

# Introduction

This is a thesis in moral philosophy. It concerns issues related to the big question: how ought we to treat one another? To a large extent it is also a thesis in the subdiscipline research ethics, dealing with issues related to a narrower question: how ought we to treat one another in the name of research?

Many of the ethical issues arising in the research context are of a general nature, arising also in other areas of human interaction. For instance the concepts and meanings of exploitation, coercion and voluntariness are of this kind.

In moral philosophy generally, the question “how ought we to treat one another” invites an answer that goes two ways in the sense that we all ought to act towards each other in accordance with the same moral principles. In research ethics our roles differ and the ethical issues uniquely concern how researchers ought to treat research participants, and not the other way around.<sup>1</sup>

The field of research ethics is highly regulated and contains extensive prescriptions concerning how to act “ethically”, such as the requirement always to obtain informed consent (operationalised in great detail) from those persons being involved as research subjects. However, underlying such prescriptive codes and guidelines are open moral questions. For instance we may ask whether we always ought to protect individual self-determination, what it means for a person to in fact consent in a morally meaningful way, whether exploitation should (always) be avoided, how important privacy is, etc. This thesis explores this codified landscape in a number of ways: Essay 1 compares the implications of codes if transferred from one area of research (that of biomedicine) to another (that of traffic research); essay 2 investigates cases where one code (the requirement of informed consent) is inapplicable and what could substitute this code in those cases; essay 3 takes the commonly proposed research ethical guidelines of avoiding coercion and exploitation seriously, and investigates the implications of these guidelines when it comes to the policy of paying people to participate in research; essay 4 challenges the often heard claim that people who are informed and voluntarily give gifts (such as those voluntarily participating in research for free) cannot be exploited. To varying degrees the analyses presented in these essays are generalisable or transferable to other areas. For instance the investigation of how different levels of payment affect coercion and exploitation has bearings in other contexts, such as that of offering money to surrogate mothers, organ or blood donation versus sales, or wage schemes in general. Most obviously the analysis of

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<sup>1</sup> In principle there is of course room for discussing also what it would mean for a research participant, *qua* research participant, to behave ethically even though I have not come across any such accounts. It could be argued that ethical behavior of research participants amounts to the same as ethical behavior of human beings in general – just like it could be argued that ethical behavior of researchers is reducible to ethical behavior in general (see discussion in section 2 of this introduction).

exploitation of gift-giving is of a general nature, relevant for interpersonal relations of all kinds.

The purpose of this introduction is to provide a background for the essays in the thesis, and a description of the context in which the problems discussed in the essays are situated. The contents of the essays will also be summarized.

## **1. Background to research ethics and the protection of research subjects**

Research ethics concerns a variety of topics: issues concerning scientific quality (prohibiting plagiarism, scientific malpractice, etc.), relations within the scientific community (authorship questions, duties of supervisors, etc.), questions concerning funding and the independence of science and the role of scientists in society (the extent of the duty of researchers to participate in the public debate and inform the public, the sometimes conflicting roles of researchers and public citizens, whether some topics such as stem cells or weapon technology should be avoided and others imperatively studied in the name of public interest or public feelings), and the treatment of research subjects. The last issue, concerning the treatment of research subjects, includes ethical requirements for the treatment of both animal research subjects and human research subjects. It is the latter of these that is of interest in this thesis.

The evolution of protective measures for human research subjects is commonly described as a reaction to infamous cases of research where participants' interests, needs and well-being have been entirely disregarded. The prime example is of course the heinous experiments carried out in Nazi concentration camps during the Second World War, where camp prisoners were placed and kept in icy water or naked outside in low temperatures in order to investigate human endurance, fed only salt water, placed in decompression chambers, infected with diseases and operated upon, to mention some of the atrocities.<sup>2</sup> The Nuremberg Tribunals that took place after the war led to the formulation in 1947 of the *Nuremberg Code* which spells out conditions for when medical research is ethically permissible – most importantly the requirement of always obtaining participants' informed consent.<sup>3</sup> The influence of the *Nuremberg Code* and its formulation of protective measures for human research subjects have been enormous. However, there were less known guidelines and directives prior to the

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<sup>2</sup> David Bogod, "The Nazi Hypothermia Experiments: Forbidden Data?", *Anaesthesia* 59:1155-1159, 2004. Less known are the experiments carried out by Japanese scientists on Chinese prisoners of war and civilians during the same period. Facts about these experiments and an analysis of why reactions to the Japanese and the Nazi experiments differed so much in the United States are provided in Howard Brody, Sarah E. Leonard, Jing-Bao Nie and Paul Welding, "U.S. Responses to Japanese Wartime Inhuman Experimentation after World War II", *Cambridge Quarterly of Healthcare Ethics* 23:220-230, 2014.

<sup>3</sup> *The Nuremberg Code*, [http://www.ushmm.org/research/doctors/Nuremberg\\_Code.htm](http://www.ushmm.org/research/doctors/Nuremberg_Code.htm). Retrieved 15 August 2013.

Nuremberg Code requiring for instance informed consent, not least in Germany at the beginning of the 20<sup>th</sup> century.<sup>4</sup>

After the Nuremberg Code, other codes and declarations were formulated – such as *the Belmont Report*, *the Declaration of Helsinki* and *the CIOMS guidelines*.<sup>5</sup> Simultaneously, however, research was carried out that would be deemed highly unethical by these same and other guidelines. Well known cases include the Tuskegee syphilis study, the Tearoom Trade and the Vipeholm dental caries experiments.<sup>6</sup> Less well known examples keep entering the limelight and include the US led studies of treatments for syphilis and other sexually transmitted diseases in Guatemala in the 1940s and 1950s (for which president Obama recently officially apologized), nutritional experiments on children in aboriginal communities in Canada, GlaxoSmithKline testing drugs on humans in China without reporting previous studies on animals, to mention but a few.<sup>7</sup>

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<sup>4</sup> Jochen Vollman and Rolf Winau, “Informed consent in human experimentation before the Nuremberg code”, *British Medical Journal* 313:1445-1447, 1996. The regulations presented in that paper include a number of demands on medical research that are similar to or even stricter than those of the Nuremberg Code and the Declaration of Helsinki. These regulations were formally in force during the Second World War and in fact prohibited much of what was carried out in the so called Nazi experiments. Hence, this was not only an example of early research ethics regulations but also an early example of such regulations not hindering violations of even the most fundamental research ethical principles.

<sup>5</sup> National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report. The Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, 18 April 1979. <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html#go1>. Retrieved 11 September 2013; World Medical Association, *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects*, amended 2008. <http://www.wma.net/en/30publications/10policies/b3/>. Retrieved 11 September 2013; Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, Geneva 2002. Retrieved 11 September 2013. These documents are in the following referred to as *the Belmont Report*, *the Declaration of Helsinki* and *the CIOMS guidelines*, respectively.

<sup>6</sup> Concerning the Tuskegee study, see Brittany Daughterty-Brownrigg, “Tuskegee Syphilis Study” in Sana Loue (ed.), *Mental Health Practitioner’s Guide to HIV/AIDS*, Springer, New York 2013. This experiment, where black American men were infected with and untreated for syphilis began in 1932 and ended in 1972. Concerning the Tearoom Trade, see Laud Humphreys, “Tearoom trade”, *Trans-action* 7(3): 10-25, January 1970. In this project the sociologist Laud Humphrey studied homosexual men meeting in public spaces. He lied about his own identity and interest, noted car license plates and then contacted them in their homes under the false pretense to make interviews on other unrelated topics. Concerning the Vipeholm experiments, see Bo Peterson, “Etik och kolhydrater: En forskningsetisk studie om Vipeholmsundersökningarna 1945-1955”, *VEST tidskrift för vetenskapsstudier* 2-3, 1991. These experiments took place between 1945 and 1955, and consisted in feeding cognitively impaired patients (considered to be “uneducable idiots”) at the Vipeholm mental hospital large amounts of toffee in order to study the development of caries. The studied group was methodologically ideal in the sense that researchers could control exactly what each person ate for long periods of time.

<sup>7</sup> The experiments in Guatemala were aimed at investigating treatments for syphilis and other sexually transmitted diseases, and involved studying people already infected but also the active infecting of others. For example, attempts were made to infect prison inmates by first infecting prostitutes who they were then allowed to have sex with. Also soldiers and inmates at the National Mental Health Hospital were infected with diseases. Research subjects were never informed or asked for consent. In contrast to the Tuskegee Study, these patients received treatment. The experiments were revealed in 2010, after

As is evident from these examples, ethical deliberation concerning the protection of human research subjects has primarily focused on biomedical research. The protective measures developed are related to the protection of patients in medical practice associated with the Hippocratic tradition of medical ethics.<sup>8</sup> However, also other professions have developed ethical codes for research involving human subjects, e.g. psychologists, sociologists and anthropologists.<sup>9</sup> Yet, many research areas do not have any specific codes, or have codes that are not very familiar to the members of the profession.

The contents of standard research ethical requirements regarding the treatment of human research subjects can be linked with three main concerns: the protection of the person's autonomy, or right to self-determination; the protection of her well-being, i.e. a concern which is paternalistic in nature; and justice.<sup>10</sup> More specifically, common contents of ethical guidelines for the protection of research subjects can be described as follows:

- **Ethical committee review**<sup>11</sup>  
All research involving human subjects must be approved by an ethical committee.<sup>12</sup> Committees evaluate proposed studies considering the other ethical requirements below.
- **Good research quality**<sup>13</sup>  
This requirement should in fact be seen as a prerequisite for involving people at all. If the project is not based on valid scientific methods, there is no potential

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which president Obama officially apologized to the Guatemalan government. See Rob Stein, "U.S. apologizes for newly revealed syphilis experiments done in Guatemala", *The Washington Post*, 1 October 2010. The nutritional experiments in Canada took place in the 1940s and 1950s, and involved denying thousands of native Indian Canadian children basic dietary requirements and health care in order to study different nutritional interventions on malnourished children. See Xavier Symons, "New evidence of unethical research on Canadian Indians", *Bioedge*, 27 July 2013. [http://www.bioedge.org/index.php/bioethics/bioethics\\_article/10619](http://www.bioedge.org/index.php/bioethics/bioethics_article/10619). Retrieved 13 November 2013. Concerning GlaxoSmithKline's tests in China, see Katie Thomas, "Drug Research in China Falls Under a Cloud", *New York Times*, 22 July 2013. In an audit from 2011 it was discovered that a pharmaceutical company had tested drugs for the treatment of multiple sclerosis and Lou Gehrig's disease, failing to report the results from previous studies on mice and thereby exposing human research participants to increased risks.

<sup>8</sup> In the Hippocratic Oath is stated that doctors ought to help sick patients and never harm them, see Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, (5<sup>th</sup> ed.), Oxford University Press, New York 2001, p. 113.

<sup>9</sup> For a useful collection of research ethical guidelines for different professions and disciplines, see [www.codex.vr.se](http://www.codex.vr.se).

<sup>10</sup> Often, the roots of research ethical requirements are described as "the four principles in biomedical ethics", namely autonomy, non-maleficence, beneficence and justice. See Beauchamp and Childress 2001. Sometimes, as in *the Belmont Report*, part B and *the CIOMS guidelines* as well as in the presentation above, non-maleficence (do not harm) and beneficence (do good) are dealt with together.

<sup>11</sup> *The CIOMS guidelines, no 2* and the *Declaration of Helsinki*, § 15. World Health Organization (WHO), *Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants*, Geneva 2011.

<sup>12</sup> The process for such review varies between countries.

<sup>13</sup> Cf *The Declaration of Helsinki*, § 12.

use of its outcome which can justify the efforts and sacrifices made by research subjects.<sup>14</sup>

- **Do not harm**<sup>15</sup>

Researchers have an obligation to ensure that participants' well-being is given priority and that they are not harmed in the research process. Participation may involve risks, but the anticipated outcome must be at least as good as if not participating. Risks must be minimized, assessed in relation to expected benefits and furthermore monitored so that studies turning out to be too risky are interrupted.<sup>16</sup>

- **Just selection of research participants**<sup>17</sup>

Apart from risks to each individual having to be acceptable in relation to expected benefits, no individual or group must be unfairly burdened in relation to other individuals or groups. In particular, disadvantaged members of society or communities should be protected from exploitation. Furthermore, individuals who are vulnerable due to incompetence, disability or health problems should not be unnecessarily used as participants. However, these groups must neither be denied possible benefits entailed in research participation.

- **Information**<sup>18</sup>

Subjects have a right to receive information about the project in which they are involved. This information should include the aim, methods and funders of the project, as well as the affiliation of researchers and what effects participation may entail for them. Information should also be given about the right not to participate and to withdraw. (In section 3(a) this requirement is discussed at greater length.)

- **Informed consent**<sup>19</sup>

The requirement to ensure that participants are informed, competent in the sense that they are able to make decisions about research participation, and that they voluntarily choose to participate is often considered to be the most important ethical requirement. (In section 3 this requirement will be discussed in more detail.)

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<sup>14</sup> *The CIOMS guidelines*, no 1. This ideal of usefulness is also the reason why the practice of not reporting research findings that are of good quality but which are not in line with the interest of the researcher and/or research funder meet criticism.

<sup>15</sup> *The Declaration of Helsinki*, §§ 4, 11, 18; *the Belmont Report*, parts B and C; *the CIOMS guidelines*, no 3.

<sup>16</sup> *The Declaration of Helsinki*, § 20.

<sup>17</sup> *The Declaration of Helsinki*, §§ 17-18, 27-28; *the Belmont report*, parts B and C; and *the CIOMS guidelines*, no 3, 10, 12 and 13.

<sup>18</sup> *The CIOMS guidelines*, no 5; *the Declaration of Helsinki*, §§ 24, 33, 34; and *the Belmont Report*, part C.

<sup>19</sup> *The CIOMS guidelines*, no 4, 5, 6; *the Belmont Report*, part C; and *the Declaration of Helsinki*, §§ 22 and 25-29.

- **Protect participants' privacy**<sup>20</sup>

Participants' privacy should be protected and their research data should be safely stored and kept confidential. Information should be provided concerning how data will be handled and possible legal limits to confidentiality.

The essays in this thesis relate to these research ethical requirements in the following ways: essay 1 deals with all of them (though briefly); essay 2 is focused on the informed consent requirement (and indirectly also with the information requirement); essay 3 analyses voluntariness, coercion and exploitation and is hence related primarily to the requirements of informed consent and justice in recruitment of participants; essay 4 which concerns exploitation is more weakly related to the requirements than the other essays, but of relevance for the interpretation of the requirement of the just selection of participants.

## **2. Is special protection warranted in research?**

As shown, participation in research is highly regulated (even though not all such regulations are *legally* binding). People are protected in virtue of participating in research; as long as we know that they are research subjects there is no need for further information about what is done to them in order to establish that they qualify for this protection. One may therefore wonder what it is that is so special with research, warranting this extraordinary protection.

First of all, we should note that a lot of things that are done in research are also done in other contexts. People face different social security set-ups as a result of mere policy changes, or as part of social experiments.<sup>21</sup> Consumers answer questions in research questionnaires and in marketing surveys. Streetlights may be turned off in order to scientifically investigate the effects or in order to diminish public expenditures.<sup>22</sup> Sometimes people are equally protected outside of research, sometimes they are not (the former is primarily true about normal clinical practice which is guided by principles typically mirroring research requirements). Is a difference in protection justifiable?

The main apparent difference between these activities when taking place in or outside of research seems to be the aim.<sup>23</sup> The aim of research is typically defined as to generate new knowledge.<sup>24</sup> The aim could also be described in broader terms referring

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<sup>20</sup> *The Declaration of Helsinki*, § 23; *the CIOMS guidelines*, no 18.

<sup>21</sup> Concerning social experiments, see David Greenberg, Mark Shroder and Matthew Onstott, "The social experiment market", *The Journal of Economic Perspectives* 13(3): 157-172, 1999.

<sup>22</sup> Example from Sven Ove Hansson, "Do we Need a Special Ethics for Research?", *Science and Engineering Ethics* 17:21-29, 2011.

<sup>23</sup> Other differences may possibly be the thoroughness of research as opposed to other activities in terms of methodology and documentation.

<sup>24</sup> See for instance the definition of research in Organisation for Economic Co-operation and Development (OECD), *Frascati Manual 2002: Proposed Standard Practice for Surveys on Research and Experimental Development. The Measurement of Scientific and Technological Activities*, OECD Publishing 2002. doi: 10.1787/9789264199040-en, chapter 2: "Research and experimental development (R&D)

to the ultimate aspiration to benefit humanity and human development, improving conditions for life on earth, etc. These are indeed laudable aims! They seem more worthy as goals than those of, e.g., marketing firms conducting surveys with the purpose to increase profit for a particular company, yet research faces stricter controls and regulations than do marketing surveys. It would not be entirely absurd to argue that the aim of research is so laudable that *more* ought to be allowed in its name than in the name of profit maximization in business.<sup>25</sup>

Hence, it is hard to see how the difference in aim between research and other activities could justify the former being more rigidly regulated than the latter. Sven Ove Hansson discusses other possible justifications: that research is more dangerous or has worse effects, that research entails less benefits, that research is easier to control, and that the social standing of research is in need of more protection. The first three suggestions are dismissed while the fourth is judged to have some plausibility. It is argued that research is constantly subjected to criticism (partly due to the existence of misconduct and research ethical “scandals”) and public skepticism is easily aroused, so if the outcomes of research are considered valuable the reputation of research must be protected.<sup>26</sup> One way of achieving this would be to demand more of research than of other activities. In other words, the fact that research has had a lot of “bad press” and the damage this causes can explain, and arguably also justify, the difference in levels of protection. This line of reasoning is based on the opinion that, from the participant’s perspective, research is not different from other activities in any significant way. It only proposes strong protection for participants in research as a public relations strategy, and if such strategies are no longer needed, there is no longer any justification for strong research ethical requirements.<sup>27</sup>

In other words, it is not obviously easy to find any absolute ways to defend this difference in protection, which might mistakenly lead to the conclusion that research is too regulated. This is not necessarily the case – we may equally well conclude that other areas are too poorly regulated. For instance, that rights to self-determination, privacy protection and information – if we care about them – ought to be better secured in areas such as marketing or in ordinary job situations (not the least in jobs

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comprise creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man, culture and society, and the use of this stock of knowledge to devise new applications.”. Also *the Belmont Report*, part A, describes the difference between normal practice and research in terms of the aim: in the case of normal practice it is to benefit individual patients or clients, in research it is to create generalizable knowledge. However, this aim is not enough to demarcate research; another crucial element is that formal methods are used in order to achieve the aim. The definition in *the CIOMS guidelines*, p. 19, is similar: “[t]he term ‘research’ refers to a class of activity designed to develop or contribute to generalizable knowledge”.

<sup>25</sup> Of course, we may also have intuitions favouring not this principle of “the more noble the end, the more dirty the means permitted” but instead demanding the exact opposite; precisely because the ends are noble, also the means allowed to be used must be noble too.

<sup>26</sup> Hansson 2011.

<sup>27</sup> Hansson 2011. Hansson acknowledges the limited scope of the proposed justification: “However, this is a somewhat indirect argument since it does not refer to inherent properties of research but to public attitudes to science that may of course change”, p. 26.

involving significant risks), and that individuals ought to have stronger rights to veto in collective decision making (this issue is touched upon in essay 2).

However, even if we were to conclude that other areas ought to include protection on the level of that in research, this does not imply that *all* activities done in the name of research warrant strict protection of research participants. Sometimes this is perhaps simply not necessary. Many would argue that if there are no risks involved, research ethical requirements are less important. Furthermore, it may be argued that the requirement of informed consent is too demanding and not always defensible (this matter is also touched upon in essay 2 where the requirement is taken for granted, and the implications that follow if we are serious about it are illustrated). In this thesis I do not take a stand on whether the established standard for the ethical use of people as research participants ought to be changed in either a stricter or less strict direction (apart from challenging the current policy on paying research participants, see essay 3). I am inclined to agree with those arguing that we need a more fine-grained approach to research ethics, but I am also aware of the risk of losing some of the benefits of a clear-cut set of rules (such as simplicity and efficiency) if a more open-ended and multifaceted approach were to be adopted in order to better capture the diversity in characteristics of research activities.

The difference in judgment depending on whether an activity is part of research or if it is not is highlighted by the example of the possible exploitation of poor people in research (when they participate either in order to earn the little money which is offered, or in order to get access to some experimental treatment for a condition from which they suffer but for which they do not possess the means to pay the existing treatment). It is regularly argued that such exploitation ought to be avoided (and this is taken as an assumption in essay 3). Given that we do think that this kind of exploitation ought to be avoided (at the price of slower progress of biomedicine, as well as obviously leaving the poor with even less options to get out of poverty and/or to get access to health care), we should reasonably also strive for the avoidance of similar exploitation in other areas. Poor people are allowed to work in sweatshops and diamond mines, for instance, which is arguably as hard and risky as many research activities. Underprivileged and vulnerable groups are burdened with the dirtiest, heaviest and worst paid jobs in society, which does not seem to be significantly different from being burdened with research participation, of which the latter is required to be avoided while the former is considered acceptable. If we object to the poor being exploited in research, it is not clear why we should accept them being exploited in other contexts. Or conversely, if we find it acceptable that the poor are taken advantage of in other areas, it is not obvious why we should not permit them to be so also in research given that the exploitation in question is “mutually beneficial”.<sup>28</sup> After all, participating in research may be one opportunity to acquire some badly

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<sup>28</sup> This means that both parties in the transaction benefit from it, when compared to a situation where there would be no transaction. Exploitation which is harmful for the exploited party is obviously to be evaluated differently. See Alan Wertheimer, *Exploitation*, Princeton University Press, Princeton 1996, as well as section 4 below.



needed benefits for someone in a destitute situation. One way of defending this difference would be to claim that research, or at least some cases of research, as opposed to for instance sweatshop labor, involve activities that ought not to be done for money or that cannot be compensated for with money (in essay 3 the issue of compensability is investigated further). Worth pointing out is that this kind of discussion occurs also in some other contexts, which in many places are regulated as stringently as research participation, such as organ sales or commercial surrogacy. In these areas the permissibility of exploitation and the possibility of compensation tend to in fact be discussed in much the same way as research participation.

In sum – it is not obvious that research participation warrants stricter protection than other activities, neither is it obvious that research participation ought to be less strictly regulated. Instead, many of the reasons justifying strong protection of research participants are valid also in contexts outside of research. Hence, some of the discussions in this thesis may be of a more general interest and not restricted to the research setting.

### **3. About the requirement of informed consent in particular**

Of the common ethical requirements on research, that of informed consent is probably the most discussed. It is being discussed what it is aimed for, what it ought to aim for, how well it succeeds in achieving that which it aims for or ought to aim for, what it requires in order to be valid, etc. Since the requirement of informed consent, as well as the ideas and values underlying it, are central for the essays presented in this thesis, some attention will be paid to it in what follows.

In addition to the many discussions on the meaning and purpose of *informed* consent, are discussions on consent *tout court*.<sup>29</sup> Often “consent” is used as short for “informed consent”, but they need not be the same. We may for instance think that what is required for valid consent, is not the same as what is required for valid *informed* consent (but typically all the requirements of the former would also be requirements of the latter). The “informed consent” of relevance in the research context is an operationalised and more demanding concept than consent *tout court*. However, also when it comes to the more specific concept of informed consent, there are underlying open questions concerning what it ought to require in order to be valid, as will be briefly illustrated below.

There are two important divergent perspectives on informed consent. According to one of those, informed consent should be understood as a mental state, as an “inner resolve or approval”.<sup>30</sup> John Kleinig rejects this view, arguing that informed consent must instead be understood as a communicative and social act if it is to be morally

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<sup>29</sup> See for example Stephen Wilkinson, *Bodies for Sale. Ethics and exploitation in the human body trade*, Routledge, New York 2003. Wilkinson talks of valid consent even though he refers to what is normally called informed consent, p. 76.

<sup>30</sup> John Kleinig, “The Nature of Consent”, pp. 3-24 in Franklin Miller and Alan Wertheimer (eds.), *The Ethics of Consent: Theory and Practice*, Oxford University Press, New York 2010, p. 5.

transformative, i.e. to make another person permitted to do something to the consentor which he would otherwise not be permitted to do. Consent needs to be expressed and communicated, not merely a secret approval, in order to alter the moral relation between the consentor and the person consented to.<sup>31</sup> It is this view of informed consent as a communicative act allowing the researcher to do something to the consenting party which would otherwise be impermissible that is the basis for the discussion below.

The notion of informed consent springs from the idea that people should decide on matters that concern them; that we have some sphere where we are to decide. As Janet Radcliffe Richards notes, we may disagree on the placement of the boundaries for individual self-rule (i.e. what matters are for the individual to decide, and what others can justly interfere with without our permission), but we commonly think that regardless of where the boundaries are to be placed, consent is needed in order to transgress them.<sup>32</sup> Radcliffe Richards further observes that consent is often not only seen as necessary for such transgressions, but also sufficient.<sup>33</sup> There are, however, contexts in which consent is by many considered insufficient in order for an act to be considered permissible. Radcliffe Richards mentions consenting to be killed (as in the case of euthanasia). Other examples are selling oneself as a slave and – for particular relevance of this thesis – participating in research.<sup>34</sup> In the case of research, therefore, there is in addition to the requirement of informed consent of each participant also a need for the approval of ethics committees, whose task it is to look after the interests of potential participants. Whether this ought to be the case can of course be questioned – perhaps people should be allowed to do with their lives and bodies exactly as they please – but will not be dwelled upon here.

As mentioned, the notion of informed consent is operationalised in order to function as a requirement in research practice. The requirement can be described in different ways. Below it is characterized in terms of the three elements information, competence and voluntariness.<sup>35</sup>

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<sup>31</sup> Kleinig 2010, pp. 9-11.

<sup>32</sup> Janet Radcliffe Richards, "Consent With Inducements: The Case of Body Parts and Services", pp. 281-304 in Franklin Miller and Alan Wertheimer, *The Ethics of Consent: Theory and Practice*, Oxford University Press, New York 2010, pp. 281-282. Note that Radcliffe Richards discusses "consent", not "informed consent", but from her discussion and the context in which it is placed (organ donation versus organ sale) I take it that she refers to what could just as well be labeled informed consent.

<sup>33</sup> Radcliffe Richards 2010, p. 282. Kleinig 2010, p. 4, says that though consent is considered necessary in certain circumstances, it is an open question whether it is also sufficient.

<sup>34</sup> Radcliffe Richards 2010, pp. 282-283. That consent is not considered to be sufficient in the research context is also mentioned in essay 2, p. 49. Other acts that some consider not to be morally permissible, or that are in some places not legally permissible, even when there is consent are prostitution, commercial surrogacy and the sale of one's organs.

<sup>35</sup> In essay 1 the requirement of informed consent is described in terms of two elements only (information and voluntariness), while in essay 2 I use the same framework as above. Radcliffe Richards 2010 and Wilkinson 2003 also characterize informed consent as consisting of these three elements, while Kleinig 2010 describes the informed consent requirement as containing four components, namely competence, voluntariness, knowledge and intention. The description of informed consent in Gert Helgesson, *Forskningsetik för medicinare och naturvetare*, Studentlitteratur, Lund 2006, p. 148, contains

### **a) Information**

In research the first element of informed consent means that the researcher has to provide adequate information to the potential participant regarding the characteristics of the studies to be carried out – i.e. what participants will do and what will be done to them – as well as background information about the research project.<sup>36</sup> The information must be given in a form and language and on a level that the potential participant is able to understand – it must in other words be comprehensible. What that amounts to obviously varies between persons.

Though it may seem fairly straightforward what the information element amounts to, there are a few complicated matters at hand. First, according to whose standard is it to be judged what information is “relevant”? In *the Belmont Report* it is concluded that a standard of what a “reasonable person would wish to know” is insufficient since a research participant may wish to know considerably more.<sup>37</sup> A demanding but reasonable interpretation would be that what researchers or most people find material ought to be presented, in addition to the satisfaction of specific information demands of each potential subject.<sup>38</sup>

Secondly, there seems to be divergent views concerning whether the information only needs to be made accessible to potential participants, or if it in fact must be taken in and understood by the potential participant. Research ethical guidelines typically

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six elements: the person must be competent, the person must not be pressurized, the person must have been given all relevant information, the person must have understood the information, the person must have made a decision, and the person must have expressed this decision, for instance by signing a consent form (my translation and summary). In Ruth R. Faden and Tom L. Beauchamp, *A history and theory of informed consent*, Oxford University Press, New York, NY 1986, informed consent is understood as “autonomous authorization” which is composed of intentionality, understanding, noncontrol and authorization.

<sup>36</sup> According to Helgesson 2006, p. 147, the following information must be included: the name of the study; who are responsible for the study and their affiliations; which questions the study aims at answering and why that is of importance; the method used (including why there is a need for participants); how potential subjects have been selected; what it means in practice to participate (which tests will be carried out, waiting time, length of participation, as well as risks of harm in the short and long term); how the collected data will be dealt with and stored; that participation is voluntary; that the participant has the right to withdraw his or her informed consent at any time and thereby interrupt his or her participation; and how more information can be obtained.

<sup>37</sup> *The Belmont Report*, part C.

<sup>38</sup> This seems to be in line with *the Declaration of Helsinki*, see § 24: “Special attention should be given to the specific information needs of individual potential subjects”. Also Faden and Beauchamp 1986 seem to support this view, when they argue that professionals first ought to disclose a core set of facts (namely what they judge that most patients/subjects consider relevant, what professionals judge to be relevant, and that the informed consent procedure involves authorization on the part of the patient/subject), then engage in a dialogue where the patient/subject may ask for information that is material to her, p. 308 passim.

require the latter, i.e. that the information provided is also adequately comprehended.<sup>39</sup>

Radcliffe Richards points to a third distinction, namely between how much and what kind of information the person asking for consent is obligated to provide on the one hand, and on the other how much someone *ideally* ought to know.<sup>40</sup> Often we would say that we ideally ought to know all contents of the information the person asking for consent ought to provide. We may also think of cases where there is in fact very little information which *can* be provided (due to scientists lacking more knowledge at the present stage), and even though we may argue that the person asking for consent ought to provide all possible information that would still be too little as compared to what we would *ideally* want to know. We could of course also argue that ideally there is no set amount of knowledge we ought to have – if we wish to ignore everything we are told, then that is perfectly fine as long as the information was provided.

To me it seems that in order for consent (*tout court*) to be valid, it is not required that attention is paid to the information is paid attention to – it is enough that the person is aware of there being information by others considered to be relevant, that she is not deceived, etc. This is very often the case in life – we know that we do not know everything, but we still think that we make valid decisions that ought to be respected. On the other hand, we may hold the normative view that when it comes to the issue of participation in research, people ought to in fact be informed and that decisions based on a disregard of such information ought not to be respected. We may in other words demand the informed consent to be informed, in order to be valid (even though, again, we may think that consent *tout court* does not have to be informed in this sense). This is not however, to argue that informed consent needs to be fully informed in a very strong sense, for instance requiring the potential research participant to study for years in order to have the right level of understanding.<sup>41</sup> And, to repeat, it remains an

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<sup>39</sup> *The Declaration of Helsinki*, § 24: “After ensuring that the potential subject has understood the information [...]”. *CIOMS guidelines*, commentary to no 4: “The investigator must then ensure that the prospective subject has adequately understood the information. [...] In some instances, the investigator may administer an oral or a written test or otherwise determine whether the information has been adequately understood”. The contents, including the suggestion of testing of understanding, is similar in *the Belmont Report*, part C. Faden and Beauchamp 1986 argue that we should focus on “substantial understanding” (that the patient/subject understands all that she considers to be material for making the decision) as opposed to “full understanding” (that the patient/subject understands all that is considered relevant by e.g. professionals), chapter 8. However, since there may be cases where what the patient/subject considers material is simply considered insufficient, by some objective standard, informed consent must also contain an “extrasubjective component” by which they mean that patients/subjects should understand all that which professionals ought to inform them about (see footnote 38), p. 309.

<sup>40</sup> Radcliffe Richards 2010, pp. 296-297. Note that Radcliffe Richards talks about “consent”, but in a way and context that makes it applicable to discussions on “informed consent”.

<sup>41</sup> It is sometimes claimed that the physician’s/researcher’s obligation to provide information has in practice gradually turned into a duty for the research participant/patient to in fact know everything about his or her health status etc. See Matti Häyry and Tuija Takala, “Genetic information, rights, and autonomy” *Theoretical Medicine* 22: 403-414, 2001, p. 407, who discuss genetic testing in the health care setting.

open question whether informed consent needs to be informed at all, as long as the information considered to be relevant is offered.

**b) Capacity to comprehend and to decide autonomously**

The second element requires that in order for a person to provide informed consent, he or she must possess the capacity to understand the relevant information, use this capacity, and make autonomous choices. The latter means, briefly, that the person must realize that he or she is the one who decides and must be able to form preferences and decide in accordance with them.<sup>42</sup> Hence, in order for informed consent to function it is necessary for the person to possess the capacity, and it must not be temporarily impeded.

Competence is typically a matter of degree. We can be more or less competent, our competence varies during life, and we may be competent in one area of decision-making but not in others.<sup>43</sup> Of relevance is that the person is considered competent vis-à-vis the decision concerning research participation. In essay 2, more is said about such qualifications.

What, then, is it to be autonomous? Autonomy is a much contested concept, given a variety of meanings although often explained simply as self-rule. Sometimes it is used as a synonym to freedom (which is unfortunate), which would mean that it is related primarily to the element of voluntariness and not to competence.<sup>44</sup> As I see it, autonomy concerns, on the one hand, issues about how our preferences, desires and beliefs are formed or shaped, and, on the other hand, whether our decisions and actions can be said to be in accordance with those preferences, desires and beliefs. What exactly this amounts to is difficult to pin down, but the preference- and decision-making process must at least not be the result of manipulation or brainwash.<sup>45</sup>

The obligation of researchers, in relation to the element of competence, is to ensure that the participants whose informed consent they seek are in fact competent. But this is not just a matter of ensuring that the participants have the capacity for autonomous decision-making – researchers must also abstain from impeding this capacity. For instance, they must not create situations where potential participants are enticed to decide in ways that are contrary to what they rationally will. This is the reason why it is

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<sup>42</sup> Faden and Beauchamp 1986 discuss the fact that the patient/subject needs to realize that she in fact makes the decision in terms of the patient/subject understanding that she authorizes, which forms part of the “Understanding” condition in their framework, pp. 300-302.

<sup>43</sup> Cf Wilkinson 2003, p. 78.

<sup>44</sup> For an explanation to why freedom or liberty should not be equated with autonomy, see inter alia Gerald Dworkin, *The Theory and Practice of Autonomy*, Cambridge University Press, Cambridge 1988, pp. 13-18.

<sup>45</sup> Cf Jon Elster, *Sour Grapes. Studies in the subversion of rationality*, Maison des Sciences de l’Homme and Cambridge University Press, Cambridge 1983. Here, Elster describes autonomy as “a mere residual, as what is left after we have eliminated the desires that have been shaped by one of the mechanisms on the short list for irrational preference-formation”, p. 24. Similar to Elster, who talks of autonomy in terms of us identifying with the processes which form our preferences (p. 21), Dworkin 1988 talks about the “procedural independence” of our motivations, p. 18 passim.

typically prohibited to present potential research participants with so called “undue inducements”. Undue inducements are rewards that are significant enough to the offerees as to “blind” them, make them underestimate risks and overestimate benefits and thus stand in the way of rational deliberation on whether to participate.<sup>46</sup> Often the option of paying participants to participate in research is dismissed by reference to it being an undue inducement, in the sense that the money offered would “blind” potential participants and make them accept to participate even though that would be contrary to what they themselves would rationally consider reasonable.<sup>47</sup> This issue is further touched upon in essay 3 in this thesis. Note however that it has been questioned whether monetary offers are in fact likely to have the effects of undue inducements but this issue will be left open here.<sup>48</sup>

The concept of undue inducements is also used by some to denote incentives that are “irresistible” to potential participants without thereby having the property of bypassing reason. The irresistibility may for instance be explained by an offer simply being very good, as in my essay 3 where I label “irresistible” monetary offers that can help people satisfy basic needs. The irresistibility then is not irrational – it is on the contrary absolutely rational. Radcliffe Richards, discussing this issue in the context of organ sales writes that “the poorer you were, the more rational it would be to risk selling a kidney, and that even if you were not competent to make that decision yourself, a benevolent paternalist might well, in principle, push you in that direction”.<sup>49</sup> Incentives that are irresistible in this sense are not a threat to participants’ capacity to decide autonomously, but may be seen as a threat to voluntariness, even though one may also argue that it is possible to voluntarily choose that which one finds irresistible (more on this in the next section).

It is also worth noting that sometimes undue inducements are mentioned just in passing, as if the meaning is clear and unequivocal, with the purpose to dismiss payment to research participants (or, for that matter, the possibility to sell one’s organs) not based on any argument that such payment would be irresistible in neither an irrational nor rational way. Instead, the underlying idea seems to be an interpretation of “undue” as something morally improper – it is simply considered inappropriate to do certain things for money. In essay 3 I discuss ideas related to such views.

The capacity to decide autonomously could also be affected in ways that are more farfetched in the context of research – through brainwash, indoctrination etc. It is hopefully not likely that researchers would engage in such activities (which in any case they ought not to), but again, it is typically also considered unethical to profit from

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<sup>46</sup> Cf *the CIOMS guidelines*, no 7 and Nuffield Council on Bioethics, *The Ethics of Research Related to Healthcare in Developing Countries*, 2002. <http://www.nuffieldbioethics.org>. Retrieved 5 October 2013, pp. 78ff.

<sup>47</sup> Cf Trisha Phillips, “Exploitation in payments to research subjects”, *Bioethics* 25: 209-219, 2011. See also essay 3 in this thesis as well as *the CIOMS guidelines*, no 7 and Nuffield Council on Bioethics, pp. 78ff.

<sup>48</sup> Phillips 2011 is among those questioning this, see pp. 6-8.

<sup>49</sup> Radcliffe Richards 2010, p. 288.

people not being autonomous due to such treatment in the past. Alan Wertheimer discusses the exploitability of persons who have “false consciousness”, namely a self-sacrificing character caused by means violating their capacity for autonomous deliberation.<sup>50</sup> In practice it seems difficult for researchers to find out whether someone’s wish to make a contribution to science is caused by such a “false consciousness” or by altruistic motives compatible with autonomous decision-making. Furthermore, as Wertheimer notes, it is an open question to what extent we ought to disregard preferences that people have but which are the results of non-autonomous processes: “Respect for a person’s autonomy sometimes requires that we respect choices that reflect values that a person presently accepts, even if we are rightly worried about the ways he or she acquired those values”.<sup>51</sup>

### **c) *Voluntariness***

Voluntariness is an even more complex concept, used in a number of different ways. The previous two elements of informed consent, information and competence, can in fact be seen as prerequisites for voluntariness. To illustrate this point: Joel Feinberg lists a lot of circumstances which may impede voluntariness including lack of sleep, lack of information, desires, etc. What Feinberg describes as “fully voluntary”, or “perfectly voluntary” is in other words very demanding and he thinks that it is in fact too strong for most purposes. Instead, he wishes to talk about what is “voluntary enough”, which he thinks varies between contexts. Others would probably refer to voluntariness at a level which Feinberg would call “not perfectly voluntary but voluntary enough” as “fully voluntary”, or simply “voluntary” if voluntariness is considered to be an either/or condition (in contrast with *inter alia* Feinberg, who sees voluntariness as a matter of degree).<sup>52</sup>

Again, some would say that the previous elements of informed consent are requirements for voluntariness. For instance, one could say that one does not act voluntarily if one is deceived, like in the Tuskegee syphilis study when the information element was not fulfilled. Similarly, it could be claimed that one does not act voluntarily if one is not capable of autonomous decision making, as in the Vipeholm dental caries experiment where participants suffered from cognitive impairments. That is one way of viewing the relations between the concepts involved. I have here chosen another conceptual framework, where the information, competence and voluntariness are on an “equal footing” as elements of informed consent. Therefore, what will be discussed below concerning problems related to voluntariness in the context of informed consent to research participation are only impediments to voluntariness

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<sup>50</sup> Wertheimer 1996, chapter 8. Wertheimer picks up this kind of idea from Elizabeth Anderson who discusses the case of surrogacy.

<sup>51</sup> Wertheimer 1996, p. 117.

<sup>52</sup> Feinberg 1986, p. 104 ff. When Feinberg writes “fully voluntary” or “perfectly voluntary”, he has in mind that which Aristotle calls “deliberately chosen”, p. 104.

caused by different kinds of coercion (and not lack of voluntariness due to deception or incompetence).<sup>53</sup>

Coercion in the context of research participation can in broad terms mean three different things. First, it can mean that the participant is *forced*, by physical means, to be involved. This is the view on someone not acting voluntarily favoured by Aristotle, who exemplifies lack of voluntariness by someone being “carried by the wind”.<sup>54</sup> In such cases the will of the participant is not involved at all, instead others make the decisions and perform the actions leading to the person ending up as a research subject. A prime example is research carried out on prisoners in concentration camps during World War II.

Secondly, coercion can mean that the participant is presented with a *threat* so that the only reasonable thing is to accept to participate.<sup>55</sup> In such cases, the participant’s will is indeed involved – she is “made to will to participate”. An example could be if the researcher informs the would-be-participant that if she does not participate, she will be denied continued access to regular health care. Of course, in order for a threat to qualify as coercive, it needs to be credible and reasonable to shun. “Silly threats” are not coercive.<sup>56</sup>

Thirdly, coercion can mean that the potential participant is *offered* a reward which it would be unreasonable for her to decline, conditional on her taking part in the project. For example, if she is poor she can be promised a significant amount of money or, if she is a prisoner, release from prison.<sup>57</sup> Also in this type of cases, the person is “made to will to participate” but through means of offers as opposed to threats.

It is the third meaning of coercion, i.e. so called coercive offers, that is of relevance in essay 3 in this thesis.<sup>58</sup> Not everyone agrees that offers can indeed be coercive (the most common view does, on the contrary, seem to be that only threats can be

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<sup>53</sup> Faden and Beauchamp 1986 talk instead of “non-control”.

<sup>54</sup> Aristotle *Nicomachean Ethics* in Michael L. Morgan, *Classics of Moral and Political Theory* (3<sup>rd</sup> ed.), Hackett Publishing Company, Indianapolis/Cambridge 2001, book III:1.

<sup>55</sup> Cf Robert Nozick, “Coercion”, pp. 440-472 in Sidney Morgenbesser, Patrick Suppes and Morton White (eds.), *Philosophy, Science and Method. Essays in Honor of Ernest Nagel*, St. Martin’s Press, New York 1969. Nozick argues that only threats can constitute coercion, hence excluding outright force.

<sup>56</sup> “If you don’t give me your money I will destroy the universe” is not a coercive threat, since it is not credible. Under most circumstances, “if you don’t give me your money I will go to the hairdresser every sixth week instead of every fifth” is not a coercive threat either.

<sup>57</sup> Proponents of the view that (also) offers can be coercive include David Zimmerman, “Coercive Wage Offers”, *Philosophy & Public Affairs* 10(2):121-145, Spring 1981; John Kleinig, “The Ethics of Consent” in *Canadian Journal of Philosophy*, Supplementary volume VIII, 1982, pp. 91-118 in Kai Nielsen and Steven C. Patten (eds.), *New Essays in Ethics and Public Policy*, Canadian Association for publishing in philosophy, Guelph, Ontario 1982; Robert Stevens, “Coercive offers”, *Australasian Journal of Philosophy* 66(1):83-95, March 1988; and Joel Feinberg, *Harm to self*, Oxford University Press, New York 1986.

<sup>58</sup> Coercive offers are sometimes called “thoffers”, e.g. by Kleinig 1982 while others, e.g. Stevens 1988 makes a distinction between coercive offers and “thoffers” where the basic difference is that coercive offers are exactly offers while thoffers are proposals that contain both an offer and a threat.



coercive).<sup>59</sup> Of those who do believe that offers can be coercive, some argue that they can only be so if the coercer caused the disparities in power or resources that make the coercee vulnerable to coercion, or if the coercer prevents the coercee from improving her situation and thereby avoid being vulnerable to coercion.<sup>60</sup> Others argue that offers can be coercive regardless of the origin of the situation in which the coercee is facing the offer.<sup>61</sup> The position needed in order to make the argument in essay 3 is the latter of these views.

It is the view that offers may be coercive (along with the view that they may constitute undue inducements), that underlies the common policy that participants in research are not to be paid. Typically, however, it is allowed to give participants small amounts in order to compensate not only for travel expenses and loss of income, but also for pain and inconvenience.<sup>62</sup> Participation by those who are so poor that even this compensation is unreasonable to decline would not be fully voluntary in the sense just described.<sup>63</sup> In essay 3 I rely on the view that offers may be coercive, but I only consider offers coercive that are in themselves unfair in the sense that they do not compensate enough for the sacrifices made by the participants (they are, in other words, disproportionate or imbalanced). A way to defend that choice is to argue that researchers have in fact an obligation to offer fair deals, but not to help potential participants by giving them money unconditionally.<sup>64</sup> The conclusion I reach is that

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<sup>59</sup> See for example Alan Wertheimer, *Coercion*, Princeton University Press, Princeton 1987 and Alan Wertheimer and F. G. Miller, "Payment for research participation: a coercive offer?", *Journal of Medical Ethics*, 34: 389-392, 2008.

<sup>60</sup> Zimmerman 1981.

<sup>61</sup> Joan McGregor, "Bargaining Advantages and Coercion in the Market", *Philosophy Research Archives* 14: 23-50, 1989. This view is also shared by Daniel Lyons, "Welcome Threats and Coercive Offers", *Philosophy* 50 (194): 425-436, October 1975. Lyons adds that for an offer to be coercive, the offer must include something that the coercer ought to, or normally would, offer the coercee unconditionally.

<sup>62</sup> It may be noted that in certain experiments where people make a lot of money, this is part of the experiment as such and does not constitute compensation for participation. In behavioral economics, decision and game theory such research takes place.

<sup>63</sup> Some authors (e.g. R. R. Kishore, "Biomedical Research and Mining of the Poor: The Need for their Exclusion", *Science and Engineering Ethics* 12(1): 175-183, 2006.) argue that because of this vulnerability of poor people, they should not be allowed to participate in research studies. Others (e.g. Joseph P. Newhouse, "Comments by Joseph P. Newhouse" [on Peter G. Brown "Informed Consent in Social Experimentation: Some Cautionary Notes"], pp. 101-104 in Alice Rivlin and P. Michael Timpone, *Ethical and Legal Issues of Social Experimentation*, The Brookings Institution, Washington D.C. 1975.) claim instead that the problem could be solved by paying poor people less than rich for their participation, in order to avoid the possibility of exploitation. I think that neither of these solutions proves satisfactory, but the issue is of crucial importance in particular for research carried out in developing countries, and therefore deserves thorough analysis that cannot fit here. Worth mentioning in this context is also that in the United States there is a large group of people earning their living as experimental subjects in the pharmaceutical industry. This is problematic since they work in many ways like employees, but are less paid, get no employment security etc. This issue is discussed in Trudo Lemmens and Carl Elliott, "Justice for the Professional Guinea Pig", *American Journal of Bioethics* 1(2): 51-53, Spring 2001, and Carl Elliott, "Guinea-pigging" in *The New Yorker*, pp. 36-41, January 7, 2008.

<sup>64</sup> This would in other words be a weak version of Wertheimer and Miller 2008 who, similar to Zimmerman 1981, argue that offers are only coercive if the coercer has an obligation to help unconditionally.

instead of offering tiny rewards for participation, we ought to offer either no rewards at all or large ones.

The issue of coercive offers highlights the question of whether consent requires there to be more than one acceptable option available.<sup>65</sup> If an offer is fair, and the alternative is deep poverty, then the choice would not be voluntary given such a view. However, we seem to consider choices made between a fair and an unfair option voluntary in many other contexts. That is also what I propose in essay 3, namely that offers that are in themselves fair are not coercive even if the only available alternative is deep poverty. Only offers that are unfair may be coercive, given the lack of acceptable alternatives.

So far the discussion concerning paying for research participation has concerned whether payment can invalidate informed consent and hence make the recruitment of participants unethical. There is another way of conceiving of this problem, which may cater better to our intuitions about the central concepts of voluntariness and consent: we may simply argue that although offers cannot constitute coercion, hence cannot impede informed consent (unless it constitutes undue inducement as discussed above), it can make informed consent *insufficient* for allowing the research project proposed. In other words, we may claim that if monetary compensation is involved and potential participants are in need of money, this means that we should not allow it even if they provide their informed consent. The reason for such an argument would typically be that such participants risk being exploited, in combination with a wish to avoid exploitation. We will therefore now turn to the issue of exploitation.

#### **4. Some remarks on exploitation**

Exploitation may mean a number of different things, and can broadly be described as one person's use of another.<sup>66</sup> Not all kinds of use of another person amount to exploitation, however – the use has to be, in one way or another, unfair or inappropriate. Typically such unfairness is described in relation to (a) the distribution of burdens and benefits received by the parties involved, and (b) the method by which this distribution came about. The distribution (a) is commonly considered unfair when the exploited party receives a disproportionately small share of the benefits or a disproportionately large share of the burdens.<sup>67</sup> The method (b) is commonly considered unfair when the exploiter takes inappropriate advantage of some feature of the exploitee.

As discussed in essay 4, some think that we only need to look at the methods by which an interaction comes about in order to judge whether there is exploitation, while

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<sup>65</sup> Cf the discussion in essay 2 concerning the need for a possibility to stay out of research.

<sup>66</sup> For a useful review and discussion on ideas concerning exploitation, see Allen W. Wood, "Exploitation", *Social Philosophy and Policy* 12(2):136-158, 1995.

<sup>67</sup> In essay 4 the unfair distribution element is described as, in an interaction between two individuals A and B, the "outcome is disproportional, in the sense that A receives a larger part of the total benefit accruing to A and B than what is fair", p. 3.

others also refer to the characteristics of the resulting distribution.<sup>68</sup> I see no need to choose among those two approaches. In this thesis, however, I primarily rely on a view closer to the latter.<sup>69</sup>

In general, but also in the research context, exploitation can be of a number of kinds. These kinds may be separated either based on the distributional outcome, or based on what “methods” that gave rise to the interaction deemed exploitative.<sup>70</sup>

### **a) Unfair distribution**

The first basis for distinguishing different kinds of exploitation in the research context is the nature of the distribution of burdens and benefits in the interaction at hand. Again, some do not find it necessary to talk of distribution, but for the purposes of this thesis it seems to be a good way to clarify the varieties of exploitation involved. Below I describe four kinds of alleged exploitation based on the burdens and benefits faced by the exploitee. In all of the categories the exploiter benefits.<sup>71</sup>

In the first kind, the exploitee is neither burdened (does not sacrifice anything) nor benefits from participating in research. An example could be when a researcher uses material about a person which the person has made available on his or her blog. The fact that the material is used by the researcher does not incur any extra costs on the blogging research subject, but it brings benefits to the researcher. Feinberg calls such cases “harmless parasitism”, and cases of this nature often involve free-riding.<sup>72</sup> Not all would consider such actions exploitative, however, since they consider the potential exploitee facing a loss to be a necessary condition for exploitation. This is also what I argue in essay 4. One way to deal with cases of this kind is to change the way we look at burdens. Instead of comparing the present situation with a situation where the interaction did not take place (in the case of the blogger, her situation would be the same had the researcher used her material or not) we may compare with a situation of

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<sup>68</sup> The former include Tea Logar, “Exploitation as Wrongful Use: Beyond Taking Advantage of Vulnerabilities”, *Acta Anal* 25: 329-346, 2010 and Robert E. Goodin, *Reasons for welfare. The Political Theory of the Welfare State*, Princeton University Press, Princeton, New Jersey 1988, chapter 5; the latter include Wertheimer 1996 and David Miller, “Exploitation in the market”, pp. 149-165 in Andrew Reeve (ed.), *Modern Theories of Exploitation*, SAGE Publications, Bristol 1987.

<sup>69</sup> This is obvious in essay 3. In essay 4 I discuss both versions and note that both of them work in the context of gift-giving.

<sup>70</sup> I here ignore that exploitation can be used also in a purely *descriptive* way, meaning simply “advantageous use”, cf Richard Arneson, “Exploitation”, pp. 350-353 in *Encyclopedia of Ethics (Volume I)*, Garland Publishing Inc, New York and London 1992, p. 350. I refer instead to the *moral* meanings of exploitation.

<sup>71</sup> Most writers considers it to be a necessary condition for exploitation that the exploiter benefits, e.g. Joel Feinberg, *Harmless Wrongdoing*, Oxford University Press, New York 1988, p. 192

<sup>72</sup> Feinberg 1988, p. 14. Feinberg discusses a well-known case where the exploiter is a driver who uses another car’s taillights for guidance in a dense fog. Cases of this kind constitute exploitation of class 1 in the framework presented in Robert Mayer, “What’s wrong with exploitation?”, *Journal of Applied Philosophy* 24(2):137-150, 2007.

fairness.<sup>73</sup> For instance, we could say in many cases of free-riding that those paying for their tickets are indeed burdened by the failure of free-riders to pay their share. By redefining burden in this way, we may move some cases from the present category to the next. Returning to the case of the blogger, it should be noted that I think of the blogger in the example as informed and capable of making decisions. If she was instead deceived, failed to understand the implications of putting her life at display in her blog (as do arguably many teenagers), or simply lacked the ability to make autonomous enough decisions, she may of course be exploited due to these limitations, even though we may consider the distribution as such as unproblematic had she not been taken advantage of in *these* ways.

In the second kind of exploitation the participant is burdened by participating without receiving any benefit at all. There are two main reasons why people participate in research yet receive no benefit: either (1) because they wish to “give a gift to science”, or (2) because they are deceived or coerced (through threats or force) into participation. Concerning (1), it seems reasonable to argue that those participating as an informed, genuine and voluntary gift are not exploited when they do not receive anything in return (that is instead the whole idea of gift-giving), since the second condition for exploitation, “unfair method” is not fulfilled. We typically consider instances of someone giving a gift as not fitting the description of being unfairly taken advantage of.<sup>74</sup> This is a common view, valid for most cases of gift-giving situations. I will, however, challenge it below – not by arguing that “gift-givers” ought to be compensated, but by referring back to the “methods” used in order to bring about a gift-transaction. Concerning (2), it seems reasonable to argue that those participating because they are deceived or coerced are exploited. However, awarding such research participants fair benefits does not necessarily imply that they are no longer wronged – they would still be victims of deceit and coercion.<sup>75</sup>

In the third kind of exploitation in research participation the subject is burdened by research participation and receives some benefit, but not to a sufficient extent for it to be fair.<sup>76</sup> In these cases, the subject does indeed benefit, but is not compensated enough. A typical case could be when research participants make significant sacrifices in return for small amounts of monetary rewards.<sup>77</sup> This kind of exploitation is relevant

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<sup>73</sup> In the literature, this would typically be framed as using not a counterfactual, but a fairness baseline. Cf Wertheimer 1996, p. 31.

<sup>74</sup> There could, however, be cases where also such “gift-givers” are exploited, namely if they would prefer participating for a benefit to participating without a benefit, but prefer participating without a benefit to not participating at all – because they find the research objectives important. Wertheimer 1996 discusses cases of this kind on p. 249.

<sup>75</sup> Wertheimer 1996, p. 31, discusses Feinberg’s fog-driving case (see footnote 77 above) in a way that would fit here. The driver is “forced” in the sense that he cannot avoid being followed, and according to Wertheimer we may argue that he indeed ought to receive some benefit, perhaps in terms of sharing the burden of driving first.

<sup>76</sup> It is in other words an instance of “mutually advantageous exploitation”, cf Wertheimer 1996, p. 14. In Mayer’s 2007 framework, this constitutes class 2 exploitation.

<sup>77</sup> The issue of gift-giving could be brought up also here, as it is possible to argue that someone may wish to give a gift to science, but finds the sacrifice involved in participating too large. Therefore, the “giver” accepts some benefits in order to compensate for the share of the sacrifice which is too much. Offering

for cases when research participation is considered compensable, which in broad terms means that there is such a thing as a fair price for the sacrifices involved. If the compensation given is too small the exchange is exploitative. In essay 3 I talk of compensation in the form of money, but compensation may also be composed of other goods and services such as health care access.<sup>78</sup>

Before moving on to the next category, it deserves mentioning that the question of what constitutes a fair reward can be approached in different ways. Liberal authors such as David Miller talk of transactions below or above equilibrium prices.<sup>79</sup> Wertheimer talks of reservation prices.<sup>80</sup> Another view, emanating from the Marxist approach to exploitation, is that a fair reward is a share of the surplus value generated by the exchange that is proportional to the contributions being made.<sup>81</sup> Compensation is not a matter restricted to market transactions, but compensation in such transactions is perhaps the easiest to conceptualize. Exactly how to determine what is a fair reward is beyond the scope of the present investigation. Here, it is enough to say that it is related to the efforts (i.e. the sacrifice) made by the research participant, rather than to the value of the outcomes of research.

In the fourth kind of exploitation in research participation the participant is burdened by research participation and receives some benefit, but of a wrong kind. This means that although the participant does receive some reward, this does not in fact compensate for the sacrifices involved in research participation. Robert Mayer explains this as the compensation not being authentic.<sup>82</sup> This version of exploitation can be present in cases where research participation is considered uncompensable in the sense that even if money is offered, the participant is not fairly compensated.<sup>83</sup> For such sacrifices, there is no such thing as a right price. Some do not acknowledge any such uncompensability. For example Rob Lawlor assumes in the context of organ sales that there are no cases where, as he puts it, the “details don’t matter”.<sup>84</sup> Michael J. Sandel, on the other hand, is open to some things being uncompensable, things the value of which would be corrupted if exchanged or done for money.<sup>85</sup> I see no need to take a stand on whether there are sacrifices which are to be classified as

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such a research participant only that small reward does not constitute exploitation, as the participant ought not to receive a larger share.

<sup>78</sup> For a useful exploration of compensation, see Robert Goodin, “Theories of Compensation”, *Oxford Journal of Legal Studies* 9(1):56-75, 1989.

<sup>79</sup> Miller 1987.

<sup>80</sup> Wertheimer 1996, chapter 7.

<sup>81</sup> E.g. Justin Schwartz, “What’s wrong with exploitation?”, *Noûs* 29(2): 158-188, June 1995. Typically the capitalist’s contribution is considered nil, implying that the worker ought to receive all surplus value.

<sup>82</sup> Mayer 2007. In Mayer’s framework, exploitation involving unauthentic compensation belongs to class 3. Examples he considers to be of this kind include prostitution. Goodin 1989 denies there being uncompensable cases, but argues that for things that are irreplaceable only compensation of an inadequate kind is possible. Hence, I take that Mayer’s “unauthentic compensation” and Goodin’s “inadequate compensation” are relevantly similar.

<sup>83</sup> Uncompensability in this sense is discussed in essay 3.

<sup>84</sup> Rob Lawlor, “Organ sales: exploitative at any price?”, *Bioethics*, doi: 10.1111/bioe.12000, 2012.

<sup>85</sup> Michael J. Sandel, *What money can’t buy. The moral limits of markets*, Farrar, Straus and Giroux, New York 2012.

incompensable – or conversely, whether there are cases which are in fact compensable. It is sufficient to note that both views seem to exist among those discussing the matter.

Hence, the first and second kinds of exploitation are of relevance for essay 4 where I discuss whether the exploitee has to be burdened (and conclude that she does) in order for there to be exploitation, and the possibility of exploitation even when the interaction is an instance of gift-giving. The third and fourth kinds of exploitation are of relevance for the issue of paying for research participation, discussed in essay 3.

The kinds of exploitation just described are based on different ways in which the distribution of burdens and benefits is unfair. So, if the first kind is indeed to be viewed as exploitation, we must either consider the distribution to be unfair even when the exploitee is not burdened – which I among many am reluctant to do – or we must judge there to be a burden involved after all. In addition to the distribution being unfair, it is also necessary that the method by which this distribution comes about is in itself considered to be unfair or inappropriate in a significant way. Otherwise there is no exploitation. Indeed, as mentioned above, some only focus on this criterion of exploitation, leaving aside that of distribution. As previously noted, exploitation of gift-giving seems not to be possible, since that would require us to consider it unfair when someone who is informed voluntarily gives a gift to someone else. That seems to go contrary to how most would consider the giving of gifts. In essay 4, however, I challenge this view, attempting to show when instances of gift-giving are indeed unfair in a way amounting to exploitation. In order to explain how, we need to elucidate the notion of unfair methods some more, and it is to this task we will now turn.

### ***b) Unfair method***

To begin with, it should be clarified that while exploitation involves someone taking unfair advantage of someone else, it does not require the exploiter having created the circumstances in which it is possible for her to take advantage of the exploitee.<sup>86</sup> Mayer writes that extortionists may be accused of exploiting their victims, but extortion is in fact a combination of two wrongs: the creation of the disadvantaged position of the victim and the taking advantage of that situation. Exploitation is the latter of those wrongs.<sup>87</sup> Similarly, John R. S. Wilson who focuses on exploitation in personal relationships distinguishes between entrapment and exploitation, where entrapment occurs when the exploiter causes the exploitee to commit emotionally to the exploiter by pretending to love or care for her – in other words to make the exploitee emotionally vulnerable. Exploitation then, is the unfair using of a vulnerability, irrespective of its causal history.<sup>88</sup> Also Feinberg puts emphasis on the

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<sup>86</sup> See e.g. Jeffrie G. Murphy, "Consent, coercion and hard choices", *Virginia Law Review* 67(1):79-95, 1981. Murphy writes that "it is unfair to exploit the vulnerabilities of a person even when we are blameless in the creation of those vulnerabilities" (p. 88).

<sup>87</sup> Mayer 2007, p. 143.

<sup>88</sup> John R. S. Wilson, "In One Another's Power", *Ethics* 88(4): 299-315, 1978, p. 300.

fact that the exploiter does not (necessarily) create the vulnerabilities which she takes unfair advantage of. Instead, “[t]he skilled exploiter plays on the other’s character in the way a pianist ‘plays on’ a piano”, and may answer any complaints by the exploitee by “I simply used you as you are”.<sup>89</sup>

What, then, can be taken unfair advantage of in cases of exploitation? There are in fact a number of suggestions commonly put forward, the main of which may be described in the following way:

- i. Lack of bargaining strength
- ii. Lack of information
- iii. Lack of competence
- iv. Dispositions (character traits, feelings, commitments etc.)

Lack of bargaining strength (i) means that a person strongly wants something which is offered by the potential exploiter, due to being poor or in need of other kinds or simply because she has strong desires for it, and lacks better ways of obtaining it. An example could be the stranded motorist described by Wertheimer, who is stuck with his car on a highway in a snowstorm when a person turns up offering to help for a fee.<sup>90</sup> The motorist needs the help in order to get going and possibly even to survive and has no alternative way of solving the problem. If the person offering help demands an unreasonably high price for his services (say, the equivalent of a month’s salary or a price we would in other contexts laugh at as “ridiculous”), he would exploit the driver.<sup>91</sup>

Lack of information (ii) means that the potential exploiter knows more about relevant aspects of the interaction than does the potential exploitee. This unequal access to information could be caused by the active deceit by the exploiter, but as clarified above, need not be. An example could be the old lady described by Miller who is unaware of the market value of an old painting she owns.<sup>92</sup> If an antiquity trader is aware of the value but offers a much lower price which the ignorant lady finds acceptable, he would exploit her.<sup>93</sup>

Lack of competence (iii) means that the potential exploiter makes use of the potential exploitee’s inability to grasp or reason rationally concerning the issue at hand. For instance, think of an adult selling lottery tickets to a child who is unable to understand the probability of winning the desired prize. Or think of undue inducements as explained in section 3 above. Inducements are called undue when they “blind” the

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<sup>89</sup> Feinberg 1988, p. 179.

<sup>90</sup> Wertheimer 1996, p. 208.

<sup>91</sup> Hence, the price must be unfair in order for there to be exploitation. As stated above, it is beyond the scope of this introduction to determine what an unfair price is but I think that we often agree on what is unfair.

<sup>92</sup> Miller 1987 pp. 158-159.

<sup>93</sup> Also Miller 1987 considers this to be exploitation, and adds: “for asymmetrical information to lead to exploitation, it has to be rooted in the circumstances of the two parties. *A* has to be better placed than *B* either because he has skills and capacities which allow him to obtain information that *B* can not obtain, or because he has somehow been provided with information that is not available to the other”, p. 159.

recipient who then overestimates the benefits involved and/or underestimates the costs.<sup>94</sup> When someone makes use of another's incompetence in evaluating an offer which is in itself unfair, there is exploitation.

The last category, dispositions (iv), means that the potential exploitee is disposed to behave and react in a certain way due to her character traits, feelings or commitments. This category is in some ways essentially different from the previous categories, in other ways there are possible overlaps between them. There is a possible overlap with the lack of bargaining power in category (i), for instance in cases where the reason why someone strongly wants something is greed, which is a character trait. Some, however, would not accept lack of bargaining power due to greed as included in (i), with the argument that only objective circumstances such as poverty are valid underlying reasons for exploitation. Furthermore, there is a possible overlap with lack of competence in (iii), if such lack is described as someone's being prone to rash decision making, for example. If lack of competence is defined in a very strict way, by reference to medically established cognitive impairments of a certain degree, then perhaps rashness is not to be included. If instead a more general description of lack of competence is adopted, then rashness may be included. Hence, there may be overlaps between category (iv) and the previous categories. If on the other hand categories (i) – (iii) are defined in ways that exclude the just mentioned overlaps, it can instead be argued that category (d) is essentially different from the others. While (i) – (iii) concern the potential exploitee's situation (or disabilities she is burdened with), (iv) concerns what kind of character she has, her emotional attachments or moral convictions. Often these dispositions are called "vulnerabilities" or "weaknesses".<sup>95</sup> Such labels are suitable in the sense that if a disposition makes one possible to exploit, then this makes one vulnerable and weak. On the other hand, these labels may seem ill-fitted in the sense that they include traits that we tend to call virtues and strengths, such as generosity, loyalty, perseverance and a loving and caring character, to mention a few. Kleinig describes the variety of exploitable traits the following way: "A sponger may exploit another's generosity, children may exploit the love of their parents, a man may exploit the insecurity of a woman, advertizing firms may exploit the gullibility of the public and politicians may exploit the fears of the citizenry".<sup>96</sup>

As stated above, there are various views on exploitation and authors define what can be taken advantage of in different ways. Two main strands can be discerned among different writers on exploitation: those who include dispositions (iv) among what can be exploited, and those who don't.<sup>97</sup> The mainstream opinion about exploitation seems to be the latter. Essay 3 takes that more narrow perspective on exploitation, given its focus on the exploitation of people in need (and disregard for exploitation of giving). The former, broader, view is the foundation on which essay 4, with its focus on

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<sup>94</sup> As stated elsewhere, there is disagreement concerning the actual existence of undue inducements. Cf Philips 2011, pp. 7-8 and p. 6 n. 33.

<sup>95</sup> E.g. Logar 2010, Goodin 1988 and Wood 1995 (in particular pp. 143 ff).

<sup>96</sup> Kleinig 1982, p. 110.

<sup>97</sup> The former view is shared by Kleinig 1982, Feinberg 1988, Wilson 1978 and Logar 2010.



the exploitation of people's disposition to give, is based. This perspective is described by Robert E. Goodin the following way:

“There are various things about people that we might exploit. We might exploit their strong backs or weak minds. We might exploit their fears, ignorance, superstitions, gullibility, or naiveté. We might exploit their generosity, loyalty or trust. We might exploit their bad luck, their joblessness, homelessness or illness. All those things, however, are merely attributes of people and their circumstances. Exploiting a person's attributes is not the same as exploiting a person. [...] We infer whole-person exploitation from the fact that certain of the person's attributes are being used if they are being used unfairly”.<sup>98</sup>

Goodin emphasizes that there is no exploitation unless a person's disposition or situation is taken advantage of in a way that is unfair. What constitutes such unfairness therefore becomes crucial. Typically, those holding the view excluding (iv) refer back to the distributional outcome of the interaction; if the outcome is unfair (as discussed above) and the method used involves the taking of advantage of any of the elements (i) to (iii), then there is exploitation. Those holding the view that also (iv) may be exploited focus less on distribution. Very often the interactions they discuss are not market transactions but the interplay in personal relationships. What constitutes unfair advantage-taking amounting to exploitation then? Goodin's answer is the following: “The generic unfairness associated with interpersonal exploitation lies, I suggest, in *playing for advantage* in situations where it is *inappropriate* to do so.”<sup>99</sup> Goodin further acknowledges that what is inappropriate depends on the “nature of the game”.<sup>100</sup> Hence, what is inappropriate varies between contexts. In essay 4 of this thesis I attempt to formulate what unfair advantage-taking of someone's disposition to give gifts would amount to. More specifically, I try to find criteria for the inappropriateness necessary for there to be exploitation, in order not to make all instances of gift-giving instances of exploitation. Apart from this, this matter will not be discussed any further here.

### **c) *What is wrong with exploitation***

Given all these different kinds of exploitation – involving harm to the exploitee or being mutually beneficial, involving too little compensation or compensation of an inadequate kind, involving taking advantage of someone's poverty or virtuous character, etc. – is exploitation one thing or many? My tentative suggestion is that, despite the differences, there is a common core of badness in all cases of exploitation even though it is not self-evident how that core should be defined. Perhaps the basic

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<sup>98</sup> Goodin 1988, p. 130.

<sup>99</sup> Goodin 1988, p. 144. Goodin then lists four kinds of conditions that make it inappropriate to play for advantage, which resemble the list (a)-(d) above, namely: 1. When playing against others who have renounced to play for advantage themselves; 2. When playing against others who are unfit or unable to play for advantage; 3. When the opponent is much weaker; 4. When your relative advantage derives from others' grave misfortunes, pp. 145-147.

<sup>100</sup> Goodin 1988, p. 143.

idea could be captured by phrases such as “the use of someone in an unfair way”, “the wrongful advantage-taking of someone” or “the treating of someone (too much) as a means to an end”. However, my aim in this thesis is not to present a general and unifying theory of exploitation, but merely to investigate instances of (alleged) exploitation separately. Furthermore, even though I think that there may be some common core in all instances of exploitation, that is not to say that all instances of exploitation are to be viewed the same way. Some kinds and instances of exploitation are undoubtedly worse than others. For instance, harmful exploitation is typically worse than exploitation which is mutually beneficial. Moreover, we are arguably more blameworthy if we take advantage of someone’s lack of basic necessities than if we take advantage of someone’s greed. In other words – the moral weight, or degree of badness, of exploitation varies.<sup>101</sup>

One element that plausibly affects the moral weight of exploitation is to what extent the exploiter is aware of crucial features of the interaction at hand. Think of an example where the exploiter in fact does not know that the person with whom he interacts is poor – he simply believes that the person genuinely likes to clean bathrooms for a low salary.<sup>102</sup> Or think of an example where the exploiter does not know that his counterpart is unable to calculate. Or, in the case of gift-giving as discussed in essay 4, the exploiter does not know that the giver takes her religion’s command to help others in need seriously and is therefore unable to deny help to a person who has spent all his money on poker instead of food – he simply thinks the giver is happy to find someone with whom to share her fortune. In all these examples, the exploiter could protest “I did not know!” to any blame expressed concerning his behavior. Would that be a satisfying excuse, exempting him from having exploited in a blameworthy way? I think it would, under the condition that it was reasonable for the exploiter not to question the impression he had and upon which he acted. If not, the attempted excuse would not free him from blame. Another way to judge the issue of exploiter knowledge, is to say that the exploiter knowing is in fact a necessary condition not for exploitation being blameworthy but for there being exploitation at all. However, whether that is a reasonable view is not necessary to settle here.

Another matter thought to affect the moral weight of exploitation, is what alternative actions were available to the exploiter. What if he was unable to do better, unable to offer a deal closer to what would be fair? Also in this regard, it could be questioned whether there is in fact exploitation if the exploiter did not have the means to act in a fair way. To me, however, it seems that there is exploitation also in such cases since the exploiter in fact takes unfair advantage, but exploitation which is less blameworthy than if the exploiter had had the opportunity to do better. An example of this kind could be the cases of exploitation discussed in essay 3: that of research subjects who need money and participate in exchange for rewards that are too small. An oft-

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<sup>101</sup> Wertheimer 1996 uses the notion “moral weight” of exploitation, and describes it as “the intensity of its wrongness – however that is measured”, p. 28.

<sup>102</sup> Some would frame this in terms of voluntariness, claiming that the exploiter thought that the exploitee’s choice was more voluntary than it actually was. See the discussion on voluntariness in section 3c above.

mentioned argument is that it is in fact impossible for researchers to offer larger rewards – there simply is not enough money involved in research projects in order to pay participants more. In essay 3 that argument is dismissed, but given that it is in fact impossible for researchers to pay more, I am inclined to say they are then less blameworthy than if they have the possibility to make offers that are fair.

When judging the degree of blameworthiness of researchers just touched upon, other issues are also of relevance: the value of the benefits the exploitative exchanges bring to the participants and the urgency of the task which the exchange renders possible. The latter of these means that it seems to be less blameworthy of researchers – irrespective of them being more or less blameworthy based on the possibility they had to act otherwise – if the aim which they seek is laudable than if it is not. In other words, it seems to be less blameworthy of researchers to exploit participants' need for money if they attempt to develop life-saving treatment for a fatal disease than if their goal is to test a new pill for the whitening of teeth – just like stealing in order to feed a hungry child is arguably less blameworthy than stealing in order to be able to show off with a fancy necklace.

This leads us to the moral force of exploitation, i.e. what (if anything) we ought to do in order to avoid it.<sup>103</sup> Like the moral weight varies between kinds of exploitation, so does the moral force. Most obvious is the distinction between exploitation that is harmful to the exploitee and exploitation from which the exploitee benefits (i.e. what Wertheimer calls “mutually advantageous exploitation”<sup>104</sup>). While it seems reasonable to aim for avoiding, even legally prohibiting in contexts where that would be feasible, the former, it is not obviously so concerning the latter. If we would argue for the prohibition of also mutually advantageous exploitation - transactions that are entered into voluntarily by both parties and from which both parties benefit - we need to say something about why such circumscribing of personal liberty is warranted. Wertheimer points to two kinds of interventions aimed at avoiding also mutually advantageous exploitation: perfectionist and strategic.<sup>105</sup> Perfectionist interventions are based on a moralistic view that it is simply wrong to take advantage of someone in a way that amounts to exploitation, because it somehow harms the character of the exploiter and/or the exploitee. Furthermore, in order to defend perfectionist interventions, we must consider such harm to outweigh the benefits of exploitative transactions.<sup>106</sup> Strategic interventions are justified by reference to the consequences for some party we wish to protect (which is not to say that consequentialism would support such interventions, as allowing exploitation may maximize overall utility). The party to be protected is of course typically the exploitee herself. We may stop transactions from which the exploitee benefits, based on concerns for her, because we think that such a policy would render another transaction which is less exploitative or

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<sup>103</sup> Also the notion of “moral force” is borrowed from Wertheimer 1996, pp. 28 ff. and chapter 9.

<sup>104</sup> Wertheimer 1996.

<sup>105</sup> Wertheimer 1996, p. 300.

<sup>106</sup> Wertheimer 1996, pp. 305-309. Note that Wertheimer ultimately dismisses the validity of arguments in favour of perfectionist interventions.

even not exploitative at all possible.<sup>107</sup> Another kind of justification for banning transactions from which the exploitee benefits is not based on the argument that the exploitee herself would necessarily have anything to gain from it, but that others *like her* will. This kind of argument could be invoked in the context of research participation, where we could say that we wish to avoid research participants being exploited even when they themselves benefit from such an exploitative policy, because disallowing that policy will improve the bargaining position for potential research participants as a group – perhaps at the cost of denying some otherwise recruited subjects the opportunity to get some income.

In many cases of exploitation, not the least in close relationships, legal prohibitions would typically be inefficient even if we were to wish for such interventions. Nevertheless, we should reason about whether exploitation in such contexts ought to be avoided or is under some circumstances acceptable. If so, based on what kinds of considerations?

We can conclude that even if we agree on how to define exploitation, there is still a lot of room for discussing how we are to judge it when it occurs. We need to balance many competing interests and values – not only the liberty, welfare and dignity of the potential exploitees but also the interests of others. We also need to make assumptions about the characteristics and consequences of the alternatives to exploitative interaction.

## 5. Looking ahead

Most questions in ethics are entangled with other questions, in a web of interrelated concepts and morally relevant aspects. When (if) we manage to sort out some part of this web, we have most often done so by pulling out some threads while pushing some hard resolved knots aside (and, if we are unlucky, even created some new ones...).

In this manner, a number of concepts and questions have been pushed aside and left unproblematized in the essays comprising this thesis. Two such topics that I find particularly interesting to explore further are the notion of a “gift” (taken simply at face value in essay 4) and ideas surrounding compensability and fair price (invoked without much analysis in essay 3, and also linked to “substitutes” which are categorized but in essence left unquestioned in essay 2).

The concept of a gift is something we frequently use and typically believe that we understand. For starters, a gift is supposed to be unreciprocated, it is a one-sided transaction. Yet we often give gifts in systematic ways, with the expectation to indeed be given something (namely, a gift!) in return. This is the practice when it comes to birthdays and holidays such as Christmas. In other contexts we may be required to give gifts, if not formally and explicitly, at least informally and implicitly. For instance, in order to be accepted in a social group we may need to give the host of a party some flowers or a bottle of wine. This kind of giving may be institutionalized to different

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<sup>107</sup> Wertheimer (1996), pp. 300-305.

degrees, and varies in content between communities and cultures.<sup>108</sup> When we are expected to give, and expect our giving to be reciprocated – are we then really talking about gifts? Similarly, we may ask whether gifts that are given in order for the giver to secure some benefit are to be considered as real gifts. Is perhaps an altruistic motivation necessary in genuine gift-giving? The answers to questions such as these are important in contexts where arguments are based on claims that gifts are different from other exchanges, that the inherent goodness involved in gifts warrants regulations as to discourage marketization of things that have previously, could or should instead be given.<sup>109</sup> Furthermore, as argued in essay 4, certain conceptions of gifts tend to lead to the view that gift-giving cannot be misused, abused or – exploited. To scrutinize the nature of gifts would therefore help us judge what is to be considered blameworthy in different situations of human interaction.

What constitutes a fair price is a question that has received philosophical attention at least since the ancient Greeks. How a good or service can be compensated, or substituted, or replaced, is one important aspect of the issue of what constitutes a fair price. As described above, we usually find it unproblematic to compensate for some time spent or some efforts made with monetary rewards – for example when it comes to most ordinary jobs.<sup>110</sup> Yet many of us seem to consider some acts, treatments or objects impossible to compensate, at least in an “authentic” way (which means that even if money is given in return for something considered “incompensable”, this would in fact not constitute compensation). The ideas behind uncompensability seem to rely on a multitude of views. For instance, in the contexts of research participation, surrogacy, prostitution and organ donation/sale, the argument can be heard that there is something special about the body, making it impossible to value in the same currency as other goods or services. What exactly this specialness (or the intuitions behind it) is about would be interesting to investigate. It is hard to deny that the body is involved in most things that we do, so in case we do wish to consider activities related to the body as special and uncompensable, we need to establish what kinds of bodily activities that qualify for this particular category. On the other hand, we can easily acknowledge that few things have perfect substitutes, and especially things of emotional value can be considered irreplaceable and therefore – perhaps – uncompensable?<sup>111</sup> We need, in other words, to explain what we mean by “compensation” and what it is that in fact happens when something is compensated.

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<sup>108</sup> Anthropological studies provide much information about how gifts are perceived in different groups. See e.g. Maurice Godelier, “L’énigme du don, I. Le legs de Mauss”, *Social Anthropology* 3(1):15-47, 1995.

<sup>109</sup> Arguments concerning the donation versus selling of blood put forward in Richard Titmuss, *The Gift Relationship: From Human Blood to Social Policy*, Allen and Unwin, London 1970, and questioned by inter alia Kenneth J. Arrow, “Gifts and Exchanges”, *Philosophy & Public Affairs* 1(4): 343-362, 1972, provides an illustration.

<sup>110</sup> The payment/salary may be described as not only compensation, however, but also for instance as “incentive”.

<sup>111</sup> Of course, we may say that the value of objects and services is simply that for which people are willing to transact it. This is one approach sometimes taken in cost-benefit analysis. There is a philosophical discussion concerning the “single currency” foundation of cost-benefit analysis, see e.g. Sven Ove Hansson, “Philosophical problems in cost-benefit analysis”, *Economics and Philosophy* 23(2):

Digging deeper into ideas of incompensability and perspectives underlying them seems to be interesting from a philosophical perspective, but also useful in the sense that if we manage to clarify the position that authentic compensation (at least in terms of money) is impossible for certain objects or activities, we may contribute to facilitating meaningful public discourse about policy issues such as surrogacy, prostitution and organ sale. It is my impression that in discussions about matters of that kind, the positions are locked: one side arguing that we only need to pay enough (based on some ideas about what a fair price is) in order to avoid the ethical problems of e.g. surrogacy, while others see the amount of money paid as unimportant in that regard. As opposed to discussions on many other topics, it seems to me that in this particular context it is not only the case that people's positions are fixed and that they don't agree with their adversaries, they don't even understand the reasoning of the other party. To conclude, the texts in this thesis touch on some key issues concerning the treatment, and conditions for the use, of human research subjects as well as broader subjects of recent heated discussion such as prostitution and surrogacy. Although a number of relevant questions remain to be answered, for instance in relation to the concepts of gifts and compensability, the thesis hopefully sheds some light on the moral problems investigated.

## **6. Summary of the essays**

### **Essay 1 (jointly written with Sven Ove Hansson)**

Traffic research shares a fundamental dilemma with other areas of empirical research in which humans are potentially put at risk. Research is justified because it can improve safety, environmental impact, or human welfare broadly perceived, in the long run. Nevertheless, people may suffer privacy intrusions, bodily injury or death in the research situation, i.e. harms similar to those involved in biomedical research, although the harms potentially suffered in traffic research also include damages to property and time delays. Hence, we need to balance short-term risks against long-term safety and other improvements, much as in other areas of research with human subjects.

In this essay we focus on ethical issues that arise when human beings are directly affected in the performance of research by examining how the ethical requirements in biomedical research can inform traffic research, or more specifically, road traffic research. Road traffic research is not homogeneous, however; instead it includes a broad array of methods, goals and objects of investigation. For instance, it is often technical (roads are built, pavement materials tested, etc), it can be of a behavioral kind (how people interact, how they react to changes in traffic rules, to what extent they stop at red lights, etc.), and it can consist in economic analyses or computer

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163-183, 2007. However, the ideas I am trying to sketch above, and which seem to be shared by many when it comes to certain things and activities are founded on views where a description of value as willingness to pay simply is inadequate.

simulations. Some road traffic research is carried out in testing sites, but to a significant extent it takes place in the public space.

We choose to compare road traffic research with the ethical requirements typically imposed on biomedical research, since the ethical discussions and guiding frameworks for research involving human subjects have been most developed in that field (other areas with a developed approach to research ethics are the behavioral sciences). In the essay, the basic ethical requirements on biomedical research are introduced, namely good research quality, the no-harm principle, assessment of risks and benefits, just selection of research subjects, information, informed consent, and privacy. Each of these requirements is discussed in relation to road traffic research. We identify the main areas where biomedical research and road traffic research differ, and whether the ethical requirements from the former can be transferred to the latter.

The first requirement, demanding that research be of good quality, is easily transferrable; just like in biomedicine only research projects from which it is possible to generate knowledge can reasonably justify the involvement of human participants.

The no-harm principle poses some difficulties, since there is often no established standard against which the research effects are to be compared; ought we to compare to the best or worst road conditions in a specific country, or ought we to look at what a specific road would look like if there were no experiment taking place? The answer to this question determines what it means to avoid “harming” participants. Another implication of the no-harm principle is that when adverse effects can be discerned, a research project ought to be interrupted. This rule can be applied also in road traffic research.

The requirement of assessing risks and benefits are likewise applicable in road traffic research. However, whereas such assessments in biomedicine are restricted to risks and benefits faced by individual patients or research subjects, assessments in traffic planning and analysis typically aggregate risks and benefits for all parties affected. When assessments of risks and benefits in road traffic research are to be measured, a choice has to be made as to whether the individual level or the collective level is to be in focus.

The requirement of just selection of research participants can partly be transferred to the road traffic context. In e.g. laboratory studies, participants can be selected in much the same way as in biomedical experiments. In research taking place in the public space, it is more difficult to apply such policies, apart from avoiding placing experiments near schools and hospitals for instance. However, in road traffic research as in biomedical research, it is not always obvious what a just selection of participants in fact entails.

Similarly, the requirements of information and informed consent are easily applicable in laboratory road traffic research but with much more difficulty in road traffic research taking place in the public space. It is hard to ensure that all those who eventually come to participate are reached by information, and it is even harder to ensure that e.g. drivers on a road where a study is carried out can provide their

informed consent in a meaningful way. Furthermore, one can only consent if there is a possibility to abstain – a feature which is often lacking when road traffic research is of a collective nature. The requirement of protection of privacy seems to be transferrable without much difficulty to the road traffic research context.

Finally, we argue that there is a need for systematic studies of the ethics of road traffic research and point to some of the issues that need to be addressed.

## **Essay 2**

The starting point in this essay is the widely held view that no research where human beings are involved as objects of investigation should take place without applying the requirement of informed consent, in order to ensure that all human research subjects participate voluntarily. The characteristics of such research vary, however, and it is not always possible to obtain informed consent. This has been acknowledged in particular for research of some kinds, typical of biomedicine and psychology, while the absence of informed consent in other kinds of research has been largely ignored. The latter kinds of research are more common in fields such as infrastructure research, and may be increasingly important due to the advancement of new technology facilitating surveillance as well as the collection and handling of large amounts of data.

This essay produces an overview and categorisation of research on humans where informed consent cannot be obtained, based on the reason why informed consent is inapplicable. These reasons are that (1) providing information to participants is counter-productive to the research at hand, (2) prospective participants lack decisional capacity, (3) it is excessively costly to ask for consent, and (4) the collective nature of the study rules out voluntary participation. The first two categories have previously been extensively discussed in the literature, whereas the other two, have received much less attention. These last two kinds of cases also bring problems to light that are significantly different from those of the first two. One question these categories give rise to is whether the fact that certain activities taking place in research ought to be regulated more strictly than if they took place outside of research, or conversely, whether the standpoint that the protection afforded to research participants is ethically defensible implies that the same protection should be applied to those affected by, it ought possibly to influence public policy implementation in general.

An important question is whether research should be permissible without informed consent, when the necessity of consent is commonly so strongly insisted upon. At least three aspects are of relevance for answering that question, namely to what extent the lack of informed consent can be compensated for, the scientific value of the research and the risks that research participants are exposed to. This essay treats the first of these, by reviewing methods proposed as substitutes for informed consent. These methods are arranged into five groups: (A) provision of information without consent, (B) consent based on partial information, (C) advance directive, (D) proxy consent, and (E) collective decision making. It is discussed in which types of situations each group of methods is applicable, and how well it compensates for the lack of informed consent.



The aim of this is to provide insights into one important aspect of relevance for the question of permitting research without informed consent, namely how well that which informed consent is meant to safeguard can be achieved by other means. Furthermore, other merits of these methods are pointed out, merits that are not restricted to how well they compensate for the lack of informed consent.

### **Essay 3**

This essay is based on the assumption that it is morally problematic when people in need are offered money in exchange for their participation in research, if the amount offered is unfair. Such offers are called “coercive”, as it is unreasonable for a person in need to decline them. There are undeniably other aspects that are of relevance for payment policies but this essay is restricted to spelling out what we ought to do in order to avoid coercive offers which is of particular interest as it is commonly argued that remuneration should be avoided as it would exploit and/or coerce potential participants.

In my conception, coercive offers contain two main elements: they are exploitative and irresistible.

I consider an offer exploitative if it is unfair. It is unfair if the reward it offers (in this context a specific amount of money) does not compensate for the sacrifice it demands (in this context what the research subject has to do, endure or expose herself to). It is a complex matter how to determine what constitutes fair compensation, but fortunately it is not necessary to settle this in order to carry out the principled discussion in the essay. The essay simply takes the normative stance that the libertarian position – that any price a person voluntarily accepts is fair – is insufficient. Furthermore, an unavoidable point to make when it comes to the matter of fair compensation, is that some consider certain objects or acts uncompensable. According to this view, there may be sacrifices involved in research participation for which there is no such thing as fair compensation – no matter how much money is offered, the sacrifice remains uncompensated. Hence, offers of money in exchange for such sacrifices cannot make the exchange unexploitative. Others prefer to consider all sacrifices involved in research participation compensable, implying that fair compensation is a matter of offering the right level of reward. The essay does not take a position concerning compensability, but shows how the policy recommendations differ depending on which view one adheres to.

While an offer’s exploitativeness is determined by the relation between the sacrifice and the reward comprising the offer, its irresistibility is determined by the relation between the offer’s reward and the offeree’s need. I argue that an offer is irresistible if the offeree is in need of that which constitutes the reward (in this context a specific amount of money) and there is no less costly way to satisfy the need. The choice to restrict irresistibility to rewards that are desirable due to needs, and not due to other kinds of wants, is normative. Perhaps it is as difficult for a greedy person to resist a reward as it is for someone in need. However, I am much more concerned about the

needy than the greedy. Of course, the analytical framework presented in this essay *could* be expanded by broadening the definition of irresistibility as to include also wants other than those based on someone's needs. What then, is a need? Generally speaking, I think of needs of basic things required for health and dignity but I don't offer a more substantial description since the analysis does not require that. We may simply fill in any view of needs we find appropriate.

An offer that is both exploitative and irresistible is defined as coercive as it is unreasonable and irrational for an offeree to refuse it. Depending on what view we take on the possibility to compensate for the sacrifices made by research participants, a wish to avoid coercive offers leads to policy recommendations when it comes to whether and how much we ought to pay people to participate in research. For sacrifices considered compensable we ought to offer either no payment or payment at a level deemed fair, while for sacrifices deemed uncompensable we always ought to offer no payment. This is not in line with the common practice to offer small amounts in exchange for research participation.

#### **Essay 4**

It is commonly claimed that if people voluntarily give something, they are not exploited. This is a (an intuitively) reasonable position, since typical cases of exploitation come about because of the exploited party's lack of power, choice or information. In this essay, however, I argue that also voluntary gift-giving may be exploited.

I begin by investigating how exploitation must be understood in order to accommodate exploitation of gift-giving. Without presenting a comprehensive theory of exploitation, two commonly proposed criteria for exploitation are introduced, namely that an interaction between two individuals A and B constitutes exploitation when (1) its outcome is disproportional, in the sense that A receives a larger part of the total benefit accruing to A and B than what is fair, and (2) this disproportion is caused by A inappropriately making use of a disadvantage that B has.<sup>112</sup> The first criterion is not seen by all exploitation theorists as necessary, but nevertheless satisfied in cases of gift-giving (since gift-giving is an inherently "disproportionate" transaction). More importantly, if the second criterion is understood too narrowly, there is no room for exploitation in cases of gift-giving. Such a narrow interpretation, proposed by many, restricts the inappropriate use of someone's disadvantage to cases where A coerces B, or where A takes advantage of B's inferior bargaining position, or where A deceives B. The genuine and voluntary gift-giving that I have in mind does not fit into such a description. However, a broader account of what it means to use a disadvantage in an inappropriate way can accommodate exploitation of gift-giving.

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<sup>112</sup> This description of exploitation differs from that used in essay 3, where "exploitative" simply denotes the first of the conditions mentioned above – the unfairness in outcome. The difference in definitions is due to their different purposes. In essay 3 "exploitative" is used to label a problematic characteristic of an offer, while in essay 4 the aim is to capture what exploitation is.

Such accounts have been presented by some authors, arguing that also a person's character traits, vulnerabilities or more generally, dispositions, can be used in ways amounting to exploitation.

However, not all uses of someone's dispositions leads to exploitation – only inappropriate uses. Similarly, not all instances of gift-giving amount to exploitation. It is therefore the aim of the second part of the paper to spell out conditions of relevance for exploitation of gift-giving as a first step towards constructing a theoretical framework for exploitation of gift-giving, enabling us to detect when gift-giving is exploited. The method of reflective equilibrium inspires this explorative analysis, which proceeds by testing intuitions about examples that embody six possible conditions for exploiting voluntary informed gift-giving. Five of these conditions – giving out of virtue, loss for the giver, initiative taken by the recipient, recipient aiming for the gift, and lack of reciprocity – have been retrieved from the general literature on exploitation. One condition – that the gift should be undeserved – is my own contribution. Three of the conditions are eventually judged to be necessary conditions for exploitation of gift-giving, namely that (1) the giver incurs a loss, (2) the recipient has aimed for the gift, and (3) the gift is undeserved. The remaining three are deemed not useful for characterizing exploitation of gift-giving.

In the concluding section the results are summarized, and some remarks are made about the blameworthiness of exploitation. I argue that even though exploitation is *prima facie* blameworthy, it is not necessarily so all things considered. Furthermore, I claim that although exploitation of gift-giving is hardly the worst kind of exploitation it does stain human interaction.

## **7. Sammanfattning på svenska**

### **Uppsats 1 (samförfattad med Sven Ove Hansson)**

Trafikforskning har ett grundläggande dilemma gemensamt med andra områden av empirisk forskning där människor kan utsättas för risker. Å ena sidan är forskningen försvarbar eftersom den kan leda till förbättringar i säkerhet, miljöpåverkan, eller mänsklig välfärd i stort. Å andra sidan kan människor drabbas av integritetsintrång, kroppsskador eller dödsfall forskningsprocessen, dvs. skador liknande de som kan drabba deltagare i biomedicinsk forskning, och därutöver skador på egendom eller i form av förseningar. Vi behöver därför balansera kortsiktiga risker mot långsiktig säkerhet och annan nytta, på samma vis som inom andra forskningsområden där människor utgör studieobjekt.

I denna uppsats fokuserar vi på etiska frågor som uppstår när människor är direkt berörda av forskning genom att undersöka hur de etiska kraven i den biomedicinska forskningen kan utgöra vägledning för trafikforskning, eller mer specifikt, vägtrafikforskning. Vägtrafikforskningen är emellertid inte homogen, utan innehåller ett brett spektrum av metoder, mål och studieobjekt. Till exempel är vägtrafikforskning ofta teknisk (vägar byggs, vägbeläggningar testas, etc.) men kan också vara av ett

beteendevetenskapligt slag (hur människor interagerar, reagerar på förändringar i trafikregler, i vilken utsträckning de stannar vid rött ljus osv studeras), och den kan bestå i ekonomiska analyser eller datorsimuleringar. Viss vägtrafikforskning äger rum i laboratorier eller särskilda testområden, men i betydande utsträckning sker den i det offentliga rummet.

Vi väljer att utgå ifrån de etiska krav som normalt ställs på biomedicinsk forskning, eftersom etiska diskussioner och riktlinjer för forskning på människor är mest utvecklade inom detta område (andra områden med ett utvecklat forskningsetiskt ramverk vad gäller försökspersoner är beteendevetenskaperna). I uppsatsen presenteras de grundläggande etiska krav som vanligen ställs på biomedicinsk forskning, nämligen god forskningskvalitet, principen om att inte skada, bedömning av risker och nytta, rättvist urval av forskningsdeltagare, information, informerat samtycke, och skydd av den personliga integriteten. Vi identifierar de viktigaste områdena där biomedicinsk forskning och vägtrafikforskning skiljer sig åt, och undersöker hur de etiska kraven på den förra kan överföras till den senare.

Det första kravet, att forskningen ska vara av god kvalitet, är oproblematiskt att överföra; precis som i biomedicin kan endast forskningsprojekt från vilka det är möjligt att utvinna kunskap rimligen motivera medverkan av mänskliga deltagare.

Principen om att inte skada innebär vissa svårigheter, eftersom det sällan finns någon etablerad standard mot vilken effekterna av forskningen kan jämföras; borde vi jämföra med de bästa eller sämsta vägförhållandena i ett visst land, eller borde vi titta på hur en specifik väg skulle se ut om inte experimenten ägt rum? Svaret på den frågan avgör vad det innebär att "skada" deltagare. Det följer också av principen om att inte skada att när negativa effekter kan skönjas så bör ett forskningsprojekt borde avbrytas. Denna regel kan tillämpas även i vägtrafikforskningen.

Kravet på att bedöma risker och nytta är också tillämpligt i vägtrafikforskning. I biomedicinsk forskning är sådana bedömningar begränsade till risker och fördelar för enskilda patienter eller försökspersoner, medan motsvarande bedömningar i samband med trafikplanering och trafikanalys vanligen gäller de samlade riskerna och den samlade nyttan för alla parter som påverkas. Då ställs man alltså inför ett val mellan att utgå från effekterna på enskilda försökspersoner eller effekter på en kollektiv nivå.

Kravet på ett rättvist urval av försökspersoner kan delvis överföras till trafikkontexten. I exempelvis laboriestudier kan deltagarna i stort sett väljas ut på samma sätt som i biomedicinska experiment. I forskning som äger rum i det offentliga rummet är det däremot svårare att tillämpa en sådan policy, utöver möjligen att undvika att placera experiment nära skolor och sjukhus. I vägtrafikforskning liksom inom biomedicinsk forskning är det dock inte alltid självklart vad ett rättvist urval av deltagare i själva verket innebär.

Även kraven på information och informerat samtycke är lätta att tillämpa i laboriebaserad vägtrafikforskning, men svårare i den som äger rum i det offentliga rummet. Det är svårt att se till att alla de som kommer att involveras nås av informationen, och det är ännu svårare att se till att exempelvis bilister på en väg där

en studie genomförs kan ge sitt informerade samtycke på ett meningsfullt sätt. Dessutom kan man bara samtycka om det finns en möjlighet att avstå från att medverka, vilken ofta är omöjligt vid vägtrafikforskning av kollektiv karaktär. Kravet på skydd för privatlivet verkar vara överförbart utan stora svårigheter till vägtrafikforskningssammanhang.

Slutligen hävdar vi att det finns ett behov av systematiskt arbete med etiska frågeställningar kring vägtrafikforskning, och vi pekar på några av de frågor som behöver angripas.

## **Uppsats 2**

Utgångspunkten i denna uppsats är den allmänt vedertagna uppfattningen att ingen forskning där människor är inblandade som studieobjekt bör utföras utan att kravet på informerat samtycke tillämpas, för att säkerställa att alla försökspersoner deltar frivilligt. Forskning där människor involveras på detta sätt är dock av varierande karaktär, och det är inte alltid möjligt att erhålla samtycke. Detta har uppmärksammats i samband med forskning av vissa slag, typiska för biomedicin och psykologi, medan avsaknaden av informerat samtycke i andra typer av forskning i stor utsträckning har ignorerats. De sistnämnda typerna av forskning är vanligare i områden såsom infrastrukturforskning, och blir allt mer betydande på grund av utvecklingen av ny teknik som underlättar övervakning samt insamling och hantering av stora mängder data.

Denna uppsats ger en översikt och kategorisering av forskning på människor där informerat samtycke inte kan erhållas, utifrån skälen till varför informerat samtycke inte är tillämpligt. Dessa skäl är att (1) det är kontraproduktivt för forskningen att ge information till deltagarna, (2) potentiella deltagare saknar beslutsförmåga, (3) det är alltför kostsamt att be om informerat samtycke, och (4) studiens kollektiva karaktär utesluter frivilligt deltagande. De två förstnämnda kategorierna har tidigare diskuterats utförligt i litteraturen medan de andra två har fått mycket mindre uppmärksamhet. De mindre uppmärksammade typerna av fall ger också upphov till frågor som skiljer sig betydligt från de andra. En sådan fråga är om vissa aktiviteter borde regleras mer strikt när de äger rum inom ramen för forskning än annars, eller omvänt, om ett konstaterande att skyddet för försökspersoner är etiskt försvarbart innebär att samma skydd borde ges till som påverkas av samhällsförändringar i allmänhet.

En viktig fråga är om forskning utan informerat samtycke bör vara tillåten, när kravet på samtycke vanligen så starkt betonas. Minst tre aspekter är relevanta för att besvara denna fråga, nämligen i vilken utsträckning bristen på informerat samtycke kan kompenseras för, vilket vetenskapligt värde den aktuella forskningen har och vilka risker forsknings deltagarna utsätts för. Denna uppsats behandlar den första av dessa, genom att granska metoder som föreslås som substitut för informerat samtycke. Dessa metoder är indelade i fem grupper: (A) tillhandahållande av information utan samtycke, (B) samtycke baserat på ofullständig information, (C) förhandsdirektiv, (D) samtycke genom ombud, och (E) kollektivt beslutsfattande. Uppsatsen diskuterar för

vilka typer av situationer varje grupp av metoder är tillämplig, samt hur väl de kompenserar för avsaknade av informerat samtycke. Syftet med detta är att bättre förstå en viktig aspekt på frågan om tillåtande av forskning utan informerat samtycke, nämligen hur väl det som informerat samtycke är tänkt att säkerställa kan uppnås med andra medel. Vidare belyses andra fördelar med dessa metoder, fördelar som inte begränsas till hur väl de kompenserar för avsaknaden av informerat samtycke.

### **Uppsats 3**

Denna uppsats är baserad på antagandet att det är moraliskt problematiskt när människor i en mycket utsatt ekonomisk situation erbjuds pengar i utbyte mot deras deltagande i forskning, om det belopp som erbjuds är orättvist. Sådana erbjudanden betecknas som tvingande, eftersom det är orimligt för en person i en sådan utsatthet att avvisa dem. Det finns onekligen andra aspekter som är av betydelse för frågan om ersättning till försökspersoner men denna uppsats är inriktad på vad vi bör göra för att undvika tvingande erbjudanden, vilket är av särskilt intresse eftersom ett ofta framfört argument mot högre nivåer på betalning är att det skulle tvinga och/eller exploatera potentiella forskningsdeltagare.

Som jag ser det har tvingande erbjudanden två huvudkomponenter: de är exploaterande och oemotståndliga.

Ett erbjudande anses här vara exploaterande om det är orättvist. Så är fallet om belöningen (i detta sammanhang en viss summa pengar) inte kompenserar för den uppoffring som krävs (i detta sammanhang vad forskningsdeltagaren har att göra, genomlida eller utsätta sig för). Det är en komplex fråga hur man avgör vad som utgör skälig ersättning, men lyckligtvis är det inte nödvändigt att slå fast detta i syfte att genomföra uppsatsens principiella diskussion. I uppsatsen intas helt enkelt den normativa ståndpunkten att den libertarianska hållningen – att varje ersättning som frivilligt accepteras är skälig – är otillräcklig. Vidare är det nödvändigt att beakta att visa är av uppfattningen att det finns föremål eller handlingar som är okompenserbara. Enligt detta synsätt kan det finnas uppoffringar inom ramen för forskningsdeltagande för vilka det inte finns något sådant som en skälig ersättning; oavsett hur mycket pengar som erbjuds, förblir deltagaren okompenserad. Erbjudanden om pengar i utbyte mot sådana uppoffringar kan alltså inte förhindra exploatering. Andra föredrar att betrakta alla uppoffringar i forskningssammanhang som ersättningsbara, vilket innebär att skälig ersättning blir en fråga om att erbjuda rätt nivå på belöning. Uppsatsen tar inte ställning beträffande kompenserbarhet, men visar hur policyrekommendationerna skiljer sig åt beroende på vilken uppfattning man ansluter sig till.

Medan ett erbjudandes exploateringsgrad bestäms av förhållandet mellan uppoffringen och ersättningen så bestäms erbjudandets oemotståndlighet av förhållandet mellan ersättningen och mottagarens behovssituation. Jag hävdar att ett erbjudande är oemotståndligt om mottagaren är i behov av ersättningen (i detta sammanhang en viss summa pengar) och det inte finns något mindre kostsamt sätt att

tillfredsställa behovet än att anta erbjudandet. Graden av oemotståndlighet ökar ju större del av behovet som tillfredsställs genom erbjudandet. Valet att begränsa oemotståndlighet till belöningar som är åtråvärda på grund av behov, och inte på grund av andra typer av önskningar, är normativt. Måhända är det lika svårt för en girig person att stå emot en belöning som det är för någon i nöd. Jag är dock mycket mer bekymrad över de behövande än de giriga. Naturligtvis skulle den analys som presenteras i denna uppsats kunna utökas genom att bredda definitionen av oemotståndlighet till att omfatta också önskningar som inte baseras på någons behov. Vad är då ett behov? Jag tänker i första hand på behov av grundläggande saker som är nödvändiga för hälsa och värdighet, men någon mer omfattande beskrivning ges inte eftersom analysen inte kräver det. Vi kan helt enkelt utgå från den uppfattning om behov vi finner lämplig.

Ett erbjudande som är både exploaterande och oemotståndligt definieras som tvingande eftersom det är orimligt och irrationellt för en mottagare av det att avvisa det. Beroende på vilket synsätt vi anammat om möjligheten att kompensera för de uppoffringar som görs av forskningsdeltagare, leder en strävan efter att undvika tvingande erbjudanden till policyrekommendationer när det gäller om och hur mycket vi borde betala människor för att delta i forskning. För uppoffringar som anses kompenserbare bör vi antingen inte erbjuda någon betalning alls eller betalning på en nivå som anses skälig, medan vi för uppoffringar som anses okompenserbare aldrig borde erbjuda någon ersättning. Detta står i kontrast till praxisen att erbjuda små belopp i utbyte mot forskningsdeltagande.

#### **Uppsats 4**

Det är en allmänt utbredd uppfattning att om folk frivilligt ger en gåva, exploateras de inte. Detta är en (intuitivt) rimlig ståndpunkt, eftersom typiska fall av exploatering uppkommer på grund av den exploaterades brist på inflytande, alternativ eller information. I denna uppsats hävdar jag emellertid att också frivilligt gåvogivande kan exploateras.

Jag börjar med att undersöka hur exploatering måste förstås för att inrymma exploatering av gåvogivande. Utan att presentera en heltäckande teori om exploatering, redovisar jag två vanligen föreslagna kriterier för exploatering, nämligen att en interaktion mellan två individer A och B utgör exploatering när (1) dess resultat är oproportionerligt, i den mening att A får en större del av den totala nytta som tillfaller A och B än vad som är rättvist, och (2) denna obalans orsakas av ett olämpligt utnyttjande av en svaghet som B har. Det första kriteriet betraktas inte som nödvändigt av alla exploateringsteoretiker, men det är i vilket fall som helst uppfyllt i fall av gåvogivande (eftersom gåvor till sin natur är en "obalanserad" transaktion). Av större vikt är att om det andra kriteriet tolkas alltför snävt, så finns det inget utrymme för exploatering av gåvogivande. En sådan snäv tolkning, som föreslagits av många, begränsar vad som utgör olämpligt utnyttjande av någons svaghet till fall då A tvingar B, eller där A drar fördel av B:s underlägsna förhandlingsposition, eller där A bedrar B.

Det frivilliga och informerade gåvogivande som jag har i åtanke passar inte in i en sådan beskrivning. Om istället en bredare tolkning av vad det innebär att använda någons svaghet på ett olämpligt sätt antas, så finns det utrymme för exploatering av gåvogivande. Sådana synsätt har förespråkats av vissa författare som menar att även en persons karaktärsdrag, svagheter eller mer allmänt, läggning, kan utnyttjas på sätt som innebär exploatering.

Allt utnyttjande av någons läggning leder dock inte till exploatering – bara olämpligt sådant. På motsvarande sätt utgör inte allt gåvogivande fall av exploatering. Den andra delen av uppsatsen syftar därför till att beskriva villkor för exploaterat gåvogivande som ett första steg i konstruerandet av en teoretisk ram för exploatering av gåvogivande, med vilken vi är bättre rustade att avgöra när gåvogivande faktiskt exploateras. Den reflektiva jämviktsmetoden har inspirerat denna explorativa analys, som är en undersökning av intuitionerna kring exempel som innehåller sex möjliga villkor för exploatering av frivilligt och informerat gåvogivande. Fem av dessa – att ge på grund av dygd, att givaren ådrar sig en förlust, att initiativet tas av mottagaren, att mottagaren strävat efter gåvan, och brist på ömsesidighet – har hämtats ur den allmänna litteraturen om exploatering. Ett villkor – att gåvan ska vara oförtjänt – är mitt eget bidrag. Tre av villkoren bedöms slutligen vara nödvändiga för exploatering av gåvogivande, nämligen att (1) givaren ådrar sig en förlust, (2) att mottagaren strävat efter gåvan, och (3) att gåvan är oförtjänt. De återstående tre villkoren anses inte användbara för att karakterisera exploatering av gåvogivande.

I det avslutande avsnittet sammanfattar jag resultaten, och gör några anmärkningar om klandervärdeheten i exploatering. Även om exploatering är *prima facie* klandervärd, är det inte nödvändigtvis så med alla omständigheter tagna i beaktande. Vidare hävdar jag att även om exploatering av gåvogivande knappast utgör den värsta sortens exploatering, så förfular det mellanmänniska relationer.

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