



Experiences of Ethical Review: Perspectives of Swedish Researchers in Social Science and Humanities

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Abstract

This paper presents the results from a qualitative study with Swedish researchers in the social sciences and the humanities. The aim of the study was to explore researchers' perceptions of ethical review (i.e. the pros and cons of the system) and to what extent the system of ethical review could possibly be reformed to better accommodate research in the social sciences and the humanities. To this end, 7 semi-structured group interviews were conducted during the spring of 2024. In total, 18 researchers from different fields of social sciences and the humanities participated, including business, language studies, history, educational science, health and society, political science, psychology, human rights, youth studies, legal studies, religious studies, gender studies, sociology, and peace and conflict studies. The results of the study show that the perceptions of the participants vary significantly when it comes to the issue of whether ethical review should be externally regulated. While some participants clearly favoured a system of self-governance, others say that ethical review should indeed be regulated externally for reasons of fairness and impartiality. Many of the participants say that the process of applying for ethical review suffers from lack of support from the Ethical Review Authority and that the bureaucracy of ethical review focuses too much on technicalities that researchers not always find relevant. They also report that the system is associated with fear of doing wrong and that some researchers sometimes deliberately choose research topics or methods that do not require ethical approval.

Keywords Ethics regulation · Ethical review · Group interviews · Social science · Humanities · Research ethics

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Introduction

It is paramount that research involving human beings is performed in an ethically defensible manner and with proper respect for the research participants. This is important for the sake of protecting the rights and interests of research participants, but it can also serve the function of maintaining public trust in research (Hansson, 2011). Human subject research must therefore often undergo ethical review before it can begin. How such review is regulated and administered, including what type of research requires ethical review, varies between different countries and jurisdictions (Johansson et al., 2023). However, it is widely accepted that ethical review should be required for at least some human subject research for the sake of protecting research participants from physical and psychological harm, as well as their integrity (Colnerud, 2015; Johansson et al., 2023).

Despite being a common practice, ethical review is not without problems. In previous research, it has been noted that the practice of ethical review is developed within the context of biomedical research. Because of that, it is often said to be less suitable for research in the social sciences and the humanities (Brown et al., 2020; Schrag, 2011; Colnerud, 2015; Dyer & Demeritt, 2009; Gelling & Munn-Giddings, 2011; Wynn, 2018; Wästerfors, 2019). This has led some commentators to suggest that the whole practice of ethical review of social sciences and the humanities should be rejected (Dingwall, 2008; Schrag, 2011), whereas others suggest that ethical review needs to become more flexible to the methodological approaches commonly used in social sciences and in the humanities (Bülow et al., 2024; Gelling & Munn-Giddings, 2011).

In this paper, we present findings from an explorative qualitative study with Swedish researchers in the social sciences and the humanities. The study focused on to what extent they experience that the Swedish ethical review system works well (i.e., its perceived pros and cons), and to what extent the system can be improved to better accommodate research in the social sciences and the humanities.

During recent years, the Swedish ethical review system has been much debated and criticized, not least from the perspective of the social sciences and the humanities (Engström, 2023). Given this recent debate on ethical review, as well as the special circumstances of the Swedish ethical review system, the perceptions of Swedish researchers present an interesting case study on ethical regulation and ethical approval of social sciences and humanities, exploring some of the challenges associated with regulating research ethics in these fields.

Background

The Swedish Ethical Review System

The Act (2003:460) on Ethical Review of Research Involving Humans (lag (2003:460) om etikprövning av forskning som avser människor) was first introduced in 2004, with substantial revisions in 2008 and 2020. The aim of the act is to protect research subjects and the respect for human dignity in research. The act states that ethical approval is needed for research that involves processing of sensitive personal data (as defined in Article 9 in the European General Data Protection Regulation) or personal data about legal offenses, crimes, criminal convictions, procedural coercive measures, or administrative detentions

(cf. Article 10 in the European General Data Protection Regulation). Ethical approval is also needed for research that is performed with a method that seeks to influence the research subject either physically or mentally, or where there is a clear risk of harm being caused to the research subject. These criteria imply that a lot of research projects in the social sciences and the humanities require ethical approval on the same basis as medical research. Conducting research without ethical approval is punishable by either a fine or a prison term of up to two years. (Ethical approval is also needed for research that involves a physical intervention conducted on a research participant or is conducted with biological material taken from a human being and which may be traced to this individual. It is also required for research with biological material taken from a deceased human being for medical purposes as well as research that involves physical intervention on a deceased human being.)

Applications for ethical review are decided by a central agency, the Swedish Ethical Review Authority (SERA). The appeal board (ÖNEP) supervises that research projects are carried out in accordance with the act. Following a regulatory change in 2020 that clarified the supervisory responsibility, the board has taken a more active role. This has increased the awareness among researchers in the social sciences and the humanities that the Act also applies to them.

As previously mentioned, there has been quite some debate in Sweden concerning the ethical review system, especially among researchers in the social sciences and the humanities (Engström, 2023). In 2023, an inquiry was appointed to investigate how the Act could be reformed, with a particular focus on whether parts of the social sciences may be discharged from the requirement of ethical approval and on the appropriateness of having criminal sanctions (Regeringskansliet, 2023). The inquiry presented its proposal in September 2024. If the proposal goes through, the SERA's remit for research in the humanities and the social sciences will become considerably narrower. (According to the proposal, some research that currently must undergo ethical review by the SERA only because it involves the processing of data should be exempt from such review. The proposed exemption would apply to research involving the processing of data that either (1) relates to a research subject who is over 18 years of age and has been provided by the person with informed consent, or (2) relates to a research subject who is over 18 years of age and has been publicly disseminated, or (3) is contained in public documents and is not subject to confidentiality. In addition to meeting one of these requirements, the research must involve only a minor risk to the health or safety of the individual or to the individual's privacy. If these requirements are met, the research project need only be reviewed by the responsible researcher's home institution.)

Previous Research

In the international research ethics literature, it has been argued that ethical review is too focused on then medical sciences to fit research in social sciences and the humanities (Bülow et al., 2024; Colnerud, 2015; Dyer & Demeritt, 2009; Gelling & Munn-Giddings, 2011; Wynn, 2018). One reoccurring claim is that the framework adopted by ethical review boards tacitly imposes a philosophical framework developed in the natural sciences and that proceeds on the basis of the *hypotechical-deductive method*. In contrast, much work in social sciences and the humanities is exploratory building

on the philosophical tradition of hermeneutics, in which research purposes, methods, and intended outcomes are fluid and evolving during the research process (Brown et al., 2020; Bülow et al., 2024; Dyer & Demeritt, 2009; Schneidman, 2024). Others have argued that the framework of ethical review risk reducing research ethics to a bureaucratic process of merely following administrative demands and ‘checking off the boxes’ instead of engaging in meaningful research ethical discussion that explores the ethical implication of one’s research (Brown et al., 2020; Schneidman, 2024). It has also been debated whether research within social sciences and humanities involve risks of harm comparable to those in medical science (Bülow et al., 2024; Dingwall, 2008; Dyer & Demeritt, 2009; Hansson, 2020; Hunter, 2014; Schrag, 2011; Schneider, 2015).

Researchers’ experience and perceptions of the Swedish ethical review system have previously been studied by Colnerud (2015). Colnerud’s study was performed with a different study population than our present study and included post-doctoral researchers in medicine as well as in the social sciences and the humanities. It was also performed before the most recent changes of the Act and the aforementioned public debate on ethical review took place. That said, Colnerud (2015) notes that the Act was largely formulated from the perspective of biomedical research ethics, which stresses the importance of protecting human research subjects from physical and mental harm as well as their integrity. In her study, Colnerud observed a few problems associated with this decision. Her respondents held that the Act “is poorly adapted to the social sciences because its starting point is to be found in a model of medical research (2015, p. 244).” Some of the respondents also expressed lack of confidence in the ethical review boards’ ability and competence to review work in the social sciences (see also Schrag, 2011). On a more general point, Colnerud observes a risk of juridification, in which the professional discourse of research ethics is replaced by a juridical one. This, Colnerud argues, could lead to a de-professionalization of the researchers, “in the sense that the researchers no longer take responsibility for the various ethical problems that arise within their research practice” (Ibid, p. 251).

Researchers’ views about the Swedish ethical review system are also explored in Engström (2023), who provides a thematic analysis of the public debate concerning the Act. As Engström points out, the Swedish debate on ethical review was at first a debate in which mainly medical scientists took part. However, around 2022 the majority of researchers voicing their criticism of the law in national newspapers and other forms of traditional media came from the social sciences and, to some degree, from the humanities. Several problems were then highlighted by the researchers who took part in this debate. One concern was that ethical approval inhibits research. Some researchers expressed the view that the system allows for little room for freedom and flexibility of the sort often required in social sciences and humanities, but also that there is a lack of clarity about for what research ethical approval is needed. Some researchers have also raised the concern that researchers are afraid of being prosecuted for not having abided by the law (ibid., p. 101-2). Like Colnerud (2015), Engström (2023) argues that research ethics in Sweden has largely been a juridical discourse where the focus is more on technical questions concerning the law rather than the ethical aspects and challenges in research.

Method

Participants

In late January 2024, not long after the inquiry was appointed, information about the study was sent to individual researchers at departments in social sciences and humanities at one university in Sweden, who were then asked to put up a poster at their department or research centre and to inform their colleagues about the study. In March 2024, the procedure was repeated and information about the study was sent to institutions at two more university. 22 individuals expressed interest and had the opportunity to participate and were scheduled for interviews. An addition of 6 individuals expressed interest in participating but could not make it on any of the available dates for interviews.

The participants were initially divided into groups of 3–4 researchers per focus group. The size was a deliberate choice, since we thought that small groups would allow each participant to elaborate more on the questions that was addressed during the interviews. We also chose to have mixed groups with people from different academic backgrounds, hypothesizing that this may help boost discussions and allow the participants to share their different perspectives with each other. Unfortunately, we had a few last-minute cancellations, which left us with four interviews with only 2 participants each. In these cases, the groups are perhaps better described as dyadic interviews. As elaborated in Morgan et al. (2013), dyadic interviews are similar to focus group interviews in the sense that they are forms of interacting interviewing. Like focus groups, dyadic interviews allow participants to share their views and perspectives with one another, which helps bring about similarities as well as differences in the perspectives of the participants.

In the end, 7 semi-structured group interviews were performed and 18 researchers participated in the study. The participants came from the following disciplines: business, language, history, educational science, health and society, political science, psychology, human rights, youth studies, legal studies, religious studies, gender studies, sociology and peace and conflict studies. 12 participants were women whereas 6 were men. 13 participants had a PhD (4 of which were full professors) and 5 were PhD students.

Method and Analysis

The interviews were semi-structured, combining a set of pre-determined open questions concerning the participants' academic background, previous experience of ethical review, their perceptions of the system, and their ideas for improvement. Each interview was 90 min long, including a short break. The interviews were performed in Swedish and recorded and transcribed into text and analysed according to content analysis. The transcription was assisted with the AI tool Whisper and performed on a local system at Uppsala University, making sure that the audio data was processed locally and securely, without being transferred to external services.

Having performed 7 group interviews, no new information emerged in the interviews. In order to ensure reflexivity in data interpretation, all authors first read the transcribed interviews and provided individual proposals for possible codes. All proposed codes were then discussed jointly within the group before the final codes were settled. The codes were then categorised into larger themes, again as a result of a deliberative process and discussion

within the group The relation between codes and final themes is exemplified in Table 1. The proposed themes were then discussed among the authors and more carefully formulated in terms of their scope and precision (Table 1).

Eight themes were identified (see result section below). All quotes in the findings have been translated by William Bülow.

Ethical Aspects

This study was approved by the Swedish Ethical Review Authority nr: 2023-01573-01. All participants received written information about the study in advance as well as in direct relation to the interviews. Informed consent from all participants was obtained prior to the group interviews, including information that they were allowed to opt-out at any time. The interviews were transcribed in with the help of the AI tool Whisper and performed on a local system at Uppsala University to make sure that the audio data is processed locally and securely, without being transferred to external services.

Findings

The findings of the group interviews are divided into the following themes: (1) Responsibility for research ethics, (2) Not knowing all research details in advance, (3) Challenges with filling in the application, (4) Two functionally different approaches to research ethics, (5)

Table 1 Example of the codebook

Theme	Codes	Quote	Definition of theme
Responsibility for research ethics	We – the researchers - are the experts	“... I wish there would be a cultural shift as well. And a cultural shift that places greater responsibility and control. That is, <i>that we as researchers feel that we are the ultimate experts on this.</i> ”	Theme concerning how to best promote research integrity and good research practice, who should bear the responsibility for ensuring ethics in research, and why.
	Promoting virtue and sense of personal responsibility/Research ethics as virtue	“I think ethics is incredibly important. Thinking about ethics. And it’s good that we’re forced to think about it. But the way we’re forced to think about it is totally, at best, ineffective, at worst, counterproductive.”	
	Institutions may lack competence or routine for handling ethical issues	“I don’t think you can take it for granted that all [research] environments have such good preparedness, or a good tradition of discussing research ethics. Or the competence for that matter.	
	Researchers don’t deserve self-governance	I think the research community has not really earned itself self-regulation on this point.	
	Fairness and impartiality in applying research ethical principles	“We need general principles that are applied the same everywhere. It is fair both for the researchers and for those participating in the project.”	

Unsuitable application form and lack of support from the SERA, (6) Feelings associated with ethical review (7) Ethical review and research choices, and (8) Disagreement with the underlying principles of ethical review. While some of the codes overlap, we present each of these themes in turn.

1) Responsibility for research ethics

A reoccurring theme in the interviews concerned whether it is appropriate to have an external governmental agency handling the ethical review (as is the case in Sweden), or whether ethical oversight is better left to the researchers themselves or their respective universities or faculties. Several participants clearly favoured the latter, arguing that it would be better if research ethics was left to the individual researchers. One participant asked:

Should there really be an ethical review board? Shouldn't colleagues, research environment and research seminars review it instead? Maybe there is such a function, like "let's have an ethics seminar about this project, in which we go through what you'll plan to do." As a form of decentralisation and bringing the issue back to us. (Group 1 participant C)

One reason why several participants favour a system of self-governance is because they believe that this may help promote a sense of personal responsibility among researchers. Several participants also emphasized that they are the prime experts on their own research. Here is how one participant summarised their view:

I would also like to see a cultural shift. A cultural shift that puts larger responsibilities and governance on, I mean, where we as researchers feel that we are the experts on all this. That I as a researcher bears a heavy responsibility. That creates a sense of morality. Nobody is looking over your shoulder. What I do matters. I must reflect! I have to think. (Group 7 participant D)

In contrast, several participants also recognized that there are problems with leaving research ethics completely to the individual researchers. Several participants, although favouring self-governance, said there are research environments that may lack the proper infrastructure for handling ethical issues properly. Another participant said that researchers and the universities, judging from past experience, do not deserve this responsibility.

I think the research community has not really earned itself self-regulation on this point. (Group 6 participant B)

And yet, another participant stressed that such a system is fraught with several problems that renders it undesirable.

We need general principles that are applied similarly everywhere. That is fair both towards the researchers as well as those participating in research projects. But there is also a risk of a lot of tension regarding these matters if colleagues have to make this sort of decision for one another. It goes without saying that there will be problems with the work environment and undue pressures and so on. (Group 5 participant A)

Another researcher stressed that importance of treating all disciplines similarly.

I don't think there should be a difference between the humanities and the natural sciences. It's about legitimacy. It is state-funded. I want the public to have confidence in

what we do. And I don't think we should trust every researcher, left and right. (Group 3 participant B).

2) Not knowing all the research details in advance

Several participants stressed that much work in the social sciences and the humanities is largely inductive, meaning that it is not always possible knowing all the details of a research project in beforehand. At least not in the sense presupposed in the context of ethical review. To the contrary, participants emphasized that their work is often explorative and data-driven, without knowing exactly all details of the research in advance or what the object of the research will be.

I think that, now that I've been around for a while – I've been a doctoral student for five years – you kind of learn more about research in the humanities. That you build up the projects a bit more gradually in the humanities. And you work with the research data and material to find your research questions. It's more of a dynamic process: a hermeneutic circle. (Group 4 participant A)

This focus on explorative and data-driven research sometimes implies that it can be difficult to make estimations of various risks and other ethical challenges that one may encounter, as described by the following participant:

There are a lot of things that happen before you enter the field, when you are in the field, and after you leave the field. And these social situations are about interactive processes: you can't predict them. It's completely impossible to say that this and that will happen. You can speculate based on experience from the research literature, previous methodological literature, and you can guess that this and that could perhaps... So, it becomes really strange to sit and write about risk assessments that you can't know will or will not happen. (Group 7 participant B)

3) Challenges with filling in the application

In relation to the perceived tension between the methods of social sciences and the humanities on the one hand, and the requirement of ethical review on the other, some participants discussed different strategies for how to handle this mismatch. Several participants described writing an ethics application as a balancing act that involves learning how to write the application as open as possible while at the same time give enough details about the project, so that it may be approved by the ethics review board. This type of balancing act may be particularly challenging for PhD students, as is reflected by the following reflection:

What felt difficult with the ethical review was that I needed to know quite a lot about my project before I had carried it out. I had probably expected that I would be able to have a bit more of a 'snowball effect' while collecting my material. That is, to look into the archives, to be able to find other material and so. But yes. It took me quite a long time to write up my ethics review because I felt like I had to know more. "What will I find?" "What could it lead to?" Also, a bit of fear of having to make an applica-

tion for revision. So, I struggled quite a bit with how to write it. So, to leave it as open as possible, but still be able to be as specific as it requires. It was a difficult balance, I thought. (Group 4 participant B)

A PhD student from one of the other group interviews reported a similar experience:

I tried to include as much as I could in the application. Like, “This is my plan, but this is a template, and it can be changed in this and that way.” For example, “I could do this and that kind of thing”. I really tried to include as much as possible. So, it worked out pretty well anyway. I wrote like, “I plan to use grounded theory at least initially”, and that was kind of fine in the application. They didn’t have any comments on that. (Group 2 participant A)

Several senior participants talked about how they have learned how to fill in the ethics application to get it approved. This often involved learning standard formulations, phrases or wordings, which they know that the ethics review board appreciate. One respondent described it as a type of ‘know-how’ or tacit knowledge for how to make sure that one can be flexible enough, for instance when conducting qualitative research. It could be about making sure to write in the application to the SERA that one’s interview guide is merely a proposal, or that the questions are but examples of the type of questions one will ask.

... when you design the interview guide, as an appendix to the ethics review application, I have a wording there. And it’s pretty short. If I had it longer and fairly specific, I would be stucked. So, you learn. And I also write that “these are qualitative interviews” “You can’t say in advance”, like that. But using that type of wording, it’s like know-how knowledge for not ending up in a [challenging] situation. (Group 1 participant A)

The same participant, as well as several others, stressed that it is important to give a span of number of participants, in case one may wish to include more research participants than one has originally planned for. A few respondents also explained that you learn which formulations or wordings to use from colleagues.

4) Two functionally different approaches to research ethics

Several of the participants said that the process of ethical review had very little to do with actual research ethics and more about them learning the correct formulations or wordings. Because of this, they also said that the system somehow distracts researchers from engaging in more substantial and, in their view, important research ethical discussions. One of the PhD students explained that they believe that the requirement of ethical review creates a system of two types of ethical approaches; one that amounts to a type of checklist ethics, and one that concerns ongoing discussions and engagement with ethical questions that arise in one’s research. A participant from another group interview presented a similar view:

I believe that we have a lively discussion about research ethics at our department. It is part of almost all research seminars and PhD Seminar. [...] but it feels like these

are two separate, parallel discussions. One of them is the “standard ethics” which is about filling in these forms, which is rather, from our point of view at least... I have the impression that that discussion is a little bit like; we do it to please someone at that governmental agency. And the “real ethics” is something that we handle every day. (Group 7 participant B)

Yet another person made the distinction between review as a bureaucratic process, and the importance of ethics.

For me, it is important to distinguish between this formal bureaucratic thing, which to me is just a burden and a hurdle without function, and thinking about how to do ethical research, especially towards the people you interview. Those are two completely different things. (Group 3 participant A)

Some of the participants said that a much too strong focus on ethical review and how to fill in the ethics application takes time away from discussion on other important topics in research ethics – not least when it comes to teaching research ethics to PhD students. Several participants noted that there are a lot of difficult ethical questions in their fields of research, which are not necessarily covered by the Act (such as how to handle unexpected events during field studies, risks associated with doing research abroad in developing countries, or whether it is ethically defensible to use data that has been made publicly available through unethical means). In the context of PhD education, however, it is natural to devote an important part of the time to helping students learn how to fill in the form properly, sometimes at the expense of promoting a lively and ongoing discussion about important research ethical matters.

Several participants said that the bureaucracy associated with ethical review also tends to spread at the expense of individual responsibility and personal engagement in research ethics.

Another thing that is specifically about bureaucracy is that my impression is that the bureaucracy of the ethical review authorities, it also spreads to the universities, who then believe that they must continue in the same spirit. (Group 5 participant A)

Several participants saw ethical approval as a form of external control that seeks to influence them. One participant said that ethical review is part of the movement of New Public Management, with an increased focus on processes and check-ups.

Even though several participants stressed that the requirement of ethical review has not helped promote much ethical reflection among them and their close peers, a few participants said that the requirement of ethical review has indeed made them more aware of research ethical dimensions of their research.

[...] in the faculty of humanities where I work, I would say that the Ethical Review Act has generated a discussion about research ethics. A higher awareness of research ethics. (Group 6 participant B)

Another participant – also coming from the humanities – stressed that the requirement of ethical review had led to a much broader ethical discussion within their field of research. Some senior participants stressed that the fact that PhD students have to write an ethics application provides a good opportunity for them as supervisors to discuss ethical aspects of their student's project at a very early stage, including ethical aspects that are not always identified by the SERA or covered by the regulation. This includes ethical aspects that arise when interacting with research participants in ethnographic field work, during qualitative interviews and when conducting research abroad. Likewise, a few of the PhD students said, despite some negative experiences, that it was good to write an ethics application and that they learned a lot from doing so, including more critical reflection on ethical review as well as research ethics more generally.

5) Unsuitable application form and lack of support from the SERA

One reoccurring theme in the interviews concerned communications with the SERA. One issue is how to interpret some of the questions in the review form, especially since many of the questions are not always considered relevant to research in the humanities and the social sciences. One participant explained that they thought that it is not always easy to translate the questions into the type of research performed in the social sciences and the humanities.

There is a lot, especially in this application, that is not relevant to fill out. Above all, it is difficult to know how to formulate it so that it somehow fits the research you are doing. In some way, it is because of the knowledge interest or the conditions that exist within your subject. Because you are not talking about test subjects, perhaps, or research subjects *in that way*. Because you are not really working with research subjects, but you are actually working with text, data, documents, like, which are not...

You are not applying to be able to talk or do studies on people, but on their products in some way. (Group 4 participant A)

Interestingly, this type of concern is raised in several interviews and by participants from different fields of study, including language studies, history and legal studies. Several participants also said that they believe that the SERA does not provide enough guidance or feedback if one has queries about the questions in their form. This lack of feedback creates a type of opacity and makes it difficult for researchers to understand what is expected of them, or why some research projects are approved whereas others are rejected or asked for revisions. This is further complicated by the fact that some participants have experienced that the SERA sometimes requests revision because of mere technicalities, such as whether one has used their preferred form for the written informed consent from research participants.

Several participants explicitly argued that they would like to see a system of ethical review in which they receive more support and proper feedback, and which help them address the ethical considerations they have. Others expressed that they would like to see an application form that is much more suited for their type of research, if it concerns document studies for example.

While several participants expressed difficulties about the form and the contact with the SERA, others said that this type of criticism of the ethical review system is exaggerated.

[...] I know there is some criticism from humanities researchers that the form or the whole process is more focused on medical and natural science research than on the humanities. And that it does not suit humanities research as well. I do not really agree with that. I think that is exaggerated. (Group 6 participant B)

6) *Feelings associated with ethical review*

In several interviews, the respondents discussed how the system of ethical review is associated with feelings of a sort that are not always conducive to good research. This is not least due to the lack of clarity and perceived unpredictability with regards to the SERA. Here is one participant elaborating on this issue:

.... it is a system that has created a huge fear of making mistakes. Much more than a willingness to discuss research ethics. That is, the substance, what is good research ethics? And... the experience of a bureaucracy where it is just about trying to get the application through and get it approved, rather than conducting good, high-quality research. [...] Then there are a lot of practical obstacles, that it costs money, and, that for PhD Students, that it risks creating hurdles in the work, and stress (Group 5 participant C).

One reoccurring theme in the interviews was that the review system causes feelings of fear and anxiety.

I don't feel that worried. But on the other hand, I see a lot of colleagues of a more anxious nature who are very worried. And it creates a lot of trouble for them. Sleep problems and the like. And often in a very, "Am I even allowed to read articles in the media if I don't, before I have done an ethics review"? That kind of questions. (Group 7 participant C)

When asked about how they handle the fear, one participant said:

I have colleagues who completely opt out of empirical research (Group 5 participant A).

Colleagues within your discipline? (Interviewer)

No, but researchers in social sciences, who choose to do other types of studies. Hmm. Because they... well, they think it's cumbersome and difficult, and doubt that the research would pass (Group 5 participant A).

Another participant said that fear of doing wrong undermines the freedom of researchers.

... but the way the system looks today, including the sanctions, doesn't mean that you as a researcher... You don't carry with you the freedom as a researcher. And you don't have... you risk being too cautious. Out of fear of breaching the boundaries. (Group 2 participant B)

Several participants, PhD students as well as more senior participants, said that fear of doing wrong is common among PhD students. One senior participant said:

For my own part, I haven't felt any uncertainties. But it is so for the doctoral students. There is so much that is new for them too; the entire academic world. So that they are very afraid of making mistakes. (Group 7 Participant A)

For the PhD students, the fear of doing wrong is partly due to the fact that they fear losing important research time, especially if having to make an amendment application, but also the fear of not being able to conduct the research project they want. One PhD student explained:

[...] you were still a little worried about it [the ethics application]. Because I can also think that as a doctoral student you know that this costs a lot of money. And, uhm, and I'll try to be as open as possible, but at the same time I want to be so clear and show that I thought this through, that I feel that I have a good chance of getting it approved. Because otherwise it just feels like I'm wasting time and money (Group 2 participant A).

The fact that there are a lot of fear of doing wrong is partly due to drastic examples that one has heard of or read about. In one of the interviews, this fear was also problematized, as illustrated by the following comment from one of the other participants in the interview.

But it's also sad. Because this fear, it's a bit of a self-playing piano. Because the vast majority of applications are approved. And a huge amount of research is allowed. So, these terrible examples, they exist, but they create more fear than they really should, I think. (Group 5 participant A)

When asked about how to reform the ethical review system, such that it no longer evokes fear and anxiety among researchers, several participants stressed that there should be no criminal sanctions for not abiding by the Act.

This thing about fines and prison and stuff. We shouldn't have that here. It just scares people in a destructive way (group 6 participant B).

Another suggestion is to encourage peer discussion:

... talking to colleagues has been important to me. And also, that I have had such conversations with anxious colleagues. That you try to calm each other down completely by exchanging that information. (Group 5 participant C)

Besides fear, participants also explained that the requirement of ethical review sometimes take away the joy of doing research. Here is one example:

But just concerning this new experience that I have [of having to write an ethics application]. Well, the start-up phase is so much longer. It takes a lot of time. And as

I said, I also think that I have lost a little bit of the joy of doing research. (Group 1 participant B)

7) Ethical review and research choices

As already noted, the fact that the system creates fear and anxiety among researchers suggests that it may sometimes discourage important research. The issue of how the system might affect research choices was also a reoccurring topic in the interviews.

A big risk, and as I see it in my subject, it is simply that we have this fear, either of making a mistake or of not getting our ethics review application approved. That we simply choose to avoid, like, source material or methods that are difficult, or those things we perceive may require ethics review. It may also be that we simply do not want to engage in the process for various reasons, because of lack of time, or financial reasons, or something like that. Which causes a... that we simply go to other materials and that important research is not carried out (Group 5 participant C).

Although quite a few participants said that they themselves had not adjusted or in other ways chosen different paths in their research, many of them said that they have colleagues who had done so. One of the PhD students reported:

I know that there are many doctoral students in my department who think that way. That, that you might choose to avoid certain types of research questions. That you choose to avoid certain types of methods, to avoid making an ethics review application. And, if you still feel that you want to do it, you might choose certain methods so that it might be easier to write the ethics review application. (Group 2 participant A)

One senior participant reported that she knew only of one concrete case:

The only concrete case I can come to think of is a PhD project that was historically oriented. There we decided the end-date for the historical period to be examined based on whether there would be any humans still living in the empirical data or not. (Group 6 participant B)

Another participant reported that there is a lot of fear associated with including children in research, as it becomes more technical and includes practical complications in terms of informed consent, which may lead researchers to exclude interviewing children in their research.

Some participants provided examples of research that might be difficult to perform because of ethical review. One example was research with teen-agers under the age of 18, who are transgender. These individuals may not necessarily be open about their gender identity to their parents. But because ethical review (with its emphasis on informed consent) require the consent of the parents and not only the child, this may also render this type of research difficult or impossible to perform.

8) Disagreement with the underlying principles of ethical review

Among the participants there is a lot of disagreement regarding ethical review and the principles underlying it. This includes both disagreement with legal requirements in terms of what type of research requires ethical approval as well as disagreements about default positions commonly assumed in the context of ethical review. Here it is worth noting that the Act has been subject to a lot of criticism from researchers in the social sciences and the humanities (Engström, 2023). This is most evident when it comes to the requirement of ethical approval for research on sensitive personal data that is publicly available (such as political opinions of public officials, courts cases or public documents). Almost no participants in the study believed that research of this kind should require ethical approval. However, some participants explicitly said that all research processing sensitive personal data should undergo ethical review.

Yes, but sensitive personal data, if I only think from our perspective, that I think it should still be reviewed. But also, when it comes to different types of risks you could expose the participants to. When it comes to interviews, you don't know what you might be talking about. Or, as I mentioned before, how one's participation may affect the situation we are in (Group 5 participant B).

In contrast to this view, another participant said that there is often an assumption that research with human subjects is always intrusive.

[...] there is an implicitly rather negative view of research within the ethics review authority. You are considered to be intrusive. So, by default, you expose the research subject to an intrusion. Which means that we must protect them and that we always have to balance the demands or desire for new knowledge versus this intrusion. But in a lot of cases, my picture is actually – both from having been a student and a doctoral student – that often it's not like that at all. Most of the time these things, interviews for example and the like, become quite rewarding conversations. (Group 1 participant C)

Like most ethical review systems, the Swedish ethical review system is largely based on principles found in research ethical guidelines concerning biomedical research ethics, such as *The Declaration of Helsinki* and *The Oviedo convention*.¹ These include importance of written informed consent and confidentiality. A few participants discussed the default positions assumed in the context of ethical review in terms of informed consent and anonymization. Starting with the latter, it was argued, contrary to the widely held view of ethical review boards, that there might sometimes be good reasons not to anonymize participants, because it would deprive someone of agency.

And also, that you should assume that everyone wants to be pseudonymized. That you should assume that people don't want to stand by what they've said. That's also an aspect of this. What it is to attribute or deprive someone of agency. (Group 4 participant B)

The question of pseudonymizing places was also addressed in another interview.

¹ As a matter of fact, the introduction of the Act was in part due to the ambition to ratify the Oviedo convention, although this has yet not happened.

A discussion that we have had, where the starting point is that you should always anonymize location, for example. That you should always anonymize where the research is done and so on. In a couple of research projects, we have done research with residents in so-called socially vulnerable areas. Where there is a point in kind of going against the territorial stigmatization, actually. And telling other types of stories. Stories that are not seen in the media, for example. (Group 7 participant B)

As for informed consent, several participants noted that the default assumption in ethical review (that participants always should provide written consent) may sometimes be problematic. As one participant carefully explained, the main rule when it comes to ethical review is that you should obtain informed consent from the research participants. But if you perform research with socially vulnerable individuals, for example migrants, asking them to sign a form might itself become an assault. In such a case, a different procedure for obtaining informed consent would be preferable from a research ethical point of view, although the SERA treats this as an exceptional case.

As already noted, the participants said that the ethical review system is overly restrictive as it requires ethical approval for research on publicly available sensitive personal data. However, a few participants expressed criticism about the system being too restrictive in other ways. One participant explained that he had been told that deception in research, for reasons of informed consent, is deeply unethical, and he thought that this might largely exaggerate the risks of participating in such research.

But there is a kind of hysteria, I think, around the fact that what we do has such incredibly strong ethical significance. And an example of that is, I don't know what you say in Swedish, but "deception" in experiments. (Group 7 participant D)

Another participant thought that the ethical review system puts too much emphasis on protecting the individuals at the expense of hindering important research. He said that the Act is too risk averse when it comes to potential risks of harm to research subjects, and that it may undermine the possibility of doing research that may have large societal benefits.

Discussion

The Swedish ethical review system is special in several ways. Prior ethical approval is required by law for many kinds of research, including a significant part of research done in the social sciences and humanities. In this article, we have presented findings from 7 semi-structured group interviews with researchers in social sciences and the humanities concerning their experiences and perceptions of ethical review in Sweden. In doing so, our aim was to explore to what extent the system is perceived to work well (i.e., the pros and cons of the system), and to what extent it could possibly be improved to better accommodate research in the social sciences and the humanities. These insights might perhaps also be relevant to policy-makers elsewhere, contemplating how to best regulate research.

There are important limitations of this study. We should note that the recruitment of participants, which involved snowball sampling, entail a risk for selection bias. Those who chose to participate in our study were probably individuals who already had strong opinions

about ethical review. Yet, it is noteworthy that the participants of this study had differing views about ethical review, which suggests that we have representativeness of different perspectives. Of course, as in any qualitative study, the findings are not generalisable.

Several participants stressed that they would prefer if the process of ethical review would function more as a learning process for the researchers rather than a mere bureaucratic check-up. They would like to see more flexibility, transparency and support from the SERA as well as other relevant personnel (i.e. administrative support) when it comes to the ethical review process. Others emphasised that the application form may be further adjusted to the methods commonly used in the social sciences and the humanities, something which has been a reoccurring criticism in the Swedish public debate on ethical review (Engström, 2023).

However, some participants were more radical. They would like to see a complete shift and expressed clear scepticism towards the appropriateness of external ethical review. Instead, they would favour a system of almost complete self- and collegial governance. However, not all agreed that ethics review should be left to the individual researchers or their respective universities either. To the contrary, some participants clearly favoured external review, arguing that it is important for reasons of legitimacy and to maintain a system that is fair and impartial. This suggests that there is important disagreement about how to best promote ethics in research and the appropriateness of regulating research ethics.

Whatever the case, the participants in this study thought there are some discrepancies between ethical review and the social sciences and the humanities. This is especially so because of how much work in social sciences and the humanities rely on inductive methods, such a grounded theory and hermeneutics. This result is in line with previous research on ethical review, where it has been argued that ethical review is too focused on medical science to fit research in the social sciences and the humanities (Brown et al., 2020; Bülow et al., 2024; Colnerud, 2015; Dyer & Demeritt, 2009; Eldén, 2020; Engström, 2023; Gelling & Munn-Giddings, 2011; Schneidman, 2024; Wynn, 2018; Wästerfors, 2019).

Several participants said that ethical review risks reducing research ethics to a bureaucratic process of merely following administrative demands and ‘checking off the boxes’, instead of engaging in meaningful research ethical discussion. This too is something that has been observed in previous research (Brown et al., 2020; Colnerud, 2015; Schneidman, 2024). Yet, not all participants held this view. Instead, a few mentioned that the Act has promoted research ethical discussion within their fields or that it allows them to discuss research ethics at an early stage, for example during PhD supervision. What is interesting from a Swedish perspective, however, is how some participants explained they, in order to navigate this bureaucratic terrain, have learned how to fill in the ethical review application in such a way that it will be accepted by the SERA. Filling in the application is then perceived as a matter of using standard phrases and finding a way of providing sufficiently many details while at the same time keeping the description as open as possible to allow for flexibility.

It is noteworthy that part of the aforementioned critique of ethical review does not necessarily speak against the idea of ethical review as such (Bülow et al., 2024). To the contrary, some of the critique primarily concerns aspects of the Swedish system that perhaps need to be improved, for example that the SERA need to be more flexible and supportive. Yet, we should also note that there are other types of arguments that speak against the very idea of ethical review of social sciences and the humanities as such. This is especially so when it

comes to the critique that research ethics should be left to the individual researchers, that ethical review undermines or distracts from more serious critical discussion on research ethics, or that it discourages important research.

Interestingly however, we believe that our findings speak against some arguments against legal regulation of ethical review. In her previous study, Colnerud (2015) anticipated that the legal regulation of research ethics may result in a de-professionalization of the research profession, meaning that researchers no longer take responsibility for the various ethical problems that arise within their research practice. The results of our study, however, indicate that this is not necessarily the case. Although some participants clearly share Colnerud's worry, other participants explain they have lively and ongoing discussions on research ethics at their departments and institutions. Some participants even said that the legal requirement of ethical review has helped create an awareness and peer-to-peer discussion of ethical issues among researchers in their fields of study.

It is indeed worrisome how several participants talked about the fear of doing wrong and the many perceived uncertainties that the system brings with it. This is made worse by the fact that failure to abide by the Act might lead to either a fine or a prison term. But even without the threat of punishment, it is problematic if feelings of doing wrong dictate, or at least influence, the choice of research questions or methods, for the sole reason to avoid ethical review. This, but also how ethical review might be perceived as overly burdensome and may undermine curiosity in research, suggests that the requirement of ethical review may discourage certain research, not because it is ethically problematic, but because researchers, including PhD students, deliberately choose research topics that are associated with less administrative work.

Conclusion

The aim of the study was to explore researchers' perceptions and experiences of the Swedish ethical review system, to what extent it works (what works well and what does not), and to what extent it could possibly be improved to better accommodate research in the social sciences and the humanities. In several ways, the participants' perceptions of ethical review clearly resemble those reported in previous research, such as the argument that ethical review is too focused on medical research. However, the result of this study also suggests researchers' perceptions of ethical review vary significantly in some respects. This is most evidently so when it comes to the issue of whether ethical review should be abandoned in the case of social sciences and the humanities, where some participants clearly favoured a system of self-governance, whereas others said that ethical review should indeed be regulated externally. Yet, all participants said that there are problems with the current system. These are problems that should be carefully considered if one wishes to improve the system. Many of the participants said that ethical review suffers from lack of support from the SERA and that the bureaucracy of ethical review focuses too much on technicalities that researchers not always find relevant. This is problematic because of how it may decrease the trust in the system but also because it may discourage researchers from doing some types of research. There also seems to be important tensions between the methods of social sciences and humanities and the requirement of ethical review, which are largely due to the explorative nature of much work in the social sciences and the humanities.

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Author contributions WB has been responsible for drafting the paper. WB has also participated in developing the interview guide, recruiting participants, conducting the interviews and analyzing the data. MJ has provided feedback on the interview guide, helped revising the paper for important intellectual content, and helped analyzing the data. VP provided feedback on the interview guide and helped revising the paper for important intellectual content and helped analyzing the data. LW helped developing the interview guide, helped revising the paper for important intellectual content and helped analyzing the data. LW have also assisted with the requirement of participants, and participated at four of the interviews. All authors have read and approved the final version of the manuscript.

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Code Availability (software application or custom code) NA.

Declarations

Ethical Approval This study was approved by the Swedish Ethical Review Authority (nr: 2023-01573-01).

Consent to Participate All participants received written information about the study in advance as well as in direct relation to the interviews. Informed consent from all participants was obtained prior to the group interviews, including information that they were allowed to optout at any time.

Consent for Publication As part of obtaining their informed consent, all participants were informed that there data will be used only for research purposes and that their data will be published as part of a research article.

Conflict of interest None.

Clinical Trial Number NA.

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