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Informed Consent

An overlooked part of ethical research in interpreting studies[1]

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Abstract: This article discusses the concept of informed consent in interpreting studies. Informed consent implies that a person must be given enough information to be able to consent to participate voluntarily in a research project. The article first gives an overview and background of the origins of informed consent, and its place in ethical research. The article then points to different areas where informed consent in interpreting studies may be delicate, and what to think about in order to obtain truly informed consent; examples are given from different research studies. The article also discusses the research participants' right to their data and what happens when informed consent is revoked. I argue in the article that research students should be taught and trained in truly informed consent, and that the informed consent process should be piloted before the initiation of a study.

Keywords: interpreting, informed consent, anonymity, confidentiality, revoking informed consent

Sammanfattning: I artikeln diskuteras informerat samtycke i tolkstudier. Informerat samtycke innebär att en person som rekryteras som deltagare i en

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forskningsstudie måste ges tillräckligt med information för att ha möjlighet att samtycka till att frivilligt delta i ett forskningsprojekt. Artikeln ger först en översikt av och bakgrund till informerat samtycke, dess ursprunget och dess plats i etisk forskning. Artikeln pekar sedan på olika områden där informerat samtycke i tolkstudier kan vara känsligt, och vad forskaren bör tänka på för att erhålla verkligt informerat samtycke, exempel ges också från andra forskningsstudier. Artikeln diskuterar vidare forskningsdeltagarnas rätt till sina data och vad som händer när ett informerat samtycke återkallas. Jag argumenterar för att forskningsstudenter ska undervisas i och öva på verkligt informerat samtycke, att informerat samtycke ska ses som en process samt att processen för att inhämta informerat samtycke ska göras som pilot innan en studie påbörjas.

Nyckelord: tolkning, informerat samtycke, anonymitet, konfidentialitet, återkallande av informerat samtycke

1. Introduction

As different aspects of research ethics gain ground in human sciences in general and also in interpreting studies (Mellinger, 2020), the issue of informed consent becomes more pertinent. I have previously discussed the issue of the interpreter as a researcher and its possible implications on research ethics (Tiselius, 2019). In that article I discussed informed consent briefly, without going into details. Since then, the European directive on data protection (GDPR[2]) has entered into force, which has had implications for researchers on the European continent. The directive is not directly aiming at research practice, but since a lot of research comprises collection and storage of personal data, it has impacted research as well. Furthermore, any application for funding at European level requires a statement on ethical considerations. Although the GDPR only covers the European Union, and although ethical rules and regulations look different in different parts of the world, it is important both for the research community as well as for the individual researcher to take responsibility for ethical research. An important part of this is informed consent.

2 https://gdpr.eu/

Ethical research revolves around the researcher's commitment to report and represent data truthfully, to be fair when citing and using the work of others and to refrain from conducting research which is not meaningful or useful (Pimple, 2002). This means that the ethical commitment starts with the researcher's sound judgement. However, since the Second World War and through different declarations, the researcher is today surrounded with different frameworks to ensure ethical research.

Ethical approval for research varies from country to country. In some countries the ethical approval for research in the human sciences is vetted by the university to which the researcher responsible for the study is affiliated, in other there are independent bodies responsible for the vetting (Sterling & De Costa, 2018). In some cases, common for interpreting and translation studies (for example text-based studies or corpora) ethical approval is not needed. However, when human beings participate in a study, they need to make informed decisions about their participation. In some extreme cases, the researcher cannot ask people to participate (an example may be register-based studies[3]). In those cases, it is even more important for the researcher to decide as to whether this research should be carried out, and if so, whether, it needs ethical approval. To take the issue one step further, the researcher is responsible for the research carried out being ethical, regardless of whether the project requires ethical approval or not. Or as Phakiti and Paltridge (2015) put it, "[i]f knowledge is gained through research processes that might harm human beings (physically or psychologically), intentionally or unintentionally, then the price of this knowledge is considered too high" (p. 22).

For an interpreting researcher, studying grown-up participants who exercise their profession in a public environment, it may seem difficult to understand how this research could be harmful. Yet, as we shall see there are many areas where there is a potential that our research may, if not harm participants, at least put them in uncomfortable situations. Consequences of this type of discomfort may be a reluctance to further participation in studies in interpreting. Therefore,

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3 Register-based research is research where register data are used. A study can rely solely on register data or register data can be used to supplement other datasets (e.g. clinical data or data obtained by a questionnaire survey). The special characteristic of register data is that the data have not been gathered for research purposes and so a number of unique features distinguish register-based research from other quantitative research (Finnish Information Centre for Register Research, https://rekisteritutkimusen.wordpress.com/register-based-research/).

the importance of responsible and understandable informed consent cannot be underestimated.

The remainder of this text will discuss research participants' informed consent, how we make sure that it is really informed, what it includes, and how to make informed consent not just words on a paper.

2. Background

Informed consent in research can be traced back to the Nuremberg Code[4], which states in its first paragraph on permissible medical experiments:

> [t]he voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

The Nuremberg code, which was included in a verdict in the Nuremberg trials towards the physicians involved in human experimentation during the war, focused on informed consent in medical experiments on humans. Since then it has been included in the declaration of Helsinki[5] on medical research on human subjects. The Helsinki declaration is aimed at medical research,

4 https://www.ushmm.org/information/exhibitions/online-exhibitions/special-focus/doctors-trial/nuremberg-code

5 https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

but has been promoted as a general standard for research on humans and has had an impact on ethics legislation worldwide. While being laid down for medical research, articles 25 – 32 on informed consent are indeed relevant for other types of research on humans. In their proposal for a theory of informed consent, Faden and Beauchamp (1986) propose that informed consent is an individual's 'autonomous action' to authorize a certain act. This autonomous action is based on three conditions; intentionality, understanding and non-control. This means that the intention of the act has to be honest, and the participant has to understand it in order to give up control of the data collected. As researchers we must do what we say that we do in our research, we cannot give a deceptive description of our aim, and we must make sure our participants understand it.

It is generally true that research on humans in interpreting and translation is not at risk of harming the participant, yet it is every researcher's duty to query themselves before involving humans in their research in order to identify possible risks, and also to understand how informed consent is obtained and what truly informed consent may be. In order to obtain truly informed consent the researcher must be conscientious. For example, a teacher seeking to obtain informed consent from his or her students must consider the power balance between teachers and students (Bland & Atweh, 2007). Another example is the 'practi-searcher' (Gile, 1995; Pöchhacker, 1995) wishing to have their colleagues as participants. This researcher might want to consider how consent is given, whether it may be revoked and what to do if it is revoked (Nilsen & Repstad, 1993). The interpreting researcher working in an area where participants include users of interpretation who may not speak the language in which informed consent is given need to think about how to get the informed consent in a way that is truly understandable to the participant.

The question of how to write an informed consent form, and the issues that might arise when collecting informed consent are present in prominent books on research methodology in the field of interpreting and translation such as Hale and Napier (2013) or Saldanha and O'Brien (2013). These publications both discuss the background of informed consent and point out delicate issues, such as understanding the form across languages and cultures as well as the necessity to sometimes understand informed consent as a process where it will need to be reconfirmed during the research process

(Saldanha & O'Brien, 2013, p. 44). This text will take the discussion of informed consent a step beyond the form, and issues around that, and discuss how informed consent also can contribute to the research process in a positive way.

Crow et al. (2006) argue that informed consent puts the research participant on a more equal footing with the researcher. Their paper contains both a discussion with positive arguments for informed consent and one with negative. From the positive approach, they promote always asking for informed consent whether required by ethical approval regulations or not. They further argue that the preparation of informed consent improves the quality of the research in general, and contributes to reflective practice in research (Crow et al., 2006, p. 85). In their study of attitudes to informed consent by researchers in the social sciences, researcher-participants having a more negative attitude to informed consent felt that if the process of getting the consent was too stressful or too complex, the participants were less likely to give honest and well-reflected answers. On the other hand, there were other researcher-participants in the study who argued that in their experience, the process of informed consent potentially leads to hampering of research where vulnerable groups (e.g.) are studied and informed consent might be difficult to get.

In research on second language acquisition, Thomas and Pettitt (2017) point out that there are some areas where it may be impossible to obtain informed consent (e.g. embedded ethnographic research). They stress the importance in such cases to have the research vetted by an ethical review board. Furthermore, they also describe situations where cultural, linguistic or educational aspects may impact the process of asking for and giving informed consent. Tauri (2018) describes how the individual informed consent tradition is counterproductive to the communal tradition of many indigenous communities.

The issue of informed consent is right in the intersection between the research institution's interest of not causing and not being held responsible for harm, the individual researcher's interest of conducting research, and research participants' right to the autonomous action to participate in research or not, and to trust the researcher with their data. Above all, the least common denominator is of course to not cause any harm, neither physical nor psychological. So how do we conduct research in an ethically responsible and

sustainable way in terms of our research participants? What can we ask from them and what can they ask from us? The threat to the research participant in our field of research is in many cases less likely to be physical harm, but harm in terms of reputational risks, anonymity, confidentiality, and power imbalance. Having said that, in some types of modern interpreting research when using equipment for data collection such as EEG or NIRS caps, MRI or PET-scan devices, there may also be studies in interpreting where the issue of possible physical harm may come up.

3. Possible Risks for Participants in Interpreting Research

In this section, I will discuss how we can contribute to truly informed consent, and also foresee mitigating actions, in case of upcoming issues of trust or revoked consent. I will go through risks to reputation, threats to anonymity and confidentiality, and how we should understand the power balance of different relationships and their impact on informed consent. I will also briefly discuss possible physical risks. Some of these topics may not be new to the reader, but there may yet be aspects of them worth considering both for new and seasoned researchers.

3.1 Understanding Reputational Risks

A participant willing to participate in a study may both over- and underestimate the reputational risks of participating in research. The results of a research study will contribute to new understanding of a certain topic. It means, for instance, that a researcher collecting data about participants' attitude to a certain phenomenon, or observing participants in a certain context, will contribute to people's understanding of that group. As a consequence, the researchers will have to ask themselves who is representing the group (Sterling & De Costa, 2018, p. 170). It means who is being asked or observed as being representative for that group, and also of course how the researcher, in turn, analyzes and interprets the data.

From the participants' perspective they may not identify themselves as being representative of the group in question (in our case an interpreter or a translator). Another aspect of this is that participants' involvement or not in a

study may depend on whether their boss, leader, informal leader or trusted peer acknowledges their participation or not. If this is the case, then one may ask whether the issue of individual informed consent is really valid, and what happens if either of the parties (i.e. leader and participant), at some point are not comfortable with the results or for some reason would like to revoke informed consent.

In experimental studies, as I have touched upon earlier (Tiselius, 2019), results may come out which could potentially be counterintuitive to participants' understanding of themselves (an understanding which may have been the driving force for participation in the study in the first place). As an example, an experienced translator may choose to participate in a study on reading patterns during translation, convinced that experienced translators have more efficient reading patterns during translation than novice translators or the general public. During the experiment, the hypothesis may not be confirmed, and the result of the study may be that translators' reading patterns are indeed the same or even less efficient than the general public. Even if results are on group level, and the individual translator is not identifiable, one might question whether the translator would have been as eager to participate had they known that the outcome may be perceived as negative by others. For the translator it may give the impression of being the one who contributes to giving a bad reputation to a certain group.

The potential over- and underestimation of reputational risks by participants, makes it important for the researcher to understand what those risks might be in a certain community, their consequences, and how to mitigate them. Evaluating reputational risks requires in-depth knowledge of the field studied, and also of one's own position in that field (Mellinger, 2020).

3.2 Understanding Threats to Anonymity

Anonymity is different from confidentiality (discussed below). Anonymous data collection means that the researcher does not know the identity of their participants. This can be upheld for instance in questionnaires where the questionnaire is distributed through the internet without the possibility to trace the participants, via traditional mail, or in person with a questionnaire on paper distributed to a group on site. In the case of the internet and mail data collection there may be an issue of knowing that the intended recipient

answered, but this will not be addressed here. Other types of anonymous data in translation and interpreting studies may be different computer tests, such as working memory, or MRI or EEG data collection. In these types of data collection, the researcher may or may not know the identity of the participants depending on whether or not the data collection involved an in-person meeting with the participant in order to collect data. Furthermore, in many cases, the simple act of signing the informed consent means that complete anonymity is compromised. Moreover, as soon as data collection involves video or voice recordings, interviews or any other type of data with identifiable features, the data is not anonymous anymore and must therefore be treated as confidential (see below).

In terms of obtaining informed consent, it's important that potential participants are not to be promised anonymity in data collection when this cannot be granted. Furthermore, one may also want to consider the fact that sometimes participants would insist on participating in their own name. Sterling and De Costa (2018, p. 173) mention an example of this, where participants wanted to use their real names in a study, and where the researcher discovered at a later stage that participants did not understand how the data would be used. Following the wishes of the participants and using their own names is thus not necessarily a straightforward decision. One way of accommodating this wish in observational or interview studies is to go back to participants at different stages of the analysis and publishing process to ask for renewed consent and approval of analysis. In the social sciences this is a process commonly used for the validation of data (Patton, 2014).

Another aspect of understanding threats to anonymity is what a questionnaire actually tells us about the participants. Let's imagine that we are surveying a population of translators. Part of the background questions contains questions about gender, language knowledge and professional training. If the group we survey counts one male who speaks Arabic and is specialized in nutrition, then the questionnaire, despite being anonymous in distribution and data collection, will not be very anonymous when analyzing the data, at least not for that participant. The reporting of the data can of course be made anonymously as the data can be aggregated at a higher data level (e.g. non-European languages, or Semitic languages, or similar). These are issues that cannot be foreseen when drafting the informed consent. But they can be addressed in the development of the questionnaire when the

researcher can ask themselves what type of information is necessary for the study and in the stages preparing data for analysis. These issues can also be addressed when reporting the data.

3.3 Understanding Threats to Confidentiality

If we cannot guarantee anonymity in most research studies, we can, and should, guarantee that data are treated confidentially. This means that the researcher knows, or has access to, the identity of the participants, but that the participants' identity is protected, and that the reporting of results does not reveal the identity of individual participants. In times of digital data handling and data sharing it means that the researcher has to take precautions in terms of how data is stored and shared. In practical terms of informed consent, it also means that data must be coded and that a code key has to be kept safe somewhere if a participant decides to revoke the informed consent.

Threats to confidentiality (and perhaps as a consequence, reputation) may be related to what our participants tell us in interviews or questionnaires. In the translation and interpreting business, we may come across recounts of a certain company, a certain trademark or a certain employer, which may seem uncontroversial, or even self-evident to the researcher, but which may not be considered that way by the company, trade mark or employer concerned. An open question in this context, and to which there are no obvious clear answers, is how we report this data in a truthful way without compromising the confidentiality of either our participant or the third-party referred to. Research should be free and independent, but research(ers) also co-exist in the same world as participants and other dependent parties. Once again a renewed consent process may be considered.

Another area where special attention has to be given to confidentiality is when reporting quotes from participants, a common and popular way to give evidence of the data analysis process in different types of content analysis methods. If a participant has a particular way of expressing themselves, or set phrases they often use, that may be a way of unintentionally giving away a participant's identity in a research report. Our study on deaf interpreters' education (Skaten et al., 2021) is an example of this as we interviewed all deaf trained interpreters in Finland. Since the group is small, it was of utmost importance to report on group level and in a way which would not give away

participants' identities. It is of course obvious that the members of the group have participated in this research, but it should also be clear in the results that it is our interpretation of the group's experience as a whole.

Neither of the two previous examples can (nor perhaps should) be foreseen or dealt with in the informed consent form, but they highlight the possible need to get renewed consent in the analysis process, and the benefits of going back to participants for data validation.

3.4 Understanding the Power Balance in Different Relationships

Urdal (2019, p. 219ff) gives a thorough discussion about researching on and together with one's own students. As teachers of translation and interpreting, we often consider our students first when recruiting for our projects. As Urdal describes, the decision to involve students in research not only needs to be vetted, but also carefully thought through by the researcher. The teacher/researcher needs to understand students' possible motivation to be involved in the research.

The power balance is to the advantage of the teacher, and although we as teachers may consider ourselves inclusive, transparent, and even on par with our students, we are not in a position to judge whether we are perceived or understood as such by the students. An event from my own teaching experience will serve as an example of this. During data collection for my PhD project, I had passed around information about my project among students in our department, looking for participants. I had also gotten some positive answers and started recruiting participants, but it was still before project start and before collecting informed consent. While doing consecutive exercises with a student who was not participating in my project, the following happened: The student rendered an interpretation and we recorded it. The rendition was unusually hesitant, and when finished the student blurted out: 'Well, that recording will give you lots of material for your project'. I was completely bewildered, but it dawned on me that the student thought that I would use the recording in my research project. Very embarrassed for having caused the student such distress, I did my best to calm the student and reassured them that no data collection would take place unless it was preceded by an active decision of enrollment in the project and duly signed informed consent.

There are no one-size-fits-all solutions to how to recruit students for research projects in an ethically secured manner, but there are some ground rules. The university may have guidelines, but on top of that, it is sensible to have the project revised by the ethical review board of the university or other similar body. Ethical approval may not be needed, but having a review board's assessment gives sound support. Furthermore, it is also sensible to review one's own values and driving forces. We may not be aware of them, and we may also not be aware of how our behavior may be perceived by students. Students are in a vulnerable position towards their teachers. Whether we believe that we are strict, correct or easy-going, we may be perceived as something completely different by our students. Urdal (2019) describes this process for her PhD work, where students were both participants in the study and also co-researchers as they contributed to gathering and analyzing data. She used two strategies in her work: as a first step she made sure to distance herself from the potential participants in the project. This means that she changed her timetable so that her colleagues taught these students. She did not recruit the students herself either, but assigned that to other colleagues who recruited and secured informed consent. The second strategy was to have other colleagues who were not part of the research participate in regular interaction with the students about the process. This was done to give them the possibility to discuss any issue that would come up and also to be able to withdraw if needed. These types of activities could be described as informed consent being a process rather than a box to check.

Another situation we may encounter as interpreting and translation researchers is having participants with very limited knowledge of the language in which we are collecting the informed consent. In this context we must also understand that the power relation between the researcher speaking the majority language and the participant with limited knowledge of that language is also to the advantage of the researcher. Informed consent may indeed, as Thomas and Pettitt (2016) point out, be misunderstood as part of, for instance, a treatment. This can of course be a language issue, but may also be due to the power balance. In this context, the researcher can make sure to have the informed consent both written and orally in the non-majority language in question, but the researcher should once again be prepared to approach the informed consent as an iterative process, with recurring confirmation.

3.5 Foreseeing, Explaining, and Avoiding Physical and Psychological Risks

As pointed out above, most of the studies in translation and interpreting studies probably involve low risk of physical injuries or discomfort. There are some studies though which may involve physical risks: these include those using MRI, which is excluded for some individuals (e.g. those with a pacemaker), and PET scanning, which involves injecting a radioactive isotope. Needless to say, these conditions must be clearly explained to participants.

As described by Labott and Johnson (2004), questionnaires and interviews may be upsetting. When addressing sensitive topics through a questionnaire or interview, it may be sensible to both have the questionnaire vetted and provide access to emotional support facilities. When we collected data from participants regarding emotionally stressful situations in their work (Tiselius et al., 2020), our informed consent and pre-interview briefing contained information about how to get support if needed. Working memory tests do not normally cause physiological risks, but it may be good for candidates to know that they are stressful and tiring. Going into a working memory test without that kind of prior information may increase the discomfort.

There is of course no complete check-list to foresee or avoid physiological and psychological risks in research. However, going through and piloting data collection and experiments as far as possible, as well as discussing them with experienced colleagues, and vetting them through review boards help mitigate possible risks and avoid injury or harm.

4. Drafting a Consent Form for Truly Informed Consent

This section will not give examples of informed consent forms; there are ample examples in the literature (notably Hale & Napier, 2013; Saldanha & O'Brien, 2013), and many universities and review boards also have examples or prescribed consent forms. Instead this section will point to some areas which may increase truly informed consent.

A recent investigation on informed consent using eye-tracking (De Nardi et al., 2019) showed that an informed consent form with low readability, where

the reader does not understand the structure, or where the reader is forced to go back and forth instead of following a clear structure of the information, contributes to hampering the understanding of the informed consent.

The use of plain language in an informed consent form will also contribute to understanding. Researchers are instructed to provide the presentation of the study in a form that a layman will understand, but I would like to push it one step further and suggest that the presentation be given in plain language. Although, as mentioned by a participant in Crow et al. (2006), some participants stop reading very early in the informed consent form, they might seem to have already decided to participate. Because the informed consent may be misunderstood, it is still a good idea to combine the information written in the form with an oral explanation. This can of course only be done if participants are present physically or digitally.

Just as we pilot the study, we should pilot the informed consent form, and just as we train students in research methods we can train them in obtaining informed consent. We can never completely understand how our counterpart will understand our information, but if we add communication to our information, chances are that we get closer to truly informed consent.

5. Participants' Right to Data and Revoking Informed Consent

In this final section, I will discuss the participants' right to their data and how a participant can revoke informed consent. Depending on the type of data collection, revoking consent is more or less complicated. As a general rule, though, if a participant voices a wish to revoke data, it should be seen as a success for the researcher who has been able to convey that the participant can truly revoke their informed consent and request their data to be destroyed.

It must however be clear as part of the informed consent what rights the participant has to their data and for how long. A participant who answers a survey anonymously (i.e. anonymous to the researcher and without any personal information collected) cannot revoke participation when the questionnaire is submitted, as it will be impossible to trace it back to the participant. This means that as long as the participant has not submitted the data they can decide not to do it, but once submitted, it will not be possible to go back on

the decision.

On the other hand, the participant in a study with tasks such as working memory tests, who is not anonymous to the researcher during data collection, and where the data can be traced to the participant through a code key, has every right to revoke their consent and ask their data to be deleted. This also holds for a participant whose data contains video or sound files or interview scripts. Different countries have different rules regulating how long participant data is to be stored. As part of the informed consent procedure, participants should be told how long their data will be stored. As long as the data is stored, the participant can always ask for their data to be deleted or destroyed. Participants of course have the right to know how their data is going to be used, and it is the researcher's obligation not to use data in any other way.

The participants' right to have their data deleted is not linked to research findings though. When data analysis is done and raw data has transcended into findings, the participant cannot claim the right to findings (Iphofen, 2020). Published, anonymized, analyzed data cannot normally be the subject of a demand for retraction from a participant. The researcher, though, has a responsibility for ensuring that the findings in a publication are correct, and should they at some point be proven incorrect due to issues with the supporting data, it may have implications for the researcher.

6. Conclusion

In this paper, I set out to explore different aspects of informed consent in interpreting studies. I aimed to discuss the process of informed consent beyond the consent form. I also wanted to describe how the informed consent process could contribute to the research in a positive way. As I hope to have shown, obtaining informed consent is a delicate, complex, and crucial process for our research. I argue that paying attention to the process of getting informed consent will increase the quality of the study. I also promote the idea that students at all levels should be trained to develop and reflect on informed consent. Finally, I would encourage colleagues to consider informed consent a process, and to include a discussion on their informed consent process in the section on ethical considerations in their publications.

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Professional Profile

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