

‘Science is really needed—that’s all I know’: informed consent and the non-verbal practices of collecting blood for genetic research in northern Sweden

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ABSTRACT *In Västerbotten County in northern Sweden a start-up biotech company has recently gained all commercial rights to one of the worlds largest population based research biobanks. The biobank and the company have publicly emphasized that all donors have given their informed consent to participate, but within the academy it has become debated whether people have been adequately informed. Based on anthropological fieldwork it is shown that many people do not read the information provided. The data do not, however, suggest that donors themselves perceive a lack of information. This article endeavours to make meaningful the apparent lack of interest among donors in the information they are offered. It is argued that the donation of blood should be analysed in its social and historical context rather than as a response to rational assessment of information of research purposes. It implies a conceptualisation of agency more aware of the intersubjective nature of moral negotiation than usually implied in studies of informed consent.*

Genetic research: is it all about being adequately informed?

Recently, a start-up genomics company, UmanGenomics AB, gained all commercial rights to a research biobank containing blood samples of the majority of the adult population in Västerbotten Region, Northern Sweden. The biobank contains blood samples donated over a period of 15 years. The company has been marketing itself as particularly ‘ethical’ and has introduced what it terms an ‘ethical model’. It is a description of organisational procedures for research approval and it has gained international attention in influential journals like *Nature* and *Science* (Abbott, 1999; Nilsson & Rose, 1999). The model prescribes public majority ownership (at least 50,1% of shares), standard use of the regional research ethics committee, and—as its main feature—informed consent. However, in spite of initial press coverage underscoring the fact that donors had signed individual consent sheets, it has subsequently been questioned whether they were actually adequately informed.

Some opponents to commercial genetic biobank research suggested that if

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only people knew more about the unfolding events, they would probably refuse to participate in this kind of biobank research. Partly as a response to an emerging disagreement within the regional research ethics committee on this issue, some members of the committee decided to initiate a survey of public attitudes to research on blood samples that involves gene technology and commercialisation. Interestingly, proponents of biobank research in the county council and the biobank initially decided not to support this survey, in spite of their claim that people had already consented. They referred to an argument well known in Public Understanding of Science (PUS) studies: People often respond with reluctance towards science if they do not know enough about it (Kasperowski & Elzinga, 1999). Hence, they suspected that a survey might create a false image of public opposition; though donors would actually support biobank research if only they knew more about the topics involved.

The author of this article has studied the public reception of UmanGenomics and consequently became involved in the survey when the ethics committee wanted me to contribute to their own efforts. Currently, I am employed on a project that (among other matters) undertakes the survey. It has provided a chance to study at close range academic reactions as they unfold, as well as reactions among donors, but my empirical data do not support either of the two positions outlined above. Both positions seem to rest on the same assumption: If only people knew what the self-proclaimed experts know they would act differently (either donate or not according to the moral stand and profession of the expert).¹ This assumption reduces the donors' agency to a matter of information levels. Rather, I suggest acknowledging even the bodily and historically informed agency in the act of donation.

Instead of perceiving the information presented in the consent sheet as the key motivation for donation, I argue that informant consent procedures in Västerbotten impose a changed sense of responsibility on each potential donor. Informed consent procedures do not necessarily revolve solely around 'information transfer', 'rational judgement', 'protection of integrity' or 'execution of autonomy' (cf. Kleinman, 1995). Agency is much more than intentions that can be articulated and expressed in rational judgement (Hastrup, 1995) and when ethics is reduced to a matter of informed consent it implies a regression to a level of mere thought, a logocentrism. Such logocentrism side-steps the actual moral negotiation that takes place when a donor entrusts his or her blood to a nurse in a public health clinic.

That blood is not donated *because of* the information provided to potential donors thanks to enhanced informed consent procedures should be discernible from the following. I was a participant observer while 29 people were asked for a blood sample and afterwards I conducted interviews with them.² The potential donors are participants in a large scale preventive healthcare programme offering medical check-ups at the age of 40, 50 and 60 years. The 'ethical model' has contributed to the introduction of a more substantial information leaflet provided to the participants in the medical programme. Of the 29 potential donors only 21 had actually received the improved information leaflet and of these 21 persons,

only eight claimed to have read it. Equally significant, only four donors remembered to have heard about the company despite the fact that the information leaflet primarily informs the donor about: 1) the existence of the new company, and 2) the possibility of withdrawing their consent. Only two interviewees knew they could regret their consent and have their blood sample withdrawn from research purposes.

Thus, it appears that in spite of the official praise of—and focus on—informed consent, people actually donating blood are not showing any particular interest in the information they are offered. This article offers reflections on the seeming lack of interest in information among donors.

The collection of blood and creation of a biotech company

Medicinska biobanken, the biobank that will be commercially explored by UmanGenomics, is one of the largest research biobanks in the world. Throughout 15 years, the majority of the adult population has donated an extra blood sample while attending a preventive healthcare programme, the Västerbotten Intervention Programme (VIP), offering an individual susceptibility profile in relation to cardiovascular diseases. It is based on an examination by a nurse, it takes a couple of hours, and it takes place at a public healthcare centre. Three different and formally independent institutions thus constitute the setting; a public healthcare programme, a research biobank, and a genomics company. Still, the council is a stakeholder in all three; it is responsible for healthcare services, contributes to the daily maintenance of the biobank and owns the right to buy shares in the company through a holding company managed by the local Umeå University. The university management likewise holds seats on the company board besides formally having a responsibility for the biobank staff.

The researchers in the biobank had initiated the biobank without any major support from the university and county council that hosted the biobank. It was a project supported by external funds and by some considered a superfluous collection of material that was not likely to be used. Then with the developments in gene technology during the 1990s, it became apparent that the biobank constituted a major scientific and commercial resource. Initially it was the biobank management that wanted commercial engagement to stimulate better utilisation of the biobank's scientific resources. They imagined a co-operation with for example pharmaceutical companies creating an economic surplus to be used for further research on the biobank material. As the university management entered the process, however, the biobank's research team became decreasingly involved in the decision making. An external advisor from the pharmaceutical industry was invited to Umeå, and as he suggested a structure separating the administration of the biobank from economic incentives, it was decided to build a new start-up biotech company and base its economic survival on exclusive commercial rights to the biobank. The advisor, Sune Rosell, was then appointed managing director of the new company. When the establishment of UmanGenomics was announced to the public in 1999, it was mainly as the result of

negotiations between the company management appointed by Umeå University, selected members of the medical faculty and the university management, besides representatives of the county council responsible for VIP. The announcement was accompanied by the ethical model and a pronounced commitment to make all research results accessible to other researchers through the biobank's database.

At this stage, the addition of a new player, UmanGenomics, was said to be relatively uncomplicated: the company should work as any other research team and have its research proposals scientifically approved by a reference group appointed by the biobank besides getting the ethical approval from the research ethics committee (the Swedish equivalent to Institutional Review Boards), as mentioned above. However, it has subsequently been debated (mainly in academic circles and by academics in the local newspapers) what exclusive commercial rights actually imply and whether exclusive commercial rights are really compatible with different features of the company's organisational setting and the ethical model.³ In May 2002 the County Council and the company re-negotiated the terms of their agreement and dismissed the principle of public majority ownership as well as the intention to make all research results accessible. Concomitantly, it was decided that the company would have access to half of the blood samples stored in the biobank and academic researchers to the other half. This became a touchstone in the strife over what was now increasingly seen as the most important resource for medical research in Västerbotten: blood. Some observers found the latter initiative in combination with a restructuring of the biobank management connected to a wish to ensure that the biobank's reference group would not obstruct the company's research.

These elements of privatisation shall be seen against a backdrop of an overly publicly financed and managed healthcare sector. In Northern Sweden, primary healthcare service is not based on a system of general practitioners, but on public provision. At public healthcare centres (in Swedish, '*vårdcentral*') you find not only doctors and nurses, but often also the local pharmacy, social workers and other kinds of county assistance.

It is at such centres the VIP programme of preventive health examinations takes place, and here people donate the blood that later can be used by UmanGenomics. The healthcare examinations are very popular though participants contribute with a symbolic amount of 100 SEK for an examination (the usual doctor's fee). Participants are convened after their 40, 50 or 60 years birthday and it is not unusual that they talk of the examinations as birthday presents from the county council. Alongside the blood tests participants fill in an extensive questionnaire concerning his or her personal well-being, social networks, dietary habits, hereditary diseases and so on. The questionnaire is stored with the extra blood sample and also used for research purposes after the examination (for an analysis of the donors' reflections on the difference between donating blood and personal information, see Hoeyer 2002). The examination begins with the blood tests and often the needle is already in the arm or lies prepared when the information on biobank research is presented and patients

are asked for an extra blood sample. I have attended both the examination and conducted a subsequent interview with each participant. The quotations below are mainly from the interviews, but a few of them build on fieldnotes.

Why donate blood?

It is a precondition for donations to the biobank that people attend these examinations, and in this sense an understanding of people's motivation for donating blood implies looking into why they attend the examinations. As I wish to draw the argument further and claim that the donation of blood must be seen as part of a social practice and not just words or reasoning, I suggest exploring the motivation for being in the clinic. This exercise provides us with important reflections on the moral domain of the clinic as a context for understanding why people donate blood without reading what the blood will be used for.

A potential donor is asked for a blood sample just before the nurse endeavours to determine the patient's susceptibility of lethal disease. Participants in these examinations often reassure themselves loudly that they feel absolutely healthy—whereby some of them implicitly express their anxiety for the results of the tests (cf. Wikan, 1992). Others announce their fear and distress and thus appeal for the care of the nurse. The most obvious interest of the donor in this situation is to create a relation of trust with the nurse in whose hands he or she places the ability to predict matters of the utmost importance. Marcel Mauss might have reminded us of the experienced logic of the gift as the best tool to use in precarious social relations, and it is, perhaps, no surprise if people choose *not* to refuse when the nurse asks for an extra blood sample for research: 'To refuse to give, (...) just as to refuse to accept [a gift], is tantamount to declaring war; it is to reject the bond of alliance and commonality' (Mauss, 2000 [1925], p. 13).

Furthermore, there is something peculiar about people's attitudes to their examination that attests to a moral value attributed to science going beyond mere calculations of the cost/benefit of attending the specific examination. Many people attend an examination while announcing faith in their own good health. When asked why, their explanations are often tautological in nature; it is good to be examined because examinations are good. People highlight both a sense of duty and a personal interest in attaining biomedical knowledge of their own bodies. One woman explained:

Well, I thought (...) if I've got high blood pressure, or cholesterol, well, then you'll have to think about it. Then, at least, you're not *fooled* by that.

Knowing that this woman had already had her blood pressure and cholesterol measured a few months earlier during her participation in a research programme, I asked somehow puzzled:

So this is kind of an extra-extra check-up?

She replied:

Yes, because you never attend a doctor when you're not ill—when there's nothing really wrong. (...) But now there's a chance and it only costs 100 kr.

The examination has a value of its own, it appears, and the value reflects her fear of being 'fooled' by her own body in respect of matters of which she has no knowledge herself. Another informant responded to my question on why she attended the examination by referring to both personal excitement and a sense of duty to contribute 'her share' to research:

I think [preventive programmes] are really good. It's like a kind of service check-up on your car (...) yeah, so I really think it's great, it's fabulous, and I don't mind doing my share for research because it's important to know more about those matters.

The sense of duty is also apparent in the following fragments of two different interviews where it is emphasised that participants are summoned (not just offered an examination) and that they have not questioned whether they should go:

Klaus: What did you expect of this examination? What did you expect to gain from it?

Informant: Well, you are summoned, you are offered ... [an examination]—and then I think you should accept it.

Klaus: Why?

Informant: Well, you don't go for an examination if you are not summoned.

Klaus: But why did you attend this specific examination? Was it because you wanted to—

Informant: No, you are summoned, you know! And you are conscribed, and then I thought, well ... yes, I'll take this one. I didn't speculate more, except I thought it is part of a routine procedure that is carried out here in Västerbotten. That we are summoned to a health control and it feels kind of preventive. Should you find out anything, I guess it's just fine.

Klaus: Is it a kind of duty?

Informant: Well, no ... I don't think so ... [doubtful voice, short break]. I do *think* that you are allowed to say no. I've never really thought about it.

That many patients sense some sort of obligation to attend a medical examin-

ation—for which they must even contribute an amount themselves—perhaps appears puzzling for an outside observer. Still, that a sense of obligation to respond to the advice of the welfare state does contribute to people's motivation becomes even more evident when a man apologises for his personal interest in his examination as seen in the following quotation. He has just explained that he attends the examination *because* he is summoned and when summoned you feel obliged. I ask why it feels like an obligation and he explains that he has had several minor health problems without attending a doctor. Then recently, he felt ill and saw a doctor who informed him that he needed treatment and should have had prophylactic medication for a certain cardiovascular disease.

Informant:—So, then, this time I felt it was a duty to turn up (pause). But I don't think I should have attended [this examination] if there wasn't just a little selfishness to it. It can't be disproved—even if I *am* willing to contribute my part to public health. Still, what brings me here is somehow my personal wellbeing—how am *I* doing?!

The patients thus combine their personal health project with a sense of contributing to efforts undertaken by the welfare state. Such a fusion of personal and shared objectives becomes even more manifest when I ask why they accept to donate blood. Rhetoric of obligation to contribute to research because *everybody* needs research dominates most interviews:

Informant:—Why you can contribute to this sort of thing, you know, it's because you can feel that you can assist with something. If it's good for humanity, it's good for me too. Those are the things I think about when contributing to research.

Another informant employed an even more profoundly altruistic idiom:

Informant: To me it's all right ... *If* I—if research in any way can contribute, if I can contribute, so that they can help just *one single soul*, then it's enough. It does not need to be revolutionising, it doesn't, as long as somebody finds help Yes. Even if they'd take a whole pint, it would be fine for me.

An altruistic idiom like this seemingly resonates with Richard Titmuss' (1997) classical conceptualisation of a gift relationship.

Changing institutional contexts and the sense of duty

Titmuss argued that social systems should be organised so as to allow 'devotion to the unspecified other' and *create* obligations of reciprocity. In this understanding the donor becomes initial 'author' of an altruistic act that henceforth obliges others to respond with similar altruism. The donation of blood and the messages conveyed at the interview can be seen as symbolic exchanges emphasising the commitment to honesty and a shared future, as it were; as gifts given with the wish attached to them that the rest of the world will feel obliged to do the same.

A majority of interviewees launched ‘openness’ (an idiom for honesty) as a topic—especially in relation to the questionnaire that rests on their personal information. Four interviewees explicitly wondered whether everybody had filled in the questionnaire truthfully, pointing out that their own ‘gift’ would have no value if others lied. Symbolic inter-actionism (e.g. Cheal, 1996 [1987]) would see such messages as part of committing others through your gifting; *do et des* (cf. Douglas, 2000 [1990], p. ix).

However, you might just as well emphasise the fact that donors are already feeling obliged: to be honest; to attend the medical examination when summoned; to donate blood when asked. John Frow (1997, p. 107) writes, ‘There can be no such thing as an originary gift: every gift is already a response, a counter-prestation. (...) [T]he “first gift” is an impossibility.’ The webs of mutual obligation that creates a sense of duty cannot be reduced to societal structures in a Durkheimian way (Durkheim, 1973 [1914]; 1979 [1904]). They are very much part of a personal frame of experience; of personal objectives (as exemplified in the personal interest in a health examination); direct negotiation with the nurse; previous encounters with the system; individual hopes for the future (cf. Rapport, 1997). It would, however, be equally mistaken to omit the institutional and wider socio-historical context of the analysis.

The Swedish welfare state, often termed *Folkhemmet* (literally, the ‘People’s Home’), has a special institutional history in which the state was expected to take paternal responsibility for the citizens, who then in turn were expected to ‘know how to behave themselves’, as one woman put it during my fieldwork. The locus of agency in the construction of the welfare state was among the voluntary associations, namely the temperance movement, the workers movement and the free churches (Ambjörnsson, 1988; Frykman & Löfgren, 1987; Gustavsson, 1991). Self-discipline was a central concern for all three movements, and it was combined with solidarity, trust in science and an overall confidence in a future to be conquered by employing rational judgement and suppressing personal idleness (Qvarsell, 1986). Today, the workers movement and the free churches still have their stronghold in Northern Sweden.

Housing policy and healthcare were prominent issues during the 50-year period that saw Sweden change from being one of the poorest to one of the richest countries in Europe. Doctors and nurses to some extent became the local personifications of the benevolent state and it was not unusual to talk of them as local ‘fathers’ and ‘mothers’ in the People’s Home (Nordberg, 1998, p. 296). During my fieldwork I met two nurses employing this idiom. They had refused to ask their patients for blood samples because, as they proclaimed, they felt like mothers to their patients and could not ask for blood if they did not know how the blood was to be used. ‘I know that if I ask for it [the blood sample], they will trust me and donate, and I am not prepared to assume that kind of responsibility,’ one of them said.

However, the former ideal of welfare provision is increasingly questioned. Liberal winds are blowing and southern Sweden has experienced several privatisation programmes in the healthcare sector. The public authorities are not

assuming the same extensive responsibility for public health standards as envisioned during the founding years of *Folkhemmet*. It partly reflects politico-economic developments too encompassing to be fairly accounted for here; partly it reflects a pressure on the state to abandon some of the privileges or rights accompanying the notion of responsibility. Together with the vision of a caring state followed an extensive set of rights to execute the care the way the state employed healthcare staff found it most appropriate. In addition to an excellent health service and internationally remarkable health standards, it led to less positively acclaimed initiatives including the much debated forced sterilisation (Lynøe, 2000; Runcis 1998), medical experimentation on poor people's dead bodies (Åkesson, 1996) and mentally retarded children (Lynøe, 1999). The latter (ab)use of privileges in the name of either eugenics or science must not necessarily be seen as matters of ill faith, but rather as specific configurations of beliefs about what society as a whole would benefit from (Koch, 1996). Then, as the vision of the caring state taking appropriate action on all matters concerning health has dwindled, the respective rights in the state-citizen relationship has changed. Together with an increasing emphasis on consumer driven healthcare service and economic incentives in the healthcare supply, this change in the medical ethics has raised the attention concerning the rights of the individual (cf. Novas & Rose, 2000). Not least, the right to make informed choices, as stipulated in informed consent.

The introduction of informed consent as a dominant topic in medical ethics, which incidentally came relatively late in Sweden (in relation to biobanks, it did not become a public issue until 1999), ought to be understood in this context of negotiations of rights and responsibilities. Every time you acquire a right, a responsibility will accompany it; when you loose a right you will free yourself of a responsibility (Løgstrup, 1996 [1971]). The state no longer holds the same rights in individual bodies, but nor is it as fully obliged to guard their well-being.

Notions of duty and obligation towards state authorities—as we hear them articulated in my interviews—echo a historical vision of a relationship between state and citizen in which the state took responsibility for healthcare decisions. It was a relationship in which people were obliged to respond to state advice if they wished to receive free healthcare, but also one that left them with limited personal (economic) responsibility. If citizens claim their own rights they simultaneously acknowledge a decrease in the rights—and thus responsibilities—of the caring state.

Nevertheless, an increasing number of patients are now beginning to employ their newly gained rights to refuse to participate in research. I spoke with four persons—two men and two women—who had abstained from donation (previously participation rates could go close to 100%). Not one of them had any discord with UmanGenomics or gene technology, three of them even thought the company sounded like a good idea, but one of the women explained, 'I do this for myself. It is *my* health examination' (see also note 2).

People do not donate blood and questionnaires because they consent to the information they are provided with, nor do they abstain from donation because

of distrust in UmanGenomics or research purposes. Their donation reflects confidence in the clinical realm of the examination; of science as a means of combating illness; and it reflects a mutual contextual trust established between nurse and patient, state and citizen.

If the donation in this sense might be viewed as a support of science and research, it is, however, striking that not once was it specified what kind of research donors had in mind. I heard nothing more concrete than the following two responses. The first is a woman who explains that she donated blood because she hopes that ‘they’ [researchers or doctors] can learn something new. Here I ask her what objects of research she imagines ‘they’ would undertake:

Informant: Well, I guess it’s medicine—I don’t know. They may research whatever they want with my blood [laughs]. As long as it’s positive.

Similarly, another woman responded:

Informant: I think it’s good that they can do research (...).

Klaus: Is it any particular kind of research?

Informant: No, no, it isn’t.

Klaus: Can you think of anything they should not be allowed to do?

Informant: [Pause] I’ve never thought about that.

Later on she revealed concerns with scientific developments and its potential abuses, especially of gene technology, but she did not link her concern to her own donation of blood to genetic research. ‘I guess we just have to trust them,’ a man said as an explanation of why he had not cared to read the information given to him. Unfortunately, I did not unravel who ‘them’ referred to. The lack of interest in specific research purposes is in unmistakable contrast to the academic strife on informed consent that centres on this very issue: are donors informed about what kind of research they (or their DNA sample B) participate in.

Moral reasoning and practice

It is not that the people I met were careless. Their donations express a concern in themselves and during interviews many doubts, fears and hopes were articulated. Some had thought of images of science gone mad, on the one hand, and a general vision of science as a means of control against the madness of nature, on the other hand (cf. Lundin, 1996). But when it comes to distinguishing the two, most of my informants claimed that they were in no position to assess which of the two fitted the biobank research. The conclusion usually was, as one woman put it, ‘Research is really needed, that’s all I know’.

How is it, then, that the moral reasoning on the ambiguity of scientific progress does not result in people scrutinising the information they are provided with? Why do they not ask more questions to the nurse? Marilyn Strathern

(1997) has argued that moral reasoning reflect different moral domains; a person does not reason independent of context. Trust in the nurse and faith in biomedical research are part of the moral domain of the clinic, and it might be that this confidence excludes questioning. Even when a nurse insists on telling the patient about the biobank, she is often interrupted by the patient eager to get on with the examination saying, 'Yeah, yeah, it's fine, just great. We really need research!'

The clinic is a practised site in which the patient assumes a passive role. The nurse holds the arm of the patient, turns it and places it so as to insert the needle. She reminds the patient where to bring the clothes, when to relax, when to get up, where to stand, when to sit—and she often does so tacitly; by taking the patient by the arm, pointing, smiling or nodding. Many patients actually praise the fact that here is finally a place for them to be nursed for a while.

The interview with the outsider, the anthropologist, is another moral domain in which the patient retains another type of responsibility—and does this in an *articulate* manner. During the interview, many quickly realise that they have not read the information given to them by the nurse. Considering the passivity of their role in the practice with the nurse, it is perhaps no surprise that most people began looking for the informed consent sheet. 'I had it somewhere, I was given some kind of information, eh ...?' several donors said, unaware of the fact that for juridical purposes the signed information sheet had already been filed together with the blood. It is difficult to imagine equivalent bewilderment in a bank or at a post office about who received the money or a contract after it was signed. But the space of the clinic is a practised place in which certain roles are lived and special negotiations of responsibility take place (de Certeau, 1984).

On the one hand, the encounters in the clinic provide a forum for expressing values central to Folkhemmet and dominant in the social movements that brought the welfare state into existence (e.g. trust in scientific progress, solidarity, a special state–citizen relationship). On the other hand, the clinic can be viewed as a workshop for the production of those very values experienced through lived practice. Trust in the medical establishment is created through the interaction with the clinic staff. The confrontation with the questions of the anthropologist creates a move into another moral domain where doubt, anxiety and critical reflections are important.

The interviews raise questions left unarticulated by the donors during the examination. Perhaps informants either felt obliged to look for answers out of simple courtesy or maybe they wished to appear 'ethical'. It seems that to appear 'ethical' you must be willing to *rationalise* your acts. The interview imposes ethical demands on its research subject. It does not suffice to show a general concern and offer your blood to the nurse. You must *know*, be *informed*, and take a *rational* justified stand on the developments of biomedical research. As social scientists interested in ethics we might have to be more aware of the unintended symbolic violence that is in this way potentially embedded in our research (cf. Callon & Rabeharisoa, 1999). One important contribution to arise

from such reflections could be increased awareness of non-verbal strategies in handling the challenges of the new medical technologies.

In spite of the often-seen emphasis on narrative as a means of creating some sense of control in recent anthropological studies of people's behaviour in medical settings, we might find that lack of articulation, bodily practices and lack of interest in the information offered can be an equally appealing option. By *not* reading the information and refusing to talk about research purposes the patient insists on keeping the emphasis on the medical examination itself; on his or her own body and health. If they should genuinely assess the actual biobank research, they would need a lot of information—which should be delivered by the same nurse that asks them to consent. During an interview one woman who had declined the request for blood began talking about how everybody demanded something from her (environmentalist groups, social scientists [!], medical researchers, third world organisations—and her teenage son on top of them all). She had to take care of herself, she told me. Perhaps she also gave a clue as to why people do not commit themselves to find out more about biobank research: they are living different lives with other concerns too. Nobody can be engaged in everything. In lived experience a nurse is a better (and more easily accessible) guarantee than an information leaflet.

Concluding remarks: regulation through liberty

From the discussion above it appears that the image of informed consent presented by the ethical model developed by UmanGenomics is not materialising. People do not read the information they are offered; their motivation to donate (or decline the donation) does not rest on knowledge of the research purposes; and they participate in a tacit practice in which they are passively enjoying the care of a nurse rather than actively and 'rationally' assessing the purpose of specific research projects.

Following Bateson's line of thought we might have to view non-verbal communication, silence and passivity as essential features of communication when understanding the success of informed consent as a primary 'ethical' practice (Bateson, 2000 [1972]; Hansen, 1997). Informed consent presents itself as an option that can be left unused. Donors may choose (though I do not use the word 'choose' in the logocentric meaning of the word implying full analytical consideration!) to trust the public authorities responsible for collecting the blood samples because they feel they have no way of really knowing 'good' research from 'bad' research anyway. In case they should not donate, no research would take place. It implies a responsibility, too. Therefore, they are stuck in a dilemma of balancing their hopes and fears attributed to science. Either they must assume the responsibility for *no* research, or for the risk of research gone mad. By not reading the information, but still fulfilling their sense of duty by donating 20 ml blood, what might be perceived as a reasonable alternative is created.

Informed consent procedures give room to manoeuvre in different ways than a system stipulating state rights in individual bodies. With individual rights, however, follows individual responsibility. Difficulties in handling such a responsibility are part of the regulation of access to bodies, genes and knowledge. Rather than simply praising informed consent as increased 'freedom' (a highly dubious concept in social analysis, cf. Rose, 1999), informed consent could perhaps be more fruitfully analysed as part of a biopolitical development (see also Hoeyer, 2001a, 2001b). The individual sense of responsibility emerging in certain situations is employed to gain access to research subjects.

Whereas the state could previously be held responsible for its decisions—as it has in fact been in Sweden with regard to forced sterilisation—it is becoming increasingly difficult to place a responsibility for the application of new technologies. It is everybody's responsibility and thus nobody's. A diffuse arrangement of responsibility does not adequately respond to the morality expressed through the donation. The mutual trust and the belief in the system are implicitly overruled when only 'information levels' are taken into account as ethically important features.

An anthropological perspective has been employed before in critiques of bioethics and informed consent procedures (see Kleinman, 1999, for an overview). It has been argued that the language of bioethics despite its universal pretension is in fact ethnocentric and incapable of accounting for moral complexity in a non-Western context. This study carried out on the fringes of the West suggests that a variance of perceptions of responsibility and trust exist in different Western contexts—even northern and southern Sweden might not be similar, and the lay person's experience and academic debate certainly depart no matter the region. Furthermore, we might find that such perceptions challenge the logocentric preconception of informed consent—rather than merely its ethnocentric prejudice. A real and important moral exchange takes place when nurse and patient agree to store a blood sample in the biobank. The moral agency in this act is expressed through a partly tacit bodily practice and has an intersubjective texture (Jackson, 1998). The kind of personhood involved in making the decision is a transitory 'we', not an autonomous 'I'. The nature of this exchange, however, is not accounted for by an understanding of ethics that mainly stipulates information levels. Unfortunately, an adequate institutional response to these problems is still to be seen.

Acknowledgements

I am very grateful for the comments made by Lene Koch, Maja Horst, Carlos Novas and the anonymous referees on earlier drafts of this article. Several of the participants at the 5th PFGS Colloquium, where this paper was first presented, have also contributed in important ways. The research is supported by The Ethics in Healthcare Programme in Sweden (grant no. 2000/56).

Notes

1. UmanGenomics resembles DeCode Genetics in Iceland in several ways, but it has had a relatively unnoticed public reception in contrast to its Icelandic equivalent that has caused extensive public and academic debate. See, among others, Fortun (2001), Morgall (2001), Pálsson & Hardorsdóttir (2002), Pálsson & Rabinow (1999), Rabinow & Pálsson (2003), Rose (2001), Sigurdsson (2001). It seems to be a feature of the academic strife on the Icelandic case to discuss whether people would or would not support DeCode if they were adequately informed (e.g. Sigurdsson, 2001). It is not my aim to engage in this kind of polemic speculation. I simply take point of departure in what people *do* know and how they *do* donate.
2. Thirty-two people were asked for an interview, resulting in 29 interviews. One informant was death-mute and the interview cancelled for practical reasons. One patient said, 'I am here for my own sake, not for research', and one patient did not give any reason.
3. For example, is the mandate of the biobank's reference group to deny UmanGenomics access to the biobank material (in case a project is deemed scientifically uninteresting) really compatible with the company's commercial rights; does the partial public ownership impede the flow of venture capital and necessitate a re-arrangement of the ownership structure; will academic research be impeded by the agreement; is the publication of research results compatible with the rules of economic competition? For a description of the conflict that evolved to some of these questions, see Rose (2003).

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