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"Only Applies to Research Conducted in Sweden . . . ": Dilemmas in Gaining Ethics Approval in Transnational Qualitative Research

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Abstract

Transnational research funders such as the European Commission and NordForsk increasingly require researchers to conduct transnational research. Yet, there is little research on what this means for seeking ethics approval, not least for qualitative researchers. Much work on ethics approval comes from Canada, the United States, and other Anglophone countries, often in a health-related context, and centers on issues between researchers and research ethics boards (REBs), or on inconsistent or inappropriate decision-making by REBs. Ethical conduct within research has, of course, generated a rich literature but not on gaining ethics approval when conducting qualitative transnational research. Rather, the underlying situation usually is that the research is conducted in the same geopolitical space as where the REB is located. Drawing on two cases studies, in which researchers located in one country, Sweden, sought ethics approval to conduct research in other European countries, we explore some of the challenges that we faced in gaining such approval and provide some suggestions how this process might be made both more efficient and more productive for researchers and research funders alike.

Keywords

ethical inquiry, feminist research, qualitative evaluation, case study, ethnography

Introduction

In 2012, Guillemin, Gillam, Rosenthal, and Bolitho argued that

> Research ethics review is an international enterprise and cross-national perspectives are important: this is particularly so where there are an increasing number of large international trials, requiring multi-site reviews in different countries. . . . This is clearly an important issue that needs further investigation. (p. 47)

The present authors could not agree more. Guillemin et al. were discussing research ethics reviewing in an Australian health research context; the present authors conduct research in European contexts, and it is within these that we explore the dilemmas that arise when social sciences researchers seek ethics approval in multiple European countries.

The establishment of the European Research Area (ERA) in 2000 heralded the explicit institutionalization of European transnational research.[1] According to the associated Marie Curie website (see https://www.mariecuriealumni.eu/newsletter/all-you-need-know-european-research-area-era, accessed April 28, 2019), ERA's legal basis is found in Article 179 of the Treaty on the Functioning of the European Union, which has "the objective of strengthening its scientific and technological bases by achieving a European research area in which researchers, scientific knowledge and technology *circulate freely*" (emphasis added). Part of this objective is "transnational cooperation and competition," and many of the European Commission (EC)–funded research projects require the participation of a minimum of three member states to secure such transnational cooperation and strengthen the internal cohesion of the European Union. Similarly, the Nordic countries (Denmark, Finland, Iceland, Norway, Sweden) under the auspices of the Nordic Council of Ministers

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established NordForsk in 2005, "a platform for joint Nordic research and research infrastructure collaboration" (see https://www.nordforsk.org/en/publications/publications_container/nordforsk-strategy-2015-2018/view, accessed April 28, 2019). It seeks to promote research cooperation, and many of its research projects too require three member countries to be involved.

For social science researchers undertaking the transnational research involved in such research cooperations, unexpected dilemmas may arise when seeking ethics approval for their work. Such approval commonly has to be demonstrated to and endorsed by the research funders. But as we shall discuss below, such approval can also be very difficult to come by, partly for reasons sometimes discussed in the context of researchers' issues in dealing with research ethics boards (REBs) or institutional review boards (Guillemin, Gillam, Rosenthal, & Bolitho, 2012; Marshall, 2003; McCormack et al., 2012; Shore, Drew, Brazauskas, & Seifer, 2011), namely the mismatch between these boards' and the researchers' understanding of what the research involves, and partly because of the fact that ethics approval remains a largely national or local phenomenon in an increasingly internationalizing and globalizing research context.

The aim of this article is to explore some of the key dilemmas social science researchers face when seeking to gain ethics approval for transnational research involving the same research methods and target groups in multiple countries. Our focus here is on the experiences of researchers with REBs in this process rather than on what happens in the field or during the actual conduct of the research. This is because gaining ethics approval is a key prerequisite for most research, and it is the issues related to this process we wish to discuss here. The issue of ethical conduct during research is itself a huge area of research in its own right, which we do not pursue here. Methodologically, we combine a brief summative literature review with a content-focused document analysis based on a range of materials including institutional documents, e-mails, ethics check reports,[2] decision documents ("beslut" letters, meaning decision letters from a Swedish regional ethics board), and secondary literature analysis. Our analyses are based on two specific case studies—one involving the EC, the other a trans-Nordic research funder—as well as on evidence gathered at a qualitative research methods workshop conducted in Ghent, Belgium, in 2018 involving EC-funded qualitative researchers from fields such as anthropology, sociology, and gender studies.

We examine what the consequences of the dilemmas social science researchers face when seeking to gain ethics approval for transnational research are for the researchers and for the conduct of their research. We discuss how we solved particular difficulties in the ethics approval process in practical terms and make suggestions for changes to the ethics approval processes that might improve the experience and outcomes for both researchers and research funders.

Engaging with the Research Ethics Approval Process as a Social Science Researcher Working Transnationally—An Underexplored Issue

Although transnational research, including in the social sciences and humanities, has been conducted for many years now, surprisingly little has been written about one of its key processes, namely, gaining ethics approval. Much of the literature on ethics approval comes from the United States and Canada, is centered on health-related research, and deals with the problematics of REBs' decision-making (e.g., Brown et al., 2010; Meadows et al., 2003). Little is written on this within the European context; even where research has been conducted in multiple (Anglophone) countries including European ones (e.g., Fitzgerald, Phillips, & Yule, 2006), nothing is said about ethics approval for transnational research projects. What research on ethics approval in transnational research within European contexts there is, is frequently concerned with matters of biomonitoring, health, and medical trials (e.g., Dumez, Van Damme, & Casteleyn, 2008), or with issues between "north" and "south" and postcolonial impositions of research ethics and practices (e.g., London & McDonald, 2014), as our extensive literature searches on search engines and databases such as Google scholar, JSTOR, and Web of Science have revealed.

Ethics as a dimension of social science research per se has resulted in a rich and detailed literature on this topic, often centering on ethical dilemmas encountered in the field in terms of power differentials between diverse actors in the ethics approval process (e.g., Aluwihare-Samaranayake, 2012; Guillemin et al., 2012; Meadows et al., 2003); on questions of access to and the treatment of research participants (e.g., Brown et al., 2010; Clark, 2012; Mero-Jaffe, 2011); on dealing with intermediaries such as gatekeepers and interpreters (e.g., Akua-Sakyiwah, 2016; McAreavey & Das, 2013; Smith, 2016); or on ethical challenges arising when undertaking particular kinds of research such as in social media and visual culture (Boyd, 2016; Markham & Buchanan, 2017; Recupero & Reamer, 2018; Toptchiyska, 2016). Schrag (2010, 2011) has reported on the dilemmas social science researchers in the United States face when dealing with institutional review boards. He has found six major critiques of ethics reviews: "(1) ethics committees impose silly restrictions, (2) ethics review is a solution in search of a problem, (3) ethics committees lack expertise, (4) ethics committees apply inappropriate principles, (5) ethics review harms the innocent, and (6) better options exist" (Schrag, 2011, p. 120). This leads him to conclude, in his 2011 article tellingly entitled "The Case Against Ethics Review in the Social Sciences," that the proof for the necessity of ethics review in the social sciences "rests with its defenders" (p. 129) as opposed to social scientists. Hemmings (2006), by contrast, seeks to find ways in which institutional review boards and ethnographers might work together more effectively, in other words, arguing for reform rather than

revolt. We are with Hemmings on this. But the issues we discuss below also bear some resemblance to the critiques enumerated by Schrag (2011), in particular to the imposition of problematic restrictions, the application of inappropriate principles, and the potential harm to researchers and their participants. We also, however, argue that some issues we raise such as the demand to comply with requirements that are impossible to fulfill and which the research funders themselves, when being challenged, then abandon, and what Hemmings (2006) describes as "bureaucratic slogs," that is, the problematic retardation of research due to inefficient processes, are not quite covered by Schrag's (2011) generally helpful typology of ethics reviews critiques.

In some writings on these topics, research ethics are characterized as an ongoing process where ethical dilemmas need to be constantly negotiated in the field in a manner that can be at odds with the one-off ethics approval process that precedes that research (Brown et al., 2010; Chenhall, Senior & Belton, 2011; Wood, 2017). For this reason, McCormack et al. (2012) call for a more participative approach to ethics reviews, with relevant researchers being more involved in the related discussions, in order to reduce such discrepancies. This call is echoed by others (e.g., Koski et al., 2005), particularly in relation to community-based research (Brown et al., 2010; Shore et al., 2011). But all this research assumes that the research ethics approval sought is for research conducted within the same geopolitical boundaries as where the REB is located. However, in the European research context, and of course not just there, this is often not the case; instead, supported by transnational research funders, research in multiple different countries is both encouraged and undertaken. Such research is also underwritten by transnational European research funders such as the EC or NordForsk, which are explicitly set up to facilitate transnational research. These research funders also seek to unify their geopolitical research area. One would expect that to include research ethics, and indeed, the EC provides both ethical guidance and ethical approval at supranational level. However, beneath that supranational level and prior to its intervention, researchers have to contend with the national ethics requirements of the European Union member states. Given their supposedly common aims and values, as expressed through their European Union membership, one might expect these to be roughly similar. However, the very diverse knowledge production histories of the currently 28 European Union member countries mean that they have widely divergent ethics review processes for the social sciences, ranging from national to regional to local bodies, or indeed to none at all. Every one of these bodies organizes its ethics approval processes differently, and it is beyond the scope of this article to detail these. The key point here is that the countries in question have, at EC and at NordForsk level, joint research agendas and values, but these, somewhat surprisingly, do not inevitably carry through to the processes by which ethics approval is gained. This raises serious questions regarding the harmonization of transnational research but also about the impacts of these discrepancies on both the possibilities of conducting transnational research and the outcomes of that research as well as its ultimate usefulness for those researched.

Managing Discrepancies in Ethics Perceptions in Transnational Research Projects

Being the Only One

The immediate first significant dilemma when conducting transnational research is as follows: Who or what organization/s is/are responsible for the ethics approval of the project? In the authors' contexts as transnational gender researchers, we have begun to think of ethics approval as a two-stage geopolitical process: the national and the transnational. Hence also the first part of the title of this article: "Only Applies to Research Conducted in Sweden . . . " This was the opening part of one section of the ethics approval decision both authors received from the relevant regional Swedish research ethics board (UREB), to which they submitted applications to conduct research with legally adult participants without mental or other impairments. The first author had sought ethics approval in relation to a project involving interviews based on identical interview guides with adult participants working in the digital humanities in Finland, Norway, and Sweden, while the second author had sought approval for interviews (group and individual) as well as an online survey with legally adult members of lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI) communities about their experiences with assisted reproductive technologies in six European countries: Austria, Estonia, Poland, Spain, Sweden, UK, and Spain. In both cases, the ethics approvals applicants, both employed at Uppsala University in Sweden, were also the researchers who would conduct the research. This is significant because their research base was Sweden; they did not have institutional affiliations in the other countries where they were to conduct their research. This does not mean that they did not know, or indeed work with, colleagues from the other countries involved—quite the opposite. But they themselves were not employed by another institution in the countries in question. Such employment would have been a necessary prerequisite to gain ethics approval there for the researchers in question. Employing "local" researchers might have been desirable in absolute terms, but this could not have been budgeted for due to the overall budget limits for each of the projects discussed here and because, in the context of individual EC-funded fellowships, for example, the expectation is that the researcher will conduct her own research. Subcontracting is explicitly forbidden.

The national circumscription of the ethics approvals involved ("Only Applies to Research Conducted in Sweden . . . ") meant that both researchers were required to seek ethics approval in all the participant countries in which they were going to conduct their research. This in itself is not unusual: many countries—though not all—have some form of ethics approval process for research by those nonresident in that country. If one arrives as a nonnational, a nonresident, or as a person unaffiliated to an institution in a given country to

conduct research there, some countries such as Botswana,[3] for example, demand that one has local government approval for conducting research there. This process can be very long-winded and also costly, with uncertain outcomes. Sometimes one can get approval only while still abroad (i.e., in one's home country); at other times, one can get approval only if one is in the country already, and sometimes quite what the procedure is, is simply not clear. But researchers conducting research abroad often provide no comment on this dimension of their work (e.g., Clark, 2012; Meadows et al., 2003). Instead, they focus on the ethical issues they found in the field itself. Lack of information about such processes means that researchers often fail to factor into their research timetable the delays caused by ethics approvals processes.

It is also not always obvious who to go to for one's ethics approval. The first author had to seek ethics approval in Finland, Norway, and Sweden. In this case, a Norwegian project partner suggested that she seek approval from the Norsk senter for forskningsdata (NSD; see http://www.nsd.uib.no/personvernombud/en/index.html, accessed April 29, 2019). Happily, the associated process turned out to be very straightforward—the NSD required one to fill in an online survey about one's research participants and assessed the need for a more comprehensive ethics review on the basis of the survey answers. The first author was told she did not need such a review for Norway. This is important because it indicates that even within what is quite a close-knit geopolitical formation such as the Nordic countries, different countries take diverse views of when an ethics review is necessary; in the aforementioned case, Sweden required one, Norway did not.

Regarding the research in Finland, on recommendation from Finnish colleagues, ethics approval was sought, and indeed given, through the university ethics board at which those colleagues who are also partners associated with the project were based. The Finnish process was much less elaborate than the Swedish one.

These differences across national boundaries can also be (re-)played within them: McCormack et al. (2012) report on having to seek ethics approval from seven different REBs who, despite following the same national guidelines, took different decisions such that "The same research proposal was eligible for expedited review in three cases but required a comprehensive review for the remaining four" (p. 31). And this, of course, was just the beginning.

Compared to the relative ease of first author's experiences of seeking ethics approval in three Nordic countries, matters turned out to be much more difficult for the second author who was required by her research funder, the EC, to gain ethics approval in each of the six European countries where she wanted to conduct her research. It turned out that these countries did not have national research ethics bodies that would provide ethics approval for a researcher of European nationality seeking to conduct research within Europe where she was supposed to be able to move freely. The so-called National Contact Points, EC-appointed individuals or organizations tasked with supporting researchers, had no clue where to go for ethics approval as a transnational researcher in the countries for which they were responsible. The national research councils such as the Economic and Social Science Research Council in the UK frequently did not even answer questions put to them regarding this matter, and national disciplinary bodies, which in some countries provide ethics approval also did not answer and/or said they were only responsible for research commissioned through them or via a research body located in their country.

The second author started asking ethical committees at the main universities of the remaining five countries, whether they could provide such an approval. Only the Research Ethics Committee of the University of Tartu (Estonia) agreed. Estonian researchers rightly thought it crucial that ethical approval for foreign research on their LGBTQI citizens be obtained because of Estonia's small population (approximately 1.3 million) and the even smaller number of LGBTQI people who might be easy to identify. Again (as already in the EC's ethics self-assessment and the UREB form), different questions had to be answered and translated into Estonian. Luckily, however, there were no additional costs for this ethical approval. However, the costs of the translations had to be added to the project budget and the time of filling in the forms, translations, getting the signatures/confirmations, and the waiting time for the outcome. Differently from the UREB's ethics approval letter, the final ethical approval by the University of Tartu's Ethics Committee was provided in English.

Four countries remained that could not provide ethical approval or a confirmation letter that no national ethical approval was required in those countries, but the relevant institutions said they could not confirm and did not know if indeed there was an institution in their country which could provide such approval. It was a catch-22 situation: no institution would give ethical approval or confirm that the latter was not needed, but the EC's ethical board required four more national approvals or confirmations. Even e-mail communication with higher national authorities did not clarify the issue (e.g., to the Austrian Data Protection Authority or the Austrian Federal Ministry of Education, Science and Research).

The key issue in each case was that without an institutional affiliation in the country in question, it was impossible to gain ethics approval there. Eventually, we decided to collect letters from "respectable" individuals/institutions in the various countries (e.g., directors of research at research universities), utilizing the first author's contacts. These letters stated that the country in question had no official body that would provide such ethics approval. Since asking for such a letter was in itself an unusual request and institutional approval for such a letter required consent from a range of intra-institutional individuals, it took considerable time to get these letters together. We then documented our search process to the EC and asked that, if they were not prepared to give ethics approval for the project based on these letters, they should suggest a practicable alternative. They did provide ethical approval on this basis.

Given the large numbers of research projects they deal with, our view is that the EC should have procedures in place to

facilitate their ethics requirements that de facto were impossible to fulfill, especially for junior research fellows with limited experience of seeking ethics approval and limited connections in the field. As it was, this junior researcher suffered a significant time delay in her project while seeking non-achievable ethics approval from several European countries and eventually coming up with her own solution in consultation with her research mentor, the first author.

In both authors' cases, the issue was that the researcher was seeking to conduct research in several countries where she had no direct institutional base. Hence, no public body considered itself responsible for ethically approving the research. In the first author's case, the process of approval seeking showed up the discrepancies among affiliated countries regarding which research they deem in need of ethics approval and quite what approval process is required; in the second author's case, it proved impossible to find appropriate ethics approvals bodies in most cases, and the researcher's work was ultimately approved without having them all.

Cross-Country and Cross-Institutional Differences Regarding Ethics Requirement Perceptions

As already indicated, in the first author's case, differences in how the various Nordic countries view what needs ethics approval led to different degrees of formal requirement—from nothing to lengthy form filling, and all for the exact same research. For the second author, things were much more complicated, since the EC ethics committee made several demands that were impossible to fulfill in its own terms. We have already discussed one major one above. A second, quite major one was the demand made in the EC's first Ethics Check Report (March 21, 2018, point 5) that "a qualified ethics advisor or mentor with clear tasks and responsibilities" should be appointed. To facilitate finding such a person the related EC guidelines state:

If you appoint an ethics adviser/advisory board, it is important that they are

- external to the project and to the host institution,
- totally independent, and
- free from any conflict of interest.

Your university or institution (or members of your consortium) may have experience with an ethics adviser or members of an ethics advisory board and may be in a position to suggest potential candidates (http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/ethics/h2020_hi_ethics-self-assess_en.pdf, accessed April 29, 2019).

We took considerable time trying to find such an advisor. The EC grant advisors in our institution had no experience with such requests, nor suggestions. Based on the first author's academic connections, we contacted various senior academics in Sweden with relevant expertise who were both external to the project and to the host institution. Several declined, one agreed provisionally but wanted further information and to be paid. It is unusual in Sweden to undertake pro bono work activities within academe—you expect, and are expected, to be paid for work you do. Hence, appointing an ethics advisor also meant paying someone and at the very high wage rates that such a senior person can command. This money was not factored into the grant application. In the end, we appointed the chair person of the UREB as our ethics advisor. As an academic at the host institution, this person could not be said to be external to it; hence, this appointment was in violation of the EC's own guidelines on this matter. In exchanges with other grant EC recipients, we found that they had faced similar problems and had also ended up making appointments that did not comply with the EC guidelines. Nonetheless, having identified this person in our response to the EC ethics check, the EC accepted this. For us, it had entailed much useless work, and it also left us with the issue of how to pay this person since no provision had been made for this in the original grant.

We faced other challenges. UREB explicitly required the second author to fill in the ethics approval request form in the national language, Swedish, and in her subsequent submission to the EC ethics committee, she submitted, as required, a copy of the original UREB's decision letter. Swedish is one of the EC languages, and there was no explicit requirement that all documentation should be in English. However, in the EC ethics board's initial assessment, they stated:

> The UREB Ethics approval only covers field work conducted in Sweden. Hence any field work taking place in other countries does not have appropriate ethics approval. The fact that this has not been revealed and that no translation of the document has been made available is not the best way to proceed to convey trust. At this moment, no research activities outside of Sweden should be started until the relevant permissions have been obtained by the relevant bodies. If any data has been gathered without approvals it may have to be destroyed. (Ethics Check Report, Grant agreement 749218, point 3)

Several points are noteworthy here: first, the assumption that there will be "relevant permissions" and "relevant bodies" which, as discussed above, was not the case. Second, the implication of deception for having submitted copy of the original UREB ethics approval which actually clearly states the approval limitations. We were, frankly, outraged by this implication and said so in our response. Third, there was the expectation that a translation should be provided for one of the EC languages, a demand nowhere outside of this ethics check report stated or made and indeed not acceptable in the EC's own membership terms. The final important point is that this ethics check which occurred 6 months into this 2-year project effectively halted the project's activities for 3 months (the final ethics check and approval then only occurred on June 5, 2018, after the first one on March 21, 2018, and the latter after a lengthy wait). Since the majority of the data collection was meant to be done abroad, this was quite an issue and impacted directly on the research process as discussed further below.

There was another issue that made the clash between national systems of ethics approval and transnational ones very apparent. This had to do with the issue of guaranteeing anonymity and confidentiality to research participants—an issue made more vexed in the European Union by the recent General Data Protection Regulations (GDPR)[4] that specify, inter alia, that researchers keep raw data, meaning data that still include all identifying markers, for 10 years. Swedish law allows any person access to such data upon request; hence, the UREB required a statement in the consent form that said that "no unauthorized person" would have access to the data since, by law in Sweden, anybody can go to court and obtain the authority to access such data. The phrase commonly used in Anglophone social sciences consent forms regarding the guaranteeing of anonymity, and confidentiality can therefore not be used by Swedish researchers. The consent form we submitted to the EC in English (since most participants would receive it in English), in line with the Swedish requirements to cover the hypothetical case of "authorized [by the courts] persons" wanting access to the data which would be stored in Sweden, had to say: "No unauthorized person will have access to your data."[5] This formulation was clearly not understood by the EC REB, which then wrote: "The informed consent documentation should make clear whether the data will be accessed by other persons. If they are authorized, these authorized persons or institutions should be identified." The EC REB did not understand that "no unauthorized person" referred to a hypothetical case, which we as researchers had to state to satisfy Swedish ethics approvals requirements and to comply with Swedish law. Instead, the EC board assumed we could provide such a list, which was obviously not the case.

From the researchers' perspective, one had a sense that the EC as a transnational body had ethics requirements and provided guidelines that were out of sync with the requirements and guidelines that existed at national levels. Indeed, it appeared that the relevant body conducting the ethics check was ignorant of the national specificities around ethics requirements and guidelines of the EC member states. What is more, it produced guidelines that could not be complied with, involving researchers in significant, time- and budget-consuming labor. The researcher was, for example, also asked to take into account the new EC GDPR that had just come into force, but these regulations had not yet been implemented in most of the countries involved in her study, including Sweden itself, where universities were still trying to decide what the practical implications of these guidelines were and what was needed by way of protocols and infrastructure to implement them. In the end, the EC granted ethics approval, accepting the violation of its own guidelines. For researchers, this is not a productive state of affairs.

The Mystery of "Incidental Findings"

We come to a final point regarding mismatches in understandings, perceptions, and knowledges around ethics at transnational level. According to the EC Assessment of Ethical Compliance, we were required to "provide an incidental/unexpected findings policy" (Ethics Check Report, 21 March 2018, point 6). We were unclear what this meant. Exchanges with other grant recipients indicated that they were likewise flummoxed. Since it was evident to us that this requirement must come from "somewhere" (but where?), the first author began to research this and discovered that—although not at all a familiar phrase in the disciplinary and national research contexts that we know—it has some traction both in the United States and in Canada where it appears to refer mainly to issues of, for example, conducting research on thyroid function and finding as a by-product of this research that a research participant has cancer. This by-product constitutes an "incidental finding," and you are expected to have a policy in place to deal with such matters. In our response to the request, and given our experience with trying to find out what exactly was meant by it, we therefore noted, and we quote this at length since it makes key points in our own words:

> We had to search for a policy example on incidental/unexpected findings since this is not a *terminus technicus* commonly used in any of the areas we are familiar with, or work in. In commonsense terms one might of course argue that all research entails the possibility of incidental/unexpected findings—that is partly why research is conducted since, if we knew exactly what we would find in advance, there would be no point in conducting research. Within those commonsensical terms the project will adhere strictly to its topic parameters. In so far as any incidental findings occur, these will be dealt with in accordance with the ethical guidelines for all findings associated with this project, in particular the principles of no harm and of maintaining confidentiality regarding the participants. Incidental/unexpected findings that are irrelevant to the project will therefore be disregarded and not used as part of the data analysis.
>
> Incidental/unexpected findings that are directly relevant to the project will be treated in accordance with the ethical guidelines for research, data protection, and processing detailed in *The European Code of Conduct for Research Integrity* (https://ec.europa.eu/research/participants/data/ref/h2020/other/hi/h2020-ethics_code-of-conduct_en.pdf) and in the British Sociological Association (BSA) Guidelines on Ethical Research (https://www.britsoc.co.uk/ethics).
>
> It seems that in the Canadian and the U.S. context, but not within Europe, incidental/unexpected findings are discussed and policies developed. We therefore propose to follow the Guideline for the Reporting of Incidental and Secondary Findings to Study Participants (https://uwaterloo.ca/research/sites/ca.research/files/uploads/files/guideline_on_incidental_findings_reporting_october_2014.pdf) in adhering to best practice in this context.
>
> Participants will be asked at the interview stage whether they want to be informed about incidental/unexpected findings if these occur, and if so, they will be given summary statements of such findings (Response to the EC Ethics Check Report, 7 May 2018, requirement 1).

We also modified the consent form to include the question of information regarding "incidental findings" though we were doubtful that we would come across such matters. Explaining

incidental findings to research participants was also often a lengthy business since the phrase is not readily understood or explained without being alarmist. Safeguarding the research participant is, of course, of utmost importance, but this imperative should result in relevant and readily implementable ethics requirements.

Some Implications for the Researcher

Conducting transnational research is increasingly common, including in not just one but potentially in several countries. Where this is the case, issues of ethics approvals processes must be carefully considered, and as much information about these as possible should be collected upfront. Even though ideally this should be done in advance of the study, de facto the processes often require information and details (such as all the documentation related to the actual research process) that may not be readily available before one has been awarded a grant and begins one's research. There are two important things for the researcher to bear in mind in this context: (A) getting ethics approval may involve expenses (e.g., getting UREB approval, cost 5000 Swedish kronor [approximately US$535] and also involved translation costs into Swedish, which we had not factored into our research costs), and these need to be accounted for in the application. We make this point because many researchers are simply not aware of this, especially if they are early career researchers. We also highlight this because there are European countries such as the Czech Republic or Bulgaria where higher education institutions, at which researchers may be employed, simply do not have money to pay for unexpectedly arising additional research costs. (B) The approvals process may take significant time (between 3 and 6 months) during which one cannot conduct research. This should also be factored into the research plan. It is, of course, possible to do literature reviews and desk searches during the ethics approval process period, but in projects of short duration, one may not have very much time for any of these normal research stages. Here, it is important to know that the EC gives no indication of the potential delays regarding ethical review prior to awarding a grant and that it also does not extend research project time to accommodate such delays. Further, it expects full delivery of the approved project's research plan and may withhold money if the latter is not fulfilled. The second author's fellowship, for example, was only of 24-months' duration. It took her three stages to fulfill the EC ethics requirements (first, the ethics self-assessment in the project application itself; second, the first EC ethics check report 6 months into the project; third, responding to that report and to a follow-up one). She also had to fill in two national ethics approval forms and have them translated into the relevant national language, and finally seek the almost impossible: to gain confirmation letters that no national ethics approval could be provided and/or was required in four countries in order to solve her catch-22 situation with the EC. Hence, the ethics approval–related delay in being able to begin the majority of the field work meant that we had to cut the numbers of interviews, and so on, we had planned to undertake, to accommodate this delay.

These problems were not mere inconveniences to the researcher or just a matter of time compression. They had obvious negative consequences, both for the researcher who could not carry out the research plan as intended and for the research participants who also constitute one of the end users of the research. If, as was the case in this instance, fewer data are collected than intended, this means that any analysis has potentially a more limited validity. It may also mean that in countries where potential participants are harder to reach, fewer participants are recruited than in those where access is easier. This issue therefore impacts not only on the researcher but also on research design and results, as well as on end users.

From our researcher perspective, the problematic requirements demanded by the funder in the case of the second author, some of which proved impossible to fulfill—a fact that should have been known to the funder—left us with much fruitless labor, and meant that we could not but violate the funder's guidelines, which they, in giving approval, effectively agreed to. Having to alter our actual research plans due to shortage of time was possible but could have been difficult if the research to be conducted had been planned in a different way. Interestingly, based on their five-nation study, Fitzgerald, Phillips, and Yule (2006) state that "few [ethics] applications are approved as submitted. In some places, no applications are approved as submitted" (pp. 389–390). This means that the process of gaining ethics approval can be lengthy and labor-intensive for the researcher, and this needs to be accounted for in the overall research plan.

By Way of Conclusion: A Modest Proposal for Transnational Research Funders

The research on seeking ethics approval for qualitative social sciences and humanities, but also health-related, projects both within and across national boundaries reveals the complexities of that process but also the fact that ethics approval processes are not an exact science, even if national or transnational guidelines exist. Judgment has to be exercised. This involves subjective estimations (Magelssen, Pedersen, & Førde, 2014; Randall & Fernandes, 1991; Tolich & Fitzgerald, 2006; van den Hoonaard, 2011; Willison et al., 2008) and can result in quite different decisions, even on the same project (McCormack et al., 2012). Within transnational ethics approvals contexts, different approval processes and understandings rub up against each other and can lead to different ethics approval requirements such as was the case for the first author's project involving research in Finland, Norway, and Sweden. One way to counter this dilemma, especially when countries are closely collaborating around research and require researchers within these countries to collaborate, would be for those countries to establish a single REB that deals with ethics approval for a given project for all participating countries. This would certainly be a way forward for the Nordic countries which—given their small populations overall and limited resources—would

make the process more efficient, more cohesive, and less labor-intensive, as well as less costly in every sense for the researcher.

In the case of the EC to which the second author submitted her grant proposal, somewhat different solutions to the dilemmas discussed above are required. First, the EC acts as a secondary ethics review body dealing with ethics reviews to be sought elsewhere. Although this is never explicitly stated, we contend that the EC regards its processes as having an educative dimension for its member countries whom it seeks to encourage to emulate what it regards as the highest standards in a given context. Hence, the ethics check reports received by the second author, which required her to undertake ethics tasks some of which could not even actually be done (such as gaining ethics approval in individual countries that had no relevant bodies to do so, or finding an ethics advisor who would be completely independent, etc.), may be seen as requirements designed to encourage changes in national practices. These changed are meant to be pushed forward through the endeavors of individual researchers alerting their countries to the countries' ethics process' "shortcomings" by making demands that cannot be met. Such notification is in effect then meant to invite these countries (or some of their research representatives, in any event) to contemplate those issues and maybe introduce the relevant measures.

While this might be one long-term EC aim, from the researchers' perspective, pressed by an often very short research project timescale and the need to produce "deliverables" or results to an agreed time frame that forms part of their research contract, other supportive measures are needed. These, first and foremost, include that the EC itself, either through its ethics officers or its National Contact Points or a specific entity set up for this matter, should be fully cognizant of what processes and procedures are in place in its member countries and, when asking researchers to refine their ethics brief, should provide clear, practicable instructions as to how these further steps are to be achieved. We know that we were not the only researchers struggling to fulfill some of the EC's ethics demands; everybody we talked to came up with their own home-made solution—a significant waste of researcher time and effort. Second, grant applications for all funders should explicitly include the requirement to factor in a time period of 3–6 months for the ethics process within the actual grant period—we have found this to be the average time needed to gain ethics approval for the social science and humanities projects we have been involved with. Third, the ethics approval process should be identified as a cost category in the contexts where such approval has to be paid for.

These three issues do not readily map onto the common critiques of institutional ethics review boards identified by Schrag (2010, 2011). They also are not quite covered by Hemmings's (2006) discussion of the "great ethical divides" between these boards and researchers. Hemmings builds her discussion on the "three basic ethical principles guiding IRB deliberations: . . . [respect for] persons, beneficence, and justice" (p. 13). These all focus on the impacts of the research on the researched. This is, of course, of paramount importance. But we have a different starting point in this article, namely, the researcher's treatment by the ethics approvals boards in the latter's dealings with the former. Here, we might argue that wasting precious research time on unfulfillable ethics requirements constitutes a disrespect for the researcher as a person. Second, since problematic, time-consuming ethics procedures impose research restrictions (around data collection, for instance) on the researcher, one might also argue that the benefit of the research to participants and other end users is reduced if the research cannot be carried out as originally designed. Third, justice is not served when fewer people than envisaged from disadvantaged backgrounds can be brought into discussions about their lives because of restrictions (of time, resources, etc.) imposed by ethics boards.

In the exhilaration we as researchers might feel when conducting transnational research, the ethics approval process is an important and integral dimension of the process. In this context, it is important that this process is made as exacting and productive as possible as it affects all concerned: the research participants, the researchers, the institutions they are affiliated to, and the research funders. To foster a situation where researchers do not see "ethics committees as a hurdle to overcome" but rather regard them as a supportive structure designed "to protect research participants, as well as ensuring that research is beneficial" (Guillemin et al., 2012, p. 43), measures such as the ones indicated above might be undertaken to make the ethics approval process more productive.

Authors' Note

"Endast avser den forskning som kommer att bedrivas i Sverige . . . " (Beslut [Decision] 2017-11-08, Ref Dnr 2017/434, Etikprövningsnämnden Uppsala).

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Notes

1. Prior to 2000, there had already existed a series of initiatives designed to facilitate research cooperation within the European Union (EU) under the heading of Frameworks (e.g. Framework 6, Framework 7 etc.).
2. Ethics check reports are issued by the European Commission (EC) as part of its research proposal assessments of any research

application made (the EC uses many different so-called research instruments, meaning kinds of research, e.g., small projects, fellowships) as part of its research endeavors. These reports, compiled by EC ethics committees made up of academics from various disciplines and from around the world, detail in template format whether or not the EC ethics requirements have been met and what needs to be done if the application is deemed not to have met those requirements.

3. Botswana is mentioned here as an example simply because the first author has knowledge of that country's ethics approval requirements in relation to the work of one of her PhD students. Other countries could also have been mentioned.
4. The EU's General Data Protection Regulations came into force on May 25, 2018. For full details, see https://eugdpr.org, accessed April 29, 2019.
5. In the original Swedish research ethics board (UREB) decision: "Ingen obehörig kommer att fåta del av dina svar" (UREB beslut 2017-11-08, point 3).

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