

When is Deception in Research Ethical?

Nafsika Athanassoulis
Centre for Professional Ethics
Chancellor's Building
Keele University
ST5 5BG
n.athanassoulis@peak.keele.ac.uk

James Wilson
Comprehensive Biomedical Research Centre and Centre for Philosophy,
Justice and Health
University College London
WC1E 6BT
james-gs.wilson@ucl.ac.uk

Acknowledgments

The authors would like to thank Stephen Wilkinson, Anthony Wrigley, Tom Walker, Jonathan Hughes and Angus Dawson for helpful comments on an earlier draft of this article. Some of James Wilson's contribution to this work was undertaken at UCLH/UCL who received a proportion of funding from the Department of Health's NIHR Biomedical Research Centres funding scheme.

Word count – 4464.

Published in *Clinical Ethics* Volume 4(1) - doi: **10.1258/ce.2008.008047**

When is Deception in Research Ethical?

Abstract

This article examines when deceptive withholding of information is ethically acceptable in research. The first half analyses the concept of deception. We argue that there are two types of accounts of deception: normative and non-normative, and argue that non-normative accounts are preferable. The second half of the article argues that the relevant ethical question which ethics committees should focus on is not whether the person from whom the information is withheld will be deceived, but rather on the reasonableness of withholding the information from the person who is deceived. We further argue that the reasonableness of withholding information is dependent on the context. The last section examines how the context of research should shape our judgements about the circumstances in which withholding information from research participants is ethically acceptable. We argue that some important features of research make it more difficult to justify withholding information in the context of research than elsewhere.

Introduction

One of a Research Ethics Committee's main tasks is to ensure that potential research participants are in a position to give valid consent. Research participants cannot give consent without adequate information, and so ethics

committees typically spend much of their time scrutinising the information to be provided to research participants. Information provision in research is an especially sensitive topic because of the uncertainty inherent in research, the difficulty of balancing the relevant harms and benefits, and the fact that research often exposes participants to risk without any compensating benefit.

There are a number of standard problems with information provision in research, such as ensuring information is provided in a manner which enhances understanding, and how to overcome difficulties in understanding the concept of randomisation. In this article we shall set all these problems aside, and concentrate on cases where a researcher wants to withhold information from the research participants on methodological grounds. If some relevant information is not communicated in the types of case we are interested in, this is not because of a mistake or incompetence, but rather because the information is withheld intentionally.

In the light of scandals such as the Tuskegee Syphilis Study, and Milgram's obedience to authority experiments, Research Ethics Committees are often very reluctant to allow research which they believe to involve deception to go ahead. However there are certain kinds of research that cannot be done without deception: in some instances providing certain kinds of information about the study will invalidate the results, as it may lead to the participants modifying their behaviour in light of this knowledge. To take just one example, research into socially disliked attitudes can usually not proceed

without some form of deception. Clearly you will not gain a true insight into the extent of discrimination against people with mental health problems if you inform your research subjects that this is what you are researching, given that people are typically reticent about admitting to attitudes which are subject to social disapproval.

As the kinds of information that can be discovered by such deceptive studies can be very useful, it seems too extreme to claim that deception in research can *never* be justified. But as often in ethics the difficult question is where to draw the line. In this article we look in detail at two cases of possible research designs – one of which we think falls on the right side of the line of ethical acceptability, and the other on the wrong side – and by reflecting on these two cases, formulate a principle to help guide judgements about when deceptive withholding of information is ethically acceptable in research.

We begin, however, by analysing the concept of deception. We argue that there are two types of accounts of deception: normative and non-normative accounts. Normative accounts of deception make the ethical question of whether a particular case of misleading is justifiable integral to the question whether it counts as a case of deception, whilst non-normative accounts do not. We argue that non-normative accounts are preferable. More specifically, we argue that where A intends to mislead B, and succeeds in so doing, this is a case of deception irrespective of whether this misleading is ethically justifiable and so the claim that ethical justifiability should play a role in the

definition of deception is false. If this non-normative account of deception is correct, then it is a mistake for ethics committees to set too much store by the question of whether a given research project involves deception, given that the fact that a piece of research involves deception does not in and of itself make it morally problematic.

The second half of the article argues that what ethics committees should be focusing on in cases of withholding information is the reasonableness of withholding the information from the person who is deceived, and that the reasonableness of withholding information is dependent on the context. The last section examines how the context of research should shape our judgements about the circumstances in which withholding information from research participants is ethically acceptable. We argue that some important features of research make it more difficult to justify withholding information in the context of research than elsewhere.

When is withholding information deceptive?

In an interesting recent article analysing the concept of deception, Sokol argues that there is an asymmetry between misleading by intentionally giving false information, and misleading by intentionally withholding information. The former is always deceptive, whilst whether the latter counts as deceptive depends on what expectations would be reasonable in the circumstances. Sokol argues for this claim as follows: “At any one time, people hold hundreds of false beliefs. They do not, however, expect others to correct them unless there is good reason to do so. Just as we hold many

false beliefs about the world, so do we withhold true beliefs from others. Because there is generally no expectation to reveal those true beliefs, it would be odd to say we are concealing them from others, let alone that we are deceiving them.” [1, p.460]

Sokol draws the conclusion that whether withholding information is deceptive in a given circumstance depends on three things: (a) the agent’s intention, (b) what expectations would be normatively reasonable in the circumstances, and (c) whether the attempted deception is successful. Hence, he argues that I can deliberately set out to mislead you about whether I have a particular book by hiding it when you come round to my house, and even if I am successful in misleading you, this will still not count as deception if your expectation that I would tell the truth about the contents of my book collection were normatively unreasonable. [1, p.460]

We have two worries about this account of deception by omission. First, it gains much of its plausibility by running together cases where someone withholds information with the intention that another person will form a false belief, and cases where information is withheld, but where there is no intention that the other person form or retain a false belief. In the latter category, someone could condone the fact that another person was fairly likely to form (or maintain) a false belief without it being their *intention* that the other person do so.

Suppose the man next to me on the bus has spinach stuck to his tooth, and I

do not mention this to him, as he is a perfect stranger and I do not want to embarrass him. In these circumstances, I may keep quiet with the intention of not embarrassing him, being aware that he may well draw the conclusion that there is nothing amiss about his appearance. We agree with Sokol that in cases such as this I do not deceive the stranger. But the reason that my silence is not deceptive need not be that there was no reasonable expectation that I mention the spinach; it could equally well be claimed that the reason I do not deceive the stranger is that I do not intend to mislead him. It follows that cases of this kind do little to support the claim that deception by omission requires that the speaker have a reasonable expectation that the truth will be told in the circumstances.

Second, we think that intentional withholding of information can still be deceptive, even if there would be no normatively reasonable expectation that the person withholding the information would reveal what they know in the given context. Take the following case.

Harry. Harry is a gifted sleight of hand magician, who happens to work in a coffee shop. When a customer asks for a glass of water, he likes to pour them the glass in plain view, and then using sleight of hand, replace this glass with another identical glass of water, which he poured a few moments before and cunningly concealed about his person. The customer is in no way harmed by Harry's sleight of hand, as the two glasses of water are equivalent in every way.

The first thing to say is that Harry does not *tell* the customer that the glass of water she receives is the same as the one she initially sees; rather he is relying on the customer's natural assumption that the glass of water she receives is one and the same as the one she saw being poured. So if this is a case of deception, it is a case of deception by omission, rather than commission.

We take it that the fact that the glass of water that the customer sees is a different glass of water from the one that she in fact receives is not a piece of information which is material to her desire to have a glass of water. And it seems hard to see that a reasonable person would have reason to object to the fact that they are not given the actual glass of water they saw being poured, but rather an identical one.¹

We think that in this case Harry *does* deceive the customer, even though the fact that the glass of water is a different one from the one the customer saw is not relevant to the fulfilment of the customer's desire for the glass of water. In other words, Harry deceives the customer *despite* the fact that there would not be a reasonable expectation for him to tell the customer that the glass of water she receives is not the original one she saw, but rather an identical one.

¹ Unless of course they thought that this was deceptive, and that they were wronged by being deceived. However this would support the claim that we are trying to get to, namely that Harry *does* deceive the customer.

If this analysis of the case of Harry the magician is correct, then it suggests that intentionally causing someone to hold a false belief is a sufficient condition for deception, whether or not the information about which the person is misled about is information that they had a reasonable expectation of being told. If this is the case, then it is false to argue that it is a necessary condition for deception by omission that the person who is deceived has a reasonable expectation of receiving the information that is withheld from them.

We also think that there is a second type of case which reveals a problem with normative conceptions of deception like Sokol's, namely where a person is engaged in action which is so immoral that they could not reasonably expect someone to help them achieve their goal. If a murderer comes to the door, and asks whether his innocent target is hiding inside, then certainly I should attempt to bring it about that the murderer does not believe that the innocent person is hiding inside. But we are not at all sure that the would-be murderer has anything like a normatively reasonable expectation that I should reveal what I know to him. Hence it looks like on Sokol's account I probably do not deceive him if I send him away with an intentionally misleading statement. But this seems counter-intuitive to us.

We think that these two problems suggest that a non-normative conception of deception is preferable. On a non-normative conception of deception, to call something deceptive is not in and of itself to make a moral judgement about the conduct. Hence on such a view, saying that a piece of research

involves deceiving the research participants is not yet to make a moral claim about the research. Whilst we do not think that the idea of reasonable expectations is helpful in thinking about what deception is, it will form a key part of our account of why some cases of deception are more ethically problematic than others. With this in mind, let us pass on to analyse our two cases about withholding information in research.

Two Cases of Withholding Information In Research

We have used the following two cases in ethics training for Research Ethics Committees as part of the Centre for Professional Ethics's Knowledge Transfer activities. *Bamforth* is fictional, whereas *Rucola* is modified version of a real case reported by a participant in one of our training days. *Rucola* was turned down by the Research Ethics Committee on the grounds that it deceived the subjects as to the true nature of the trial. We shall be suggesting that the committee in question made the wrong decision, and for the wrong reason.

Bamforth. John Bamforth is an internationally recognised expert in human communication studies. He approaches you, prior to seeking ethics committee approval, to see if you (and your Cancer Care Centre) would be willing to participate in his newest study. He is interested in discovering the techniques by

which healthcare professionals attempt to break bad news; and he hopes that the results of his research will in the future help to improve best practice in this difficult area. For his latest research project, he proposes to set up a relatively unobtrusive unattended camera in the room in which the healthcare professional breaks the bad news to the patient. He will analyse the communication (both what is said and what is unsaid), and the body language of both participants, and write a number of papers on the subject of the best way to break bad news.

He proposes to seek consent from all the healthcare professionals to be involved in the study, and also all the patients. He does not want to scare the patients beforehand, so he will tell them merely that he is interested in how doctors talk to patients, and will not specifically mention the issue of breaking bad news. All persons will be anonymised for the purpose of the study, and he will destroy his tapes as soon as he has completed the relevant publications.

Rucola. Professor Rucola is a nutritional scientist and proposes to carry out a study measuring salad eating habits in the general public. She will ask members of the public to fill in a questionnaire on their eating habits *in general* over a period of time and from this material she will gather information on salad consumption. Her consent form will explain that she is carrying out research on eating habits, but will not mention that she is

only interested in salad consumption as she is worried that revealing this fact will distort the results, i.e. if people know that she is measuring salad eating habits, and given assumptions about healthy eating and the benefits of eating salad, her subjects will either change their eating habits or inaccurately report their eating habits for the duration of the trial.

Most people (in our admittedly unscientific sample of research ethics committee members) tend to think that *Bamforth* is much more ethically problematic than *Rucola*, and when asked to justify this, tend to explain the difference as being in large part due to the fact that *Bamforth* involves deception, whilst *Rucola* does not. We agree with the claim that *Bamforth* is more ethically problematic, but we do not think that deceptiveness has anything to do with this, for two reasons. First, as we have just argued, whether withholding information is deceptive or not does not *by itself* make any difference to the moral judgements we ought to make. Second, there are reasons for thinking that *Rucola* is as deceptive as *Bamforth*: both cases are similar insofar as disclosure of the precise purpose of the study would invalidate the study's methodology; as in both cases participants would alter their behaviour if they knew it was being measured during the trial.

Moreover, in both cases the researchers deliberately withhold information which is relevant to understanding the purpose of the research, and in so doing intentionally mislead the trial participants as to the purpose of the research. Given a non-normative conception of deception, we think that it is very plausible to say that both studies involve the researcher deceiving the

research participants. (The inclination to say that *Rucola* is not deceptive comes, we think, from an erroneous attachment to a normative account of deception).

However, to say that the researchers are deceptive in both cases is not to say that they act wrongly in both cases: rather, we shall argue that only *Bamforth* involves *wrongful* deception, as the deception in *Rucola* – like the magician case – is one that a reasonable person would have no reason to object to.

In *Bamforth*, the fact that the observer is interested only in interviews that break bad news seems significant to the decision whether to participate. Participating in a trial on the breaking of bad news seems significantly different to participating in a trial on doctor-patient communication in general. The reason for this is that the nature of the news being communicated is potentially very sensitive and very distressing. A potential participant who would be willing to participate in a general communication trial, may not be willing to participate in a trial where she is observed while being told very sensitive and very distressing news.

In *Rucola*, the information that the observer is only interested in salad eating habits is innocuous in that it would not affect a reasonable participant's willingness to participate. Participants who decided that the aims of a trial on nutrition are significant enough to persuade them to give up their time to record their eating habits would not alter their decision by finding out that

this was indeed a study on specific rather than general eating habits. Salad eating habits are not contentious in the way that being told bad news is. Therefore, the fact that this is a trial on salad eating habits is not crucial to making the decision of whether to participate or not.

Hence we think that it would be best for an ethics committee to reject *Bamforth* on the grounds of wrongful deception as it stands, whilst the deception in *Rucola* is not ethically problematic. It might be objected that in the *Bamforth* case the deception does not increase the risk of harm inherent in the breaking of bad news, and that hence the fact that the overall context is one in which there is a risk of harm does not show that there is a moral difference in the deception in the two cases. We think this is a mistake. One of the relevant moral differences concerns the potential violation of privacy in *Bamforth*. Notice that whilst violations of privacy will very often be harmful, it is plausible to think that violations of privacy can be wrong even where they *do not* cause harm. Such actions would fall into the category that Joel Feinberg described as “harmless wrongdoing”.^[2] If this is right, then even if no additional risk of harm occurs as a result of the deception in *Bamforth*, the researcher’s actions might still be wrongful in virtue of being a breach of privacy.

We conclude that the operative moral principle should not be whether or not a given piece of research involves deception, but whether it involves deception that is *prima facie* wrongful. (To say that deception in a given circumstance is *prima facie* wrongful is to say that deceiving in this case

would be wrong if there were no other moral principles relevant to the situation. Where there are other moral principles such as non-maleficence operative, we may sometimes judge that the prima facie wrongfulness of a given piece of deception can be outweighed. Providing an account of how such balancing is to be performed is beyond the scope of this article).

One could object here that there is nothing stopping *Bamforth* from re-describing the aims of the trial to involve general communications issues. This raises two possibilities. It might be the case that *Bamforth* then intentionally misdescribes the aims of the trial in order to obtain ethics approval. However this is clearly unethical as *Bamforth* is then seeking to deceive the ethics committee as to his true purpose. On the other hand, it might be the case that *Bamforth's* initial aims are rather broad, e.g. doctor/patient communications in general, but a more narrow theme emerges during the trial, e.g. claims relating to the breaking of bad news. In such a case, as long as researchers are acting in good faith in their original description of the project there is no deception, it's simply that the aims of the trial have changed during its course.²

We suggest that ethics committees should take deceptive withholding of information to be prima facie wrongful only where it deprives a research participant of information that would be relevant to the decision of a reasonable person as to whether to join the research project. Notice that there may be some people who *would* object to the withholding of

² This change may necessitate re-affirming consent to participate, but this issue is outside the scope of this paper.

information that a reasonable person would not object to. For instance in the *Rucola* case, there might be someone who had a pathological hatred of salad, and who was most unhappy at the prospect of taking part in a piece of research which could form the basis of a campaign to increase salad uptake.

Whilst it is important for ethics committees to be representative, and to make sure that they do not make judgements of 'reasonableness' which reflect their narrow cultural or class interests, it is impossible for ethics committees to take into account every possible set of values, however unusual, in thinking about information provision. The primary job of an ethics committee is to determine whether a given research project is suitable for researchers to invite participants to take part in it. This is a general task, which by definition cannot be tailored specifically to each possible set of values. Hence where the participants recruited are competent adults the participants must bear some responsibility for informing researchers of unusual values they may have that research ethics committees might not have taken into account in thinking about whether the research project is ethically acceptable.

Our principle for determining when deceptive withholding of information is ethically acceptable relies on the idea of reasonableness, and so is in an obvious way indeterminate. In part this is an inescapable feature of principles. However, in the final section we shall attempt to flesh out the principle a bit, by arguing that there is good reason to think that our standards of reasonable revelation of information should be higher in

research than elsewhere.

Why Research as a Context Creates a Strong Presumption of Revelation

The profile of the risks in research is most unusual, and this has effects on the way we should conceive of reasonable provision of information in research. In short, the nature of research as a context creates a presupposition that more rather than less information will be provided, and hence makes it more difficult to justify deceptive withholding of information than elsewhere.

Hansson and Hermansson [3] argue that in any risk management problem there are three parties. First, there are those on whom the risk is imposed; second there are those who control the risk; and third there are those who benefit from the risk being run. Their chief thought is that the first thing we should do in looking at a risk management context is ask whether it is a context in which the same person occupies all three roles, or whether it is a context in which the controller of the risk and the beneficiary of the risk are different from the person who is subjected to the risk.

Where one and the same person benefits from the risk and can control the risk that they are exposing themselves to, then the context of risk is least ethically problematic: a case of this sort would be when an experienced mountaineer climbs a difficult mountain. Most ethically problematic are

those cases where the risk-exposed neither benefit from their risk exposure nor can control their exposure to the risk: a case of this kind would be where a company pollutes the local water supply because this is cheaper than disposing of their waste properly, and local residents have no option but to continue drinking the water.

Research has two features that push it towards the more ethically problematic end of the risk management spectrum. First, research does not aim specifically to benefit the participants: instead the aim is to generate new knowledge. Even in cases of so-called therapeutic research, what makes the intervention *research* as opposed to treatment is the attempt to generate new knowledge, and the specifically research elements of the treatment do not seek directly to benefit the patient. [4, p.21] Given that those exposed to the risks of research are not intended to benefit from the risk imposition, this immediately makes the risk context more problematic than the mountain-climber case.

Second, the research participant has limited control over his or her risk exposure: the typical research participant is very unlike the experienced mountaineer who can see the rockface above (and has probably climbed the route before), and can at each stage decide which way to ascend in order to ensure safety. The chief ways research participants can control the risks they are exposed to are the informed consent process, and their right of exit from the research project. Given the typical power relations between researchers and researched, ethics committees are usually rightly reluctant to place too

much of the needed weight of risk management on the right of exit from research. It follows that a great deal of the problems of risk management in research need to be solved by the informed consent process. Valid consent requires that the participant be given information adequate to making a reasonable decision as to whether to take part in the research or not. Where the information revealed is less than all that is relevant, then the participant does not have adequate control of the risk, and the risks imposed begin to look more like those in the water pollution case than in the mountain climber case.

Given the nature of the risk management problems that the context of research presents, we think that there is a reasonable presumption that all facts, which would be relevant to making the decision to take part in the research project, will be revealed. And therefore, given this reasonable presupposition, the failure to do so will in general be prima facie ethically unacceptable. However, where methodological considerations require deceptive withholding of information from participants, and the information withheld is not relevant to the decision that a reasonable person would make as to whether to participate in the research, deceptive withholding of information is permissible.

References

- [1] Sokol, D. (2006). "Dissecting 'Deception'", *Cambridge Quarterly of Healthcare Ethics* **15**, pp.457 – 464.

[2] Feinberg, J. *Harmless Wrongdoing*. Oxford: Oxford University Press, 1990.

[3] Hansson S.O. & Hermansson H. (2007). "A Three-Party Model Tool for Ethical Risk Analysis ". *Risk Management*, 9(3):129-144.

[4] Franklin G. Miller and Howard Brody. (2003). "A Critique of Clinical Equipoise: Therapeutic Misconception in the Ethics of Clinical Trials", *The Hastings Center Report*, **33**(3) (May - Jun., 2003), pp. 19-28.