of my fieldwork. I was in an audience of around 40 in a lecture room on the very top floor of a university hospital building, the panoramic view of the city darkening as the sun went down. We in the audience were mostly strangers to one another, but I suspected many had Parkinson's disease or were family members, since they all were of the age when Parkinson's disease usually first presents, that is in their fifties, sixties, or seventies. A few had visible symptoms of the disease, however, and then there was a scattering of my own sort—medical and social scientists.

The critical moment of the evening, which I remember so clearly, was when the first speaker, a senior specialist, started his presentation. Everyone listened carefully because he was well known as a successful, experienced clinical scientist at the university clinic. He had been part of the clinical trials conducted in the 1980s, and he was expected to be involved in new clinical trials in the near future. In his presentation, he gave an overview of the status of the ongoing research and listed some of the challenges ahead.

I experienced his presentation as professional and objective. He gave no unfounded promises; his was a realistic account of what the immediate future might hold. The audience seemed satisfied with his picture of things. Still, they had a great many questions afterwards. One of course was when clinical trials were expected to start. The specialist, whose calm and neutral way of reasoning never deserted him, could not point to any specific time.

He was not the only speaker that evening. Two people with Parkinson's disease also gave presentations. Like the specialist, they were quite well known to the audience, being leading patient activists. On this occasion they presented their views on what science can do for patients with Parkinson's disease and their families. What struck me was that their presentations gave us a more personal view on how scientists and patients can work together to achieve new treatments for Parkinson's disease. Both had a grasp of the science and could discuss their disease using scientific insights—but they could also talk about their personal experience of the disease in a compellingly authentic way. The audience seemed enthusiastic. Like the senior specialist, the two patients were peppered with questions and reflections afterwards.

During my time with the biomedical research programme I attended three or four co-productive events of this sort. What I encountered at these events were two kinds of objective, embodied ways of relating to the biomedical knowledge that was discussed. On the one hand, there were the explanations by the scientists, who spoke and 'framed' the issues individually and mostly from the front of the lecture room. They were, in Anthony Giddens's words (1991, 109–143), the expertise at these events. On the other hand, I saw a different kind of participation, which was more indirect and personal and mostly realized in the seats of the lecture room—what laypeople do when following discussions about scientific progress on-site. In this case it was, in Giddens's perspective, more a manifestation of lay views on biomedical knowledge, which hold a great deal of embodied expertise in the specific setting.

These events, flagged as science cafés, were arranged on the initiative of members of a highly prestigious research programme on cell transplantation that hoped to launch new clinical trials with Parkinson's patients within a few years. Inspired by the French tradition of *cafés scientifiques* (Russell 2010, 92–3), they were meant as a way of communicating science in mutual dialogue with people in general and patients in particular. The plan was to have at least two meetings a year, one in the spring and one in the autumn. Mainly it was seen as a possibility for patients and relatives to learn about the science that was taking place at the university hospital, but it was also for the scientists to learn about the families and their situation. The unspoken ambition was that laypeople and scientists would meet as equals at these events (Russell 2010, 92–3).

What the science cafés represent is a keen co-productive approach, which it was hoped would overflow into how scientists and participants work together in clinical trials. With their lectures and audiences, they may be seen as a form of start-up for the patients' participation in clinical trials; an active learning platform where potential subjects in future trials and their family members can find out about the science involved. Listening to a specialist give a lecture is like reading the patient association's periodical (*Parkinsonjournalen*)—a way to take responsibility and be informed about one's own illness. A central aspect of this learning moment is that all the individuals are exposed to the instrumental use of Parkinsonism bodies in clinical science, and are forced to imagine their own body's possible 'usefulness' in upcoming trials (see Goodman et al. 2003).

For the clinical scientists, in their turn, it is important that patients reflect on the research. The more conscious their patients are about the science, the easier it is for the scientists to do science—that at least appears to be the argument. Transparency turns out to be a crucial ideal for scientists and research nurses. But of course, theirs is a partial or tactical transparency. There is no question of full openness about what takes place in laboratories and operation theatres; rather, a relative openness that can interest people in supporting

developments (Idvall 2003). As patient, one becomes entangled in the scientific process and feels more and more committed to the goals that science offers in that particular situation.

De/signing consent

The process of informed consent can start in the lecture room or the science café, but the document itself—the co-productive tool—is never in evidence at this stage. As a patient, one can add one's name to a list to receive further information about the research, or, like one research subject did, hand one's business card to a lecturing researcher, but the informed consent form will not be produced until the moment comes to enrol potential participants in a clinical trial. This is done by the researchers who plan and design the project's procedure of informed consent. The informed consent form is drawn up in a pre-phase of the clinical trial. In drafting the research protocol, the scientists turn to an ethics committee and propose a procedure for how to recruit patients to the project with informed consent: the principal investigator is thus responsible for the design of the informed consent procedure in dialogue with the ethics committee. The protocol, which directs everything in the research project, is central to how informed consent is structured and put into practice.

Subjects are not presented with an informed consent form until they are to be enrolled in a trial. The co-productive tool is part of a process that often begins with the clinical scientists approaching patients who they have met in the clinic—their 'own' patients—although in some cases others who do not attend the clinic contact the scientists and ask to take part in a study (see Hansson 2017). One clinical scientist (Interview no. 19) explained that when this happens she needs to judge whether the person is eligible to be a research participant. For example, she has to consider whether there are indications of 'cognitive weakness', or a tendency to fail to come to appointments. As a scientist she never says yes immediately, for example by email. Instead, she asks the patients to send

her copies of their medical notes (*patientjournal*). Sometimes she has to reject patient requests when they do not meet the study's inclusion criteria.

The informed consent form is signed either at the potential research subject's home or at the university clinic; where exactly will depend on the nature of the research project—whether it is invasive or not—and whom the patients are to interact with. When the research project in question is less invasive it is expected that potential participants can make the decision on their own or together with a family member, in which case they usually sign at home. They may receive a letter from the clinic, asking that if they agree they return the completed consent form back to the clinic. In more invasive studies, potential participants may receive information at home, but wait until their next meeting at the clinic to sign there in the company of a doctor or a nurse.

With a co-productive approach, in the early phase of recruiting research subjects and possibly obtaining consent, both written and verbal information is included. Some of the interviewees stated that the written information was the most important for them. One man (Interview no. 6) who took part in a trial together with his wife felt that he needed to revisit the information more than once. This is an important argument for having written information: to be able to reread it at home, with extra time to consider one's options. It can also be a way to discuss the alternatives with one's family. One interviewee (Interview no. 12) thought that verbal information can always be misunderstood, and he needed written information in order to be able to discuss it with his wife at home, whom he felt was more perceptive than he was about this kind of question.

However, verbal information had its proponents too. One woman (Interview no. 5) explained that the verbal information made it possible for her to put direct questions about the surgery to the clinical scientist. Another interviewee (Interview no. 15) described how he accepted participation in a trial on the spot. He was not interested in reading any information, the verbal information had convinced him to participate because some of the scientists who

were responsible for the project had been involved in earlier trials, and therefore in his view had important insights about how best to do this new project. This research subject was focused on the scientists' authority rather than on the risk–benefit assessment offered in the written information.

Proof, verification or contract?

What does the signed consent form, the two signatures, represent for the individuals concerned? For the researchers, the two signatures are proof that information has been given and consent has been obtained in that specific situation. Regarding signing, the scientists explained that by doing so they certified that the research subject had had the chance to ask them questions. One research nurse (Interview no. 21) stressed that the act of signing is an active stance by the participants. The signed consent form here becomes a kind of declaration of responsibility which the participants express towards science. Signing, in the eyes of the scientists, also becomes a way of preventing patients from taking participation too lightly: some are 'quite fast' when deciding to take part in a study. As a clinical scientist, one needs to make sure that the patients really have read the information and understood it. A patient must from this viewpoint be aware that by signing a consent form they have a responsibility to understand the information that they have received.

Proof was perhaps not what the research subjects first thought of when they reflected on the meaning of informed consent. Still, a few realized that the signing of the consent form was more for the scientists than for the sake of the subjects. One woman and her husband (Interview no. 8) said that by signing it protects the scientists; it gives them *carte blanche* in that particular situation. The signing of the consent form means that the scientists are taking a belt and braces approach—'*både hängslen och livrem*'—in order to be certain in their work, as one participant put it (Interview no. 3). However, most of the interviewees agreed on what the scientists

thought about it—signing is a sort of verification of their responsible participation in clinical science. Perceptions of responsibility can in this way be something that all participants experience when signing a consent form. One woman (Interview no. 5) explained that she had a responsibility as a research subject; one should not withdraw from a research project on a whim, or mismanage one's medication, if participating in a trial. For another of the interviewees (Interview no. 9), consent in writing was 'a type of contract', since participation in the trial would be 'a big thing'.

In sum, the de/signing of the informed consent form appears to be, as Nikolas Rose (1999, 154) would have it, a form of governing style where 'responsibilization' becomes an essential cultural ingredient in how individuals act towards research within the frames of a neoliberal society. Responsibilization here is intimately linked with a certain degree of parallel freedom—'autonomization', as Rose calls it—for both the research subjects and the scientists: a dyadic or co-productive process of governing, which, as will be seen, is essential in the next phase of how informed trust is formed.

Documenting consent

In the phase of the research process when the participants are subject to different tests and interventions, signed consent becomes a tool that exists both on paper and as an electronic copy in a range of contexts. The participant's signed consent form is saved in the original in a folder that is stored in a locker or on a shelf in a locked room. The signature therefore exists as a physical object, safely archived in the university hospital for the lifetime of the research project. Electronically, the signed consent form is also included in the participant's medical notes, making their participation in the clinical trial plain to all their caregivers.

A paper copy of the signed consent form is also offered to the participants themselves. In this case the signed form exists as a reminder of an action in the past, brought home for keeping by a

multitude of individuals with different routines for saving medical information and ‘important papers’.

This anxious documenting of informed consent reflects the fact that consent is always negotiable, and in that sense must be defended throughout a research process. The fragility of mutual trust stems from the continuous straddling of the co-production process between Rose’s two principles of responsabilization and autonomization (1999). The signed informed consent form is, as we have seen, a responsabilization tool, but it only works as long as both sides—the researchers and the patients—know they can act with autonomy relative to the other. For the researchers, this autonomy comes with the act of documenting consent. Armed with this documentation, the researchers have some sort of recourse when faced by unexpected events not of their own making. In some instances, research subjects can misunderstand or even forget what they have consented to. For the doctors and nurses, the archived consent form can serve as proof in dealings with research subjects who fail to comprehend what they approved to earlier. The document is almost never referred to in this process. However, if a patient were to forget a test or intervention needed in order to fulfil the project criteria, the research staff can discharge their responsibility by showing the patient the document, even though, given the situation, they might not insist on continuing the collaboration.

Thus, if discharge is a way out for the researcher, withdrawal is what the research subjects can do in order to assert their autonomy in relation to the research project. The withdrawal alternative is included in the informed consent agreement from the beginning. If a research subject decides to withdraw they do not have to explain why; it is a way out that does not have to be defended. In my interviews with research participants, none had withdrawn, even though some had been disappointed by their participation in a project. One man (Interview no. 15) told me that he started in an observation group before he was randomized into a transplant group, but after a while he was reassigned to the control group of the cell transplant study. This was very hard on him psychologically. He had got used

to the idea that he was going to have a transplant, and nursed the hope that he would be cured. He indicated his disappointment with his participation in the biomedical research throughout the interview. Still, when I asked him if he was considering withdrawing from the project he replied without hesitation that he was not.

As previous studies show (Brown 2003; Lundin 2004; Novas 2006; Rubin 2008), patients have expectations of their participation in research projects. A certain treatment can be a reason for participation, with the project a chance to get something beyond the regular treatments. One of my interviewees (Interview no. 10) spoke frankly of considering withdrawing from a project when he realized that he was not going to get the experimental treatment he was hoping for. Finding himself in the control group, he sensed that he no longer had a goal. It felt like ‘a kick in the stomach’ when he realized he was not going to get the cells and, as he saw it, eventually be cured. Still, he decided to stay in the project, and afterwards he felt he could use his experience against the project—for example, when he attended a hospital appointment abroad in order to take some tests which were mandatory for the trial, he ordered, at the expense of the research project, a hotel room that was a bit larger than standard and he also got a special flight ticket. Moreover, when the scientists heard that he was considering opting out, it was his impression that they offered him something in return if he stayed on: after the project was finished, he would be going to be first in line for participation in two other projects that were about to start. In effect they offered him, as the participant expressed it, ‘a small sack of candy’. The promise of being prioritized as a candidate for other studies with experimental treatments can be motivation enough for people in the control group of a clinical trial.

The motives for withdrawing have many elements. Disappointment is one of them. Being a research subject is in itself a vulnerable position and, like Tove Godskesen (2015) demonstrates in her dissertation *Patients in Clinical Cancer Trials*, may in some instances generate unrealistic hopes among individuals, which can eventually lead to great disappointment as well. However, it

does not always have to be disappointment that drives someone to withdraw from a project. In my material, it happens mostly because research subjects become more ill or experience growing tiredness due to their chronic disorder. One way of handling this kind of risk of withdrawal is for the research staff to offer participants house calls instead of meeting them at the hospital. A scientist together with a research nurse may decide to conduct the tests on the trial participants at home, sparing participants the journey to the hospital.

Withdrawal and discharge are thus essential aspects of autonomization for how the documentation phase of the trial process eventually moves on to the stage when the results are ready to be communicated in various scientific contexts. In this latter phase, which ostensibly ends the participation of the trial subjects, mutual trust between researchers and participants is still defended in the form of the ethical format of the scientific periodicals.

Reporting consent

The protocol was reviewed and approved by the institutional review board of each participating centre as well as the performance and safety monitoring board of the National Institutes of Health. After providing written informed consent, patients underwent laboratory screening and were excluded from further participation if they had evidence of infection with human immunodeficiency virus, hepatitis, or syphilis. (Olanow et al. 2003, 404)

The quote is from a scientific article in which a number of North American scientists described a cell transplant study where placebo surgery had been used to study the effect and survival of foetal cells in the brain of Parkinson's subjects. These surgeries were not uncontroversial, and gave rise to an ethical debate about whether it was acceptable to use placebo or sham surgery on the research subjects under such circumstances (Idvall 2017a, 132–6). In the article, the research subjects' written consent to participate in the research is treated as little more than a technicality—'After providing

written informed consent' is all that is said about the presumably long process of teaching, de/signing, and documenting consent—and as such the consent process is reduced to an anonymous and collective event in the past. Each individual informed act of consent is not communicated. Instead, what is reported is a type of collective consent, summarizing how a whole group chose to become research participants.

After clinical trials have ended, informed consent thus loses its character as evidence for the scientists and instead becomes an active element in the reporting of the results. Usually the obligatory section on methods and source materials in a scientific article includes a description of how the informed consent procedure was conducted. It is rarely as brief as in the article quoted above, but regardless, what is said about the consent procedure is essential in the reporting context. Without this ethical format, biomedical scientists may not be allowed to publish their results in scientific periodicals, since most journals have rules which prohibit publication if informed consent is not reported in the study.

The anonymous reporting of collective consent may be seen as an example of a disentanglement of the particular embodied 'gift' which the 'useful body' of the research subject represents in the context of clinical studies. Waldby and Mitchell's discussion (2006, 69–73) of how embryos, as body parts used in science, emerge out of embodied social relations, but are disentangled from this complexity by means of informed consent processes, is eye-opening in this respect. They describe informed consent as a form of surrogate property contract between recipients and donors. Informed consent becomes a way for the recipient of embryonic cells and tissues to disentangle the embodied gift from the donor, as well as the complex context in which the donated cells and tissues have their origin, making it possible for the recipient to take control of the embodied gift.

In cell transplant research the disentanglement that reporting consent achieves means that researchers ultimately take symbolic control of the research subjects' bodies—those 'useful' bodies that

were examined and subjected to interventions in the earlier stages of the research process, but which are now transformed into numbers and figures. For the research subjects themselves, the disembodiment of individual consent that disentanglement leads to becomes a question of how to continue their participation in science. Taking part in a clinical trial is often associated with the chance of obtaining more information than patients in general. Participants seem to expect communications that are adjusted to their ability to understand the essentials of the results. In my interviews with research subjects, many felt they lacked information about how far the research was from a breakthrough or a new discovery. Perceptions of slowness of science were ubiquitous among patients and their family members. The time frame set by what they perceived as the slow progress of science (Idvall 2017b; see also Wiszmeg 2019) far exceeded their own lifetimes. One patient (Interview no. 11) explained that she had had Parkinson's disease for more than ten years. During that period she had heard about stem cells continuously, but nothing happens, she exclaimed. A man (Interview no. 14) who had been ill for twelve years thought that things did not move fast enough for the scientists. He felt that a lot more could be done, but he guessed that there was not enough funding.

The lack of information can be quite unsettling for many participants. One research subject (Interview no. 10) expressed his frustration at getting very little information, saying that no one asked how the 'rat' felt (his way of articulating his sense of being a guinea pig). He added that participants and scientists will never be equals, since the participant does not have a clue about what the scientist is doing and the scientist has a 'helicopter perspective'. Similarly, one woman (Interview no. 5) said that she felt a disadvantage next to the scientists, since she had not received any results or information after her last tests. Another person (Interview no. 11) explained that only a 'short call about the benefits' of the research that she had participated in would have been 'enough' to make it acceptable. One couple (Interview no. 14) acknowledged that their research participation felt a bit 'thin' after they received no feedback

about the findings following the tests. A man (Interview no. 15) who was currently participating in a project complained that he had not had any information about research outcomes, whether personally from the researchers or from the project website, because of that he felt he had no influence at all on the research.

The opposite can also be the case, for not all participants are interested in the results. As one man (Interview no. 6) explained, it was a good thing that he and his wife joined in a clinical trial, but they were never really interested in the potential findings. Another interviewee (Interview no. 7) emphasized that one does not have to be interested in the specific research project in order to participate. It is more a question of being willing to help for the good of all—it is part of one's responsibility, as she said.

Movements of informed consent

I have shown how the co-production of biomedical knowledge and mutual trust are dependent on the ethical tool of informed consent, which involves a process of negotiation between scientists and participants. In this process, informed consent takes different forms—verbal, paper, electronic—and goes through different phases. In an early phase, scientific cafés can be a way of establishing an effective co-productive dialogue between researchers and research subjects. A teaching mode is central to preparing for informed consent. In the recruiting phase the actual negotiation starts between the scientists and the participants. A critical decision-making situation is struck up between individuals, representing the two negotiating parties when the consent form is designed and signed: a form of entangling responsabilization is enacted by researchers and research subjects in a mutual dialogue. Further on, in the test and intervention phase, the fragility of informed consent is a consequence of different techniques of autonomization. Withdrawal is open to research subjects who are too ill, tired, or disappointed to continue. For scientists, freedom is grasped through the sort of discharge of responsibility that a completed informed consent

form can offer in situations of uncertainty and disagreement. In the final phase, informed consent procedures can be traced in the scientific publications, often in the sections on material and method. By this stage the individual bodies of the research subjects have been disentangled from the embodied social relations of the original informed consent. At the same time the research subjects can experience this end-phase of the scientific project as marking their exclusion from information flows and from actual participation.

Thus, teaching, de/signing, documenting, and reporting consent and mutual trust together make up the various aspects of an embodied ethics, which deals with the moral dilemmas of clinical science and the vitality of the human body (Rose 2007, 254), but which also, paradoxically, includes a disembodiment factor, through the impact of the scientific journals, that blurs and de-personalizes how the knowledge was originally co-produced.

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