Chapter 20

Without Informed Consent

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ABSTRACT

The requirement of always obtaining participants’ informed consent in research with human subjects cannot always be met, for a variety of reasons. This paper describes and categorises research situations where informed consent is unobtainable. Some of these kinds of situations, common in biomedicine and psychology, have been previously discussed, whereas others, for example, those more prevalent in infrastructure research, introduce new perspectives. The advancement of new technology may lead to an increase in research of these kinds. The paper also provides a review of methods intended to compensate for lack of consent, and their applicability and usefulness for the different categories of situations are discussed. The aim of this is to provide insights into one important aspect of 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.

INTRODUCTION

Research where human beings are involved as objects of investigation may be of many different kinds. There is wide agreement that no such research should take place without the practice of informed consent, in order to ensure that all human research subjects participate voluntarily. However, 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, or at least under-analysed.

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 situates the problems investigated in this contribution within the scope of the growing field of technoethics.
The present paper 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. Again, some of these – 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.

Of course, an important question becomes 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 paper 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 will be discussed for which types of situations each group of methods is applicable, and how well they compensate for the lack of informed consent. Furthermore, it will be pointed out what the merits are of these methods, merits that are not restricted to how well they compensate for the lack of informed consent.

SITUATIONS WHEN INFORMED CONSENT IS NOT APPLICABLE

Informed consent is commonly viewed as a necessary but insufficient condition for permissible research where human beings are involved. It is necessary in order to ensure that people do not participate in research against their will. It is insufficient because people should not participate in research projects that do not pass the scrutiny of research ethics committees (ascertaining, in addition to participants’ consent, that they are not exposed to great risks of harm, do not participate in projects with low scientific value etc.) even if they would accept to participate in such research.

The aim of informed consent is to ensure that a person who participates in research does this because she wants to do so. The best way to achieve this is to make sure that she herself decides whether to participate or not. In order for such a decision to constitute valid consent, it must contain three elements: information, decisional capacity and voluntariness. The information element is relatively straightforward: it means that the subject must have all relevant information available. There is, however, a tension between the view that potential research participants must in fact assimilate the information provided, and the view that it suffices that the information is offered – the potential participant may or may not choose to take it all into account (Beauchamp & Childress, 2001; Hayry & Takala, 2001). The latter of these views is favoured in this paper. The element of capacity is more complex; it means that the subject must be able to understand the information, to form a will and to make decisions in line with that will. Furthermore she must understand that she is making such a decision, and perceive this decision as voluntary. She must not, for instance, believe there to be anyone threatening her to participate or that she is ruled by some superior force etc. Finally, in order for her capacity to decide to be effective, she must be able to communicate her decision to others. The element of voluntariness means that there must not only be perceived, but also de facto voluntariness. This includes the absence of threats or undue inducements making the subject accept participation. Furthermore, the person must not be outright forced into participation through the
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