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Human Research Ethics Review Challenges in the Social Sciences: A Case for Review

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Abstract
Ethical conduct is a maxim in scholarly research as well as scholarly endeavour generally. In the case of research involving humans, few if any question the necessity for ethics approval of procedures by ethics boards or committees. However, concerns have been raised about the appropriateness of ethics approval processes for social science research arguing that the orientation of ethics boards and committees to biomedical and experimental scientific research, institutional risk aversion, and other factors lead to over-protection of research participants and overly restrictive processes that delay and sometimes prevent important social science research. This is particularly significant when social science research is required to respond to social, environmental, or health emergencies and in contract research projects for the reasons explained. This analysis of an ethics approval case study adds to increasing concerns that ethics approval processes can have perverse effects in the social sciences. While a single case study does not provide generalizable findings, in-depth analysis of a significant case can identify issues that need to be further explored. Recommendations offer pathways for facilitating social science research including in emergency situations in which timeliness is important and in collaborative approaches such as participatory action research, while maintaining high ethical standards.

Keywords Ethics · Human ethics · Research · Ethics approval · Institutional review boards

Introduction

This analysis reports and reviews the ethics approval process for qualitative research commissioned by the World Health Organization to identify the knowledge levels and capabilities of its communication staff in its region and country offices in evaluating the effectiveness of their work and to identify their training and support needs. The research was commissioned

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as part of global evaluation of WHO public health communication during the COVID-19 pandemic to optimize its effectiveness in preventing serious illness and potentially death. The WHO and the academic researchers contracted to conduct the research expected the proposed online interviews of WHO professional staff to be classified as low risk by the university Human Research Ethics Committee. However, the research was viewed as high risk requiring substantial additional information, resulting in delays in approval. The case reveals that national guidelines relating to risk arising from the research to be assessed in relation to *likelihood*, *severity*, and relative *benefits* were not fully applied. Instead, risk avoidance and a narrow *deontological* approach resulted in a lengthy, bureaucratic process involving micro-management that jeopardized health communication interventions at a critical time. The case illustrates a need for careful consideration of consequences (*teleological* approach) as well as Kantian principles related to morals and duty, and understanding of social science methods and the risks they pose relative to those in biomedical scientific research.

Background: Ethics Theory and Guidelines

Human research is justifiably subject to high levels of scrutiny. Few, if any, question the importance of ethics approval for human research, and it is widely accepted that review of ethics applications needs to be rigorous.

Ethics Approval of research is informed broadly by established bodies of moral philosophy. As is well known, a *deontological* approach, commonly referred to as Kantian ethics, is focused on duty, or what Kant called the "categorical imperative" under moral law to act ethically. Perhaps most significantly, in a deontological view, the rightness or wrongness of an action exists in the action itself, not the intention of persons concerned or the circumstances or consequences (Guyer, 2007). Action is guided by rules in this approach such as those proposed by W. D. (David) Ross (1887–1971), who advocated the importance of *beneficence* (doing good), *non-malfeasance* (avoidance of doing wrong), *justice*, *self-improvement*, *promise-keeping*, and *reparation* when wrong has been done or injury caused (Ross, 2002).

In contrast, or in addition, a *teleological* perspective looks beyond duty to act in a certain way to consider the consequences of actions, thus referred to as a *consequentialist* approach. As the name suggests, this view holds that the consequences are the ultimate basis for judgement about the rightness or wrongness of an action or conduct (Brink, 2006). There are a number of streams of consequentialist ethics such as *utilitarianism* grounded in the work of Jeremy Bentham, whose maxim is commonly interpreted as 'the greatest good for the greatest number'.[1] While some versions of consequentialist ethics focus on the greatest good (or happiness) for the greatest number of individuals, others focus on the good of the state, or society as a whole.

At an applied level, the principles applying to ethics in research are enshrined in national guidelines, such as the *National Statement on the Ethical Conduct of Human Research* in Australia (National Health and Medical Research Council, 2018) and the *Framework for*

[1] Bentham drew on the work of predecessors including Hume, Helvétius, and Beccaria and first pronounced this maxim as "it is the greatest happiness of the greatest number that is the measure of right and wrong" (Crimmins, 2019).

Research Ethics (FRE) produced by the Economic and Social Research Council (2020) in the UK. In the USA, a number of federal agencies have regulations governing the conduct of research involving humans including the Department of Health and Human Services (DHHS) through its Office of Human Research Protections (OHRP); the Food and Drug Administration (FDA); and the National Science Foundation.

In turn, these guidelines are interpreted by boards and committees of universities, research institutes and centres, hospitals, clinics, and other institutions engaged in research involving humans. These bodies, variously called ethics review boards (ERBs), institutional review boards (IRBs), human research ethics committees (HRECs), and research ethics committees (RECs), establish procedures for approval of research administered by their institutions. They are typically supported by an Ethics Office or Secretariat which often conducts preliminary review of applications as well as administration.

Strict attention to ethics in relation to research involving human participants is important because there have been abuses of human rights and welfare in many fields of research over the years. Widely-cited examples range from the trials on humans conducted in Nazi Germany during World War II and the "widespread lapse in ethical issues in clinical medical research" in the United States in the 1960s identified by Beecher (1966) to recent use of electrical shock therapy (White, 2020). The social sciences are not without blemish. As co-author of *Research Ethics for Social Scientists*, Mark Israel says: "Although economists, political scientists and psychologists have not been responsible for the same level of abuses that have occurred in biomedical research, the social sciences have witnessed their share of old-fashioned scandalous behavior" (Israel, 2014, para. 10). In this journal, Beauchemin et al. (2021) identified a range of ethical issues that arise in conducting research.

However, as noted in the following section, scholarly literature reflects concern among many researchers that human ethics approval processes can become a barrier to important research. Before examining this literature and the case studied, it is relevant to reflect on the commonly ascribed objectives of ethics board and committees and the overall purpose of human research, because these also form part of the theoretical framework within which practices should be analyzed.

Based on principles identified in landmark studies such as *The Belmont Report* (National Commission for the Protection of Human Subjects, 1979), there are three widely-cited objectives of ethics boards and committees as follows:

1. "Protect human participants";
2. "Ensure that research is conducted in a way that serves interests of individuals, groups and/or society as a whole"; and.
3. "Examine specific research activities and projects for their ethical soundness, looking at issues such as the management of risk, protection of confidentiality and the process of informed consent" (Walton, 2020).

The order of these objectives as listed by multiple authors (Grady, 2015; Walton, 2020) and many institutional review boards (e.g., University of Pittsburgh, 2018, p. 2) reflects a primary focus on the protection of individual participants—a principle that, if over-emphasized, can conflict with the second objective of serving the interests of non-participant individuals and "an obligation to society" (Gelling, 1999). Furthermore, the overarching purpose of research, which is the advancement of human knowledge that can benefit humanity, can be

undermined if the protection of participants and management of risk are considered without carefully weighing them against the affordances and benefits of proposed research.

Rising Concerns in Contemporary Literature

Concerns and questions about ethics approval of research have been voiced for some time, with claims of a significant disconnect between ethical practice as theorized by academic researchers and ethical practice as managed by ethics review boards and committees, particularly in the humanities, arts, and social science (HASS) disciplines. Historian Schrag (2010) stated: "For anyone who values scholarship" university ethics boards and committees are "a matter of concern" (p. 2). He argued that they often apply "an ill-fitting biomedical model" (p. 9) to research across all disciplines, with the result that HASS researchers contend that research is "seriously threatened by ever more generalizing and standardizing processes of ethical review" (Kohn, 2014, p. 379). Israel and Hay (2006, p. 43) similarly argue that most ethics regulations and guidelines including those applied to social science have been written primarily from a biomedical perspective because of the risks associated with this type of research.

Relationships between HASS researchers and ethics boards and committees have been described as "grudgingly fearful" (Schrag, 2010, p. 5), and "marred by distrust and conflict" (Allen, 2008, p. 105). Studies indicate that a majority of HASS researchers engage in "some form of resistance" toward ethics boards and committees – either through explicit rejection of the legitimacy of ethics policies, or through "creative compliance" (Taylor & Patterson, 2010, p. 162).

When the *Journal of Applied Communication Research* invited researchers to provide anonymous accounts of their interactions with ethics boards and committees, in the 56 responses received "the majority of the narratives were clearly negative" (Dougherty & Kramer, 2005: 188). Deidentified communication researchers described their experiences as "arduous" (p. 207) "invariably … frustrating" (p. 213), with no "benefit" for "the extra work created" (p. 213). Some referred to their "distress" and even "disdain" for ethics boards and committees (p. 221). Fitch (2005) reported that many researchers felt a profound sense of "powerlessness" when dealing with these bodies (p. 276).

Based on interviews with 34 Australian ethics committee members and 54 health researchers, Guillemin et al. (2012) found disagreement in relation to the roles of ethics boards and committees to "protect participants". Researchers interviewed in this study expressed concern that, on one hand, ethics boards and committees are "over-protective toward research participants" and, on the other, that they often "work to protect the institution's interests" (i.e., institutional risk minimization rather than participant risk minimization). Guillemin et al. concluded that this "has the potential to lead to poor relations and mistrust between ethics committees and researchers" (p. 38).

Particular challenges in gaining ethics approval have been reported in relation to qualitative methods such as ethnography (Mapedzahama & Dune, 2017) and autoethnography (Murray et al., 2012). Also, at the *CHI 2020* conference, held virtually because of the COVID-19 pandemic, Hodge et al. (2020) presented a paper in which they reported that "many prominent interdisciplinary research approaches, such as participatory design and qualitative work with vulnerable populations in HCI [human computer interface], can be

considered ethically questionable by ERBs." This echoed an earlier claim by Bell and Elliott (2014) that many approaches to research ethics approval "align with biomedical and experimental scientific methods, which fail to reflect the multiple ways of generating knowledge that encompass the third wave of HCI" (n.p.).

Close examination of the effects of ethics approval processes for human research is important because researchers working within other highly formalized governance systems such as measurement and evaluation in fields ranging from business to medical practice and policing have shown that such systems can create perverse outcomes and become dysfunctional (Cugueró-Escofet & Rosanas, 2017; Grace, 2022; De Bruijn, 2007).

The Case: WHO Communication in the COVID-19 Crisis

Spread of the highly infectious and potentially fatal coronavirus, COVID-19 that was declared a global pandemic on 11 March 2020 (World Health Organization, 2020a) created the largest global crisis in terms of human health risk, impact on economies, and social and political upheaval since the Second World War. By mid-2020, almost 20 million cases had been reported worldwide and more than 700,000 people had died of the disease, with the largest outbreaks and death tolls in the United States of America, Brazil, and the United Kingdom (World Health Organization, 2020b). High levels of suffering and mortality were also occurring among low socioeconomic and low social capital groups in Asia, the Indian subcontinent, Africa, and other South American countries. During the first half of 2020 it became clear that the pandemic would not be easily or quickly brought under control and that many more would suffer or die.

A further development in the pandemic was instrumental in commissioning the research that was the subject of the human research ethics application analyzed here. In addition to recognizing the vital role of communication to effectively convey health messages, such as the importance of hand washing and physical distancing,[2] misinformation and disinformation spread rapidly. As well as conspiracy theories, which caused some people to ignore health advice, a range of fake cures were promoted through social media (McAweeney, 2020). These ranged from unproven claims about the beneficial effects of *hydroxychloroquine*, a treatment for arthritis and malaria (World Health Organization, 2020d), to suggestions by US President Donald Trump that ingesting disinfectants might prevent COVID-19. Manufacturers such as Clorox and Lysol pleaded for people not to ingest or inject their products (Rogers, 2020). Nevertheless, media and medical journals reported deaths in Africa, Asia, Mexico, South American countries, and the USA from drinking disinfectants such as bleach, household cleaners, and hand sanitizer (Chang et al., 2020; Fazio, 2020).

Consequently, the World Health Organization (2020c) declared COVID-19 an "infodemic" as well as a pandemic, and UNESCO referred to it as a "disinfodemic" (Posetti & Bontcheva, 2020), largely due to social media content. UN Secretary General, Antonio Guterres, stated in relation to COVID-19 that "our enemy is also the growing surge of misinformation" (United Nations, 2020).

Because of the importance of effective communication of health messages during the COVID-19 pandemic, and particularly because of the public misunderstanding and confu-

[2] The term 'social distancing' is widely used by governments and some health authorities, but the World Health Organization and many social welfare groups recommend use of the term 'physical distancing', while maintaining social connection.

sion created by misinformation and disinformation, the WHO commissioned research in early 2020 with two broad objectives: (a) to evaluate its public health communication in relation to COVID-19 as well as world health days and weeks and (b) help it increase its capability to effectively deliver health information and counter misinformation and disinformation. After an initial pilot project conducted with the WHO Western Pacific Region Office (WPRO) headquartered in Manila –close to the epicentre of the COVID-19 pandemic – WHO International headquartered in Geneva funded research to evaluate and inform effective WHO health communication.

A contract was awarded to a team of researchers at a 'top 100' university (Quacquarelli Symonds, 2023) in Australia because of their international expertise in evaluation of communication, health communication, and emergency communication specifically. It is relevant to the following analysis to note that the lead researcher is a Distinguished Professor with 30 years research experience in Australia, Asia, the UK, and Europe, and the co-lead is a full professor with 25 years research experience in the USA and Europe and is a Fellow of the International Communication Association (ICA). Both have conducted and researched crisis communication and the co-lead has worked in emergency communication for more than a decade.

In accordance with the contract issued, the planned research project for the WHO involved exploring the following research questions (RQs).

1. What are the current levels of knowledge of WHO communication staff internationally in relation to evaluation to ensure effective communication and combatting of misinformation and disinformation?
2. What are the main challenges faced by WHO communication staff internationally?
3. What training and support are required to help WHO communication staff deliver effective public health communication?
4. What are the main channels of WHO health communication and what measurement and evaluation are currently conducted in relation to those channels?
5. What data sets and methods are available to reliably inform planning and evaluation of WHO communication?

RQs 4 and 5 were able to be answered with secondary data such as existing reports, website statistics retrieved through Google Analytics, media monitoring, and social media analysis (non-human research). However, RQ1–RQ3 required human research with a sample of WHO communication staff to understand their existing knowledge, practices, challenges, and needs. This collaboration was considered important by both the WHO and the researchers, as the research was framed within a participatory action research (PAR) approach.

The proposed sample for human research involving semi-structured interviews was 25–30 WHO communication officers who voluntarily consented to be interviewed by one of the researchers with de-identification. Being semi-formal qualitative research, representativeness was not required, but wide distribution of the interview invitation was proposed to seek views from a number of countries, cultures, and specialisms (e.g., media relations, social media, Web communication, etc.).

Methodology

The following analysis reports the processes in gaining human research ethics approval for the research commissioned by the WHO in the early months of the COVID-19 pandemic as a case study in human research ethics approval. As identified by Stake (2008), Yin (2014), and others, while not producing generalizable findings, a single case study can provide "detailed description and in-depth understanding of behaviours, processes, practices, and relationships" in a particular context (Harrison et al., 2017, p. 35). This is particularly so when the research involves an *instrumental* case study as described by Stake (2008) – one that is "examined mainly to provide insight into an issue", rather than simply focus on the organization or event involved (p. 123). Because of the existential nature and urgency of the context of the research, the case could also be classified as an *exemplary* case, as discussed by Miles and Huberman (1994: 34) in relation to qualitative research sampling.

This case study is based on autoethnography by the author who submitted the ethics application and document analysis of time-dated forms, e-mails, and written requests for more information and changes to the research design and procedures. While recognizing the potential for subjectivity in autoethnography, documents cited provided empirical evidence to support personal observation and reflection.

Discussion: A Case of Ethics Review Creating an Ethical Dilemma

An ethics application was commenced on April 2, 2020 for the human research component of the project and took two days to complete, totalling 25 pages when printed as a PDF, made up of a 19-page form plus attachments including a *Participant Information Sheet* (PIS) describing the research and a *consent form* based on university templates. The length and the complexity of the ethics application form was the first point of contention in this case, as explained in the following. The application was submitted to the university Human Research Ethics Committee (HREC) Secretariat on April 4, 2020. It proposed that interviews would be conducted with a sample of 25–30 WHO communication officers in various countries on the basis of:

1. Initial notification to WHO communication officers of the research by WHO communications management (proposed so that staff were aware that the research was approved and not a commercial survey or a scam)[3];
2. Voluntary participation, with e-mail invitations to participate distributed directly by the researchers with the participant information sheet and the consent form; and.
3. De-identification of all responses in reporting and using the findings.

The proposed participants were all professionally trained communication staff of the WHO, working in head office and WHO country offices around the world. Almost all have undergraduate degrees, and some have graduate qualifications. As such, all were considered to be fully capable of voluntarily giving informed consent. Furthermore, it is noteworthy that proposed participants are employed by a United Nations agency

[3] During the COVID-19 pandemic many scam surveys were conducted in attempts to access personal information, conduct direct marketing, or perpetrate identity theft.

committed to human health and welfare with high ethical standards – a factor that indicates participants are likely to be safe, supported, and able to voluntarily consent.

Risk Assessment Criteria

Expedited processing was not requested because it was assumed that the research would be assessed as low risk and receive prompt approval, particularly given the existential crisis gripping the WHO and the world. The researchers noted that the *National Statement on the Ethical Conduct of Human Research* in Australia states: "The expression 'low risk research' describes research in which the only foreseeable risk is one of discomfort" (National Health and Medical Research Council, 2018, p. 13). Because of the research design described and the education level, training, and working environment of the proposed participants, the research was assessed by the researchers as being no more than discomfort through possible embarrassment in the event of revealing ineffective communication practices. Even this was considered unlikely because WHO communication officers had proactively reported that health messages were "not getting through" in many places. WHO Communications requested the research; it was not a study imposed on them. Risk was further assessed as unlikely given that preliminary online meetings indicated that participants were supportive and even eager to access research to help them meet the critical communication challenge of a pandemic and a *disinfodemic*.

However, the project was classified by the university's Ethics Secretariat as 'high risk' based on a Yes/No question in Section 1 A of its application that asks if the research involves:

People in / from countries that are politically unstable; where human rights are restricted; and/or where the research involves economically disadvantaged, exploited or marginalized participants from such countries e.g., includes countries that score < 50 on the Transparency Index.[4]

This question is so broad that is serves as a catch all. While the second part refers specifically to participants who are economically disadvantaged (i.e., poor), exploited or marginalized, the first part refers to people per se in or from countries that are politically unstable or where human rights are restricted. Thus, even highly educated, affluent, and powerful people are included as being at high risk simply because they live in a country that has some political instability or human rights restrictions. Furthermore, the measure applied is a "Corruption Perceptions Index" calculated by Transparency International, an organization founded and operated by bankers that focusses primarily on financial corruption (Transparency International, 2023). This question has subsequently been changed to be even broader, asking if the research involves "targeted recruitment of people in other countries".

[4] This question has subsequently been removed from the university' ethics application, but was included for almost a decade.

Timeliness of Ethics Application Processing

A month after planning the interviews and three weeks after submission of the ethics application, WHO management was perplexed and frustrated by delays in starting this important part of the research project that was expected to be straight forward. In the wake of controversial and misleading statements by Donald Trump and media reports of deaths from ingesting disinfectants, an e-mail to the researchers from WHO International head office in Geneva stated: "We need your urgent support" (De-identified WHO Communications Coordinator, April 21, 2020, personal communication). The researchers were placed in an embarrassing position trying to explain why interviewing communication staff of the WHO at their request was high risk and subject to considerable delays in gaining ethics approval.

Risk Assessment Criteria and Interpreting Risk Guidelines

On April 29, 2020, almost four weeks after submitting the ethics application, a response was received from the university's Ethics Secretariat. The following is a summary of just some of the issues raised and the lengthy and time-consuming explanations and retorts that had to be prepared and provided to the Ethics Secretariat even before the ethics application would be presented to the Human Research Ethics Committee.

While the national guidelines relating to human research ethics require risk to be assessed in terms of *likelihood* and *severity* (National Health and Medical Research Council, 2018 p. 12), the Ethics Secretariat's one-page response used the term 'might' seven times as well as "may", "potential", "possible", and "if" in discussing risk. Such language suggests a low likelihood of perceived risks manifesting. No evidence of likely or probable risk was identified. Furthermore, the severity of perceived risk was limited to "may feel embarrassed", which by any logical assessment fits within the National Statement's category of 'discomfort', which is described as low risk.

Furthermore, the *National Statement on the Ethical Conduct of Human Research* states in Sect. 1, Clause 1.1 of its guidelines for research merit and integrity that "research that has merit is justifiable by its potential benefit", adding that even when risks are present, benefits may outweigh the risks (National Health and Medical Research Council, 2018, p. 10). In this case, the WHO had explicitly stated in its brief requesting the research that improved effectiveness of public health communication could save lives, as well as reduce suffering caused by illness and bereavement. Also, the credibility of the WHO was under attack by US President Donald Trump and his supporters and by media for alleged communication failures (e.g., *National Review*, 2020). It is argued that any reasonable assessment would determine that the perceived risk of "embarrassment" for a small group of professional staff was far outweighed by the benefits of providing potentially life-saving information for millions of people.

The Ethics Secretariat response specifically objected to the researchers' proposal that the WHO would write to its communication officers "urging their input" to plan-

ning improved communication and increasing their capabilities by participating in interviews, claiming that this would constitute "coercion". Urging and encouraging participation are common in social science surveys and interviews, particularly those conducted within small populations based on purposive sampling, in order to gain adequate and relevant data. Urging and encouraging participation do not constitute coercion by any common definition of the term, particularly when participants are de-identified. For example, the *Merriam-Webster Dictionary* (2023) defines coercion as "to compel to an act or choice", "to achieve by force or threat" and "to restrain or dominate by force". The *Cambridge Dictionary* (2023) describes coercion as "the use of force to persuade someone to do something that they are unwilling to do". The proposal that WHO communications management would send an initial notification of the research involved no force or threat. The WHO considered it important that its employees knew that the research was commissioned by the WHO for planning its public health communication, and not by an unknown third party because many fake and predatory surveys were circulating during the COVID-19 pandemic, designed to solicit personal data for exploitation. The ethics application made it clear that, after the initial notification of the research by WHO management, the researchers would invite participation in interviews and manage all contact with the participants affording them full de-identification.

The Ethics Secretariat also directed the researchers to change a 'no' declaration to 'yes' in relation to Sect. 7 of the application, which asks if there are 'Pre-existing relationships'. This was a misreading of the university's own ethics application form. The question in the application form asking 'Are there likely to be any pre-existing relationships with research participants?' relates to whether the *researchers* have any pre-existing relationships with the participants, to which the correct answer was 'no' as stated. The Ethics Secretariat's direction that the "employee/employer" relationship between participants and the WHO should be acknowledged in this section was unwarranted.

A Blurred Border between Ethics and Micro-Management in Research?

On May 4 at 5.53 pm, after a detailed response to the Ethics Secretariat communication discussed above was sent and following a request for urgent out-of-session consideration of the application by the university's HREC, the Ethics Secretariat sent a further three pages of questions to the lead researcher. A number of these required substantial additional work by the researchers. Three examples of questions posed by the Secretariat, which required responses that further delayed the research, are discussed in the following.

- *Confirm who will be facilitating the interviews and what experience, qualifications and/or training they have had to respond to potential adverse reactions during the interview* – The names and qualifications of each of the researchers involved in the project, including the two researchers nominated to conduct the interviews, were provided in the ethics application. Their extensive experience, summarized previously, includes hundreds

of in-depth interviews, including during crises and emergencies and with vulnerable groups. The lead researcher, a full professor, had served at the university for 13 years at the time and successfully completed more than 20 externally funded human research projects. The full profiles and research records of the researchers were on the university's website. Therefore, requests by the Secretariat for additional information about the researchers' capability before the application would be presented to the Ethics Committee was considered unnecessary.

- *Provide a draft of the e-mail invitations to participants from both the WHO and the research team that highlights the voluntary nature of participation* – The Participant Information Sheet (PIS) for the project that was attached to the ethics application explicitly stated that "participation in this study is voluntary" and it further emphasized in simple language: "It is completely up to you whether or not you decide to take part." In accordance with research procedures, the researchers undertook to provide the PIS and a university approved consent form to all potential participants as part of the invitation to participate. The additional requirements for the researchers to write and submit the full text of e-mail communications that they would send to WHO communication officers invited to participate, and particularly e-mail communications that WHO management would send to its communication officers, were considered unnecessary and inappropriate. Given that voluntary participation had been clearly identified in the design of the research and in written materials to be provided to potential participants, the requirement to draft operational communications before ethics approval would be granted was seen as stepping beyond consideration of ethics into micro-management of the research project. Furthermore, demanding to review and even dictate communications of an independent external organization to its employees raised questions about the legal right of the university to engage in such processes. These requirement further delayed research that was requested and agreed as urgent and of vital importance, and it conveyed mistrust of the researchers and the funding organization, which created a high level of frustration.
- *Provide additional information regarding the "larger non-human research project* – The researchers could not understand why the HREC was involving itself in non-human research. The researchers were required to spend valuable time explaining other methods to be used such as website statistics analysis using Google Analytics and media content analysis. This was seen as a waste of the researchers' time during a major emergency and over-stepping the role of the Ethics Secretariat and the HREC.

Faced with 11 such questions requiring further information, repeated communications from the WHO emphasizing the urgency of the research, and hearing that people were dying after acting on disinformation, the lead researcher asked to withdraw the ethics application and cancelled plans to conduct the interviews. Under pressure to assist the WHO in developing effective health communication and address the 'disinfodemic', the WHO contract research project was adjusted to make recommendations on WHO communication strategy based on theory and analysis of secondary data such as traditional and social media content analysis. While the interviews were considered integral to a consultative approach and customizing recommendations to local cultures and practices, meeting the requirements for ethics approval threatened to delay the

research to the extent that the findings would be too late to inform planning of 2020 WHO health communication.

After a lengthy series of discussions, which included intervention by the director of the university's central research office, a reduced requirement for additional materials was presented to the researchers and, after six weeks of 'to and fro', human research ethics approval was granted. In total, more than 60 pages of information had been provided to gain approval to conduct 25–30 interviews with WHO communication officers. Ultimately, many of the interviews did not proceed because of unfolding events in the global emergency.

Conclusions and Recommendations

At a moral philosophy and theoretical level, this case study illustrates the importance of applying, or at least incorporating, a consequentialist (*teleological*) approach to human research ethics approval that considers and give weight to questions such as 'what are the consequences of doing this research?' Equally importantly, a consequentialist approach demands consideration of the consequences of *not* doing the research. Furthermore, a greater focus on consequences for not only the participants in research but for other individuals and society as a whole, which are recognized in medical research and other fields (Schuwirth & Durning, 2019), is also important. Broader interpretation of a "favourable benefit-risk ratio" (Wikler, 2017) beyond a small group of WHO employees would have presented an incontrovertible case for expedited ethics approval in this instance. While Kantian principles related to morals and duty are evergreen, a focus on rule-based virtue ethics can skew and even obviate the required balancing of *benefits* and *risks* and the weighing of both *likelihood* and *severity* of risks. In this case, the severity of risk was acknowledged as low (embarrassment); the likelihood was low given that the participants were educated professionals employed in a United Nations organization dedicated to health and welfare; and the benefits were potentially thousands of lives saved and reduced suffering for millions through more effective health communication. It could be argued that, in the circumstances, delaying this research through bureaucratic processes, redundant requests, and micromanagement was itself *prima facie* unethical. In the least, the application and approval process produced perverse effects.

At a disciplinary level, the experience of researchers in this project supports claims that some ethics boards and committees and their secretariats continue to have a biomedical bias and an inadequate understanding of research in the social sciences, particularly qualitative research. While social science research can pose risks for participants, in most cases it involves studies in which both the severity and the likelihood of risk are substantially less than interventionist research such as experiments and clinical trials. In this case, it seems clear that the Ethics Secretariat and the HREC over-emphasized risk and under-estimated or failed to consider the significant benefits potentially resulting from the research. Over-emphasis on and an over-estimation of risk fanned by risk aversion can present substantial barriers to conducting important research, as demonstrated in this case study.

At a practical level, greater focus needs to be placed on the timeliness of ethics approval given the speed of change in a 24/7 online digital world and events affecting human society

such as pandemics and natural disasters. Equally, 'creeping' exigencies such as discrimination, marginalization, and vilification, particularly in the online world, need to be addressed by social science researchers with urgency. Ethics review boards and committees typically meet monthly, or less frequently, and often insist on long lead times in submitting applications. While expedited review is sometimes offered, even this can involve many weeks of negotiations, revisions, justifications, and debate, as demonstrated in the case study reported. While this may be acceptable for research funded by multi-year grants and clinical trials with long lead times, social research in a globalized digital world needs greater responsiveness.

This case also brings to the fore operational factors related to contract research,[5] which is sought by universities as well as research institutes as research grants become increasingly competitive and research organizations seek to engage with industry and non-government, intergovernmental, and non-profit organizations. Unlike independent research supported by research grants from national or international research funding bodies, contract research is usually (1) a *requested* intervention rather than an intervention proposed (and potentially *imposed*) by the researchers and (2) involves a 'client' organization. While these factors do not obviate or lessen ethical requirements, and they introduce their own governance challenges, they need to be considered in reviewing methodology such as sampling and recruitment. For example, the contracting organization might justifiably specify the sample to achieve the objectives of the research and its endorsement of the research might be necessary (e.g., in the case of employee studies). Also, social science contract research often involves in-depth qualitative research methods such as participatory action research (PAR) that requires a high level of collaboration and even co-design by the researchers and the participants. In such methods, participants are often willing and even keen to be involved and even take on the role of co-researchers. Even in many surveys, interviews, and focus groups, members of the studied population want to 'have their say'. These factors and their implications need to be considered by ethics secretariats and boards.

Also, at a practical level, this case demonstrates that some, or even many, of the demands made of researchers in relation to ethics are made by ethics secretariat staff rather than by ethics boards or committees which are typically made up of senior researchers. While some staff supporting ethics boards and committees are trained in ethics and experienced in human research, others have administrative backgrounds and may have limited or no experience in the research methodologies and methods on which they pass judgement. Ethics secretariat staff act as 'gatekeepers' and, while their role in triaging applications and supporting ethics boards and committees is essential, this can result in misjudgements when they are inexperienced or unfamiliar with a discipline or field. The training and expertise of staff supporting ethics boards and committees need close attention to ensure they are appropriate for research in all disciplines within their purview and the varying processes and power relations in contract research.

As illustrated in this case study, the detailed and often exhaustive processes of ethics approval are largely focussed on 'paperwork' such as lengthy application forms, information sheets for participants, consent forms, and templates for communication with participants. Interaction with the researchers in relation to this important research was restricted to

[5] Contract research refers to research commissioned by government, industry, or non-government bodies, which often has shorter time frames than research funded by grants and in which people such as customers, members, or employees often want to participate.

completion of forms, e-mail messages, and one telephone conversation only after the matter was escalated to the Director of the Research Office. It needs to be better recognized that no amount of paperwork can ensure ethical research. Ethical research practices are arguably more effectively achieved through a deeper level of engagement with researchers such as workshops, giving advice, and mentoring in a helpful rather than a regulatory or policing approach.

Furthermore, heavy emphasis of up-front ethics approval ignores that ethical conduct of research is located in practice, not in forms or templates, or pre-approved questionnaires and protocols. In the course of conducting research, particularly social science field research, researchers need to adapt and respond to local conditions and contexts. The ultimate delivery of ethical research depends on what researchers *do* far away from the meeting room or online discussion of ethics review boards, committees, and secretariats. Greater recognition of the role of researchers in exercising sound judgement and applying ethical principles in dynamic 'real world' environments will arguably contribute to ethical practice more than seemingly endless forms, templates, and proformas. Affording a level of flexibility and discretion (and trust) to researchers could be balanced by providing case studies for critical reflection on procedures and incidents that arise in practice. While research training is provided in most universities, ethics beyond basic principles is often not on the agenda.

At a macro-social level, the restrictions placed on research identified in this case study can have the effect of silencing minorities, marginalized communities, and millions of people in countries that are politically unstable or where there are human rights violations. Such restrictions have precisely the opposite effect to those advocated in the principles of ethical social research. While the different approaches of social science and humanities researchers compared with biomedical research have been discussed for a decade or more, a lack of understanding remains. While ever it is easy and quick to get ethics approval for research among educated white people in developed Western countries, including student populations, but often slow and difficult to get ethics approval for research among marginalized and vulnerable people and almost anyone in "other countries", particularly those that are regarded as politically unstable or in violation of human rights, research will not adequately serve social justice goals.

In summary, this case study suggests that in our social world facing existential threats, injustices and inequities to which organizations need to respond, often expeditiously, and in which social science can play a key part, ethics secretariats and ethics review boards and the institutions that house them can further facilitate and support valuable social science research by ensuring:

- A *focus and understanding broader than biomedical and scientific research*;
- *Teleological as well as deontological assessment* of ethics applications to consider the consequences of doing the research as well as the consequences of *not* doing the research, which ensures that risk is weighed against benefits, not viewed in isolation;
- *Timeliness in reviews*, particularly in emergencies and crisis situations affecting large sections of society;
- *Understanding the different methodologies and power relations of social science research* including methods such as participatory action research, appreciative inquiry, and interpretative phenomenological analysis (IPA), which might require *additional training of staff involved in reviewing ethics applications* and *better balancing of disci-*

plinary and methodological knowledge on ethics review boards;
- *Understanding of the dynamics of contract research* as discussed; and.
- *A focus beyond 'paperwork'*, which is the basis of most ethics approval processes. Greater focus should be placed on helping social science researchers *do* ethics when they are in the field often facing changed circumstances to those envisaged in the cossetted offices of universities and research institutes. For example, this could include training and guidelines on 'what to do if … happens' and illustrative case studies for guidance.

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Declarations

Ethical Approval Ethics approval for the analysis in this paper was not required as no human research was involved. It is based on analysis of documents. Ethics approval for the WHO research discussed was granted – UTS HREC REF NO. ETH20-4895.

Competing Interests The author has no competing interests.

Disclaimer In identifying evidence of bureaucratization and institutionalization of prejudicial processes in ethics approval of research, particularly in the social sciences, this critical analysis recognizes the importance of careful consideration of ethics in all research and the valuable advice and guidance of many academic and professional staff in institutional review board (IRBs) and equivalent human ethics committees and secretariats.

References

Allen, G. (2008). Getting beyond form filling: The role of institutional governance in human research ethics. *Journal of Academic Ethics*, *6*, 105–116. https://doi.org/10.1007/s10805-008-9057-9.

Beauchemin, É., Côté, L., Drolet, M., & Williams-Jones, B. (2021). Conceptualizing ethical issues in the conduct of research: Results from a critical and systematic literature Review. *Journal of Academic Ethics*. Advance online publication. https://doi.org/10.1007/s10805-021-09411-7.

Beecher, H. (1966). Ethics and clinical research. *New England Journal of Medicine*, *274*(24), 1354–1360. https://doi.org/10.1056/NEJM196606162742405.

Bell, K., & Elliott, D. (2014). Censorship in the name of ethics: Critical public health research in the age of human subjects regulation. *Critical Public Health*, *24*(4), 385–391. https://doi.org/10.1080/09581596.2014.936727.

Brink, D. (2006). Some forms and limits of consequentialism. In D. Copp (Ed.), *The Oxford handbook of ethical theory* (pp. 380–423). Clarendon.

Cambridge Dictionary (2020). Coercion. https://dictionary.cambridge.org/dictionary/english/coercion.
Chang, A., Schnall, A., Law, R., Bronstein, A., Marraffa, J., Spiller, H., Hays, H., Funk, A., Mercurio-Zappala, M., Calello, D., Aleguas, A., Borys, D., Boehmer, T., & Svendsen, E. (2020, April 24). *Cleaning and disinfectant chemical exposures and temporal associations with COVID-19 — National poison data system, United States, January 1, 2020–March 31, 2020*. Morbidity and Mortality Weekly Report. Center for Disease Control and Prevention.
Crimmins, J. (2019). Jeremy Bentham. *Stanford Encyclopedia of Philosophy*. Stanford University. https://plato.stanford.edu/entries/bentham.
Cugueró-Escofet, N., & Rosanas, J. (2017). The ethics of metrics: Overcoming the dysfunctional effects of performance measurements through justice. *Journal Business Ethics*, *140*, 615–631. https://doi.org/10.1007/s10551-016-3049-2.
De Bruijn, H. (2007). The perverse effects of performance measurement. In de H. Bruijn (Ed.), *Managing performance in the public sector* (2nd ed., pp. 17–33). Routledge.
Dougherty, D., & Kramer, M. (2005). A rationale for scholarly examination of institutional review boards: A case study. *Journal of Applied Communication Research*, *33*(3), 183–188. https://doi.org/10.1080/00909880500149270.
Economic and Social Research Council (2020). Framework for research ethics. *UK Research and Innovation*. https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics.
Fazio, M. (2020). 3 die in Mexico after drinking hand sanitizer, officials say. *The New York Times*, 26 June. https://www.nytimes.com/2020/06/26/us/3-dead-drinking-hand-sanitizer.html.
Fitch, K. (2005). Difficult interactions between IRBs and investigators: Applications and solutions. *Journal of Applied Communication Research*, *33*(3), 269–276. https://doi.org/10.1080/00909880500149486.
Gelling, L. (1999). Role of the research ethics committee. *Nurse Education Today*, *19*(7), 564–569. https://doi.org/10.1054/nedt.1999.0349.
Given, L. (2017). It's a new year … so let's stop the paradigm wars. *International Journal of Qualitative Methods*, *16*, 1–2. https://doi.org/10.1177/1609406917692647.
Grace, S. (2022). The perverse impact of performance measures on policing: Lessons from the rise and fall of out of court disposals. *Policing and Society*, *32*(2), 200–220. https://doi.org/10.1080/10439463.2021.1906667.
Grady, C. (2015). Institutional review boards: Purpose and challenges. *CHEST*, *148*(5), 1148–1155. https://doi.org/10.1378/chest.15-0706.
Guillemin, M., Gillam, L., Rosenthal, D., & Bolitho, A. (2012). Human research ethics committees: Examining their roles and practices. *Journal of Empirical Research on Human Research Ethics*, *7*(3), 38–49. https://doi.org/10.1525/jer.2012.7.3.38.
Guyer, P. (2007). *Kant's groundwork for the metaphysic of morals: A reader's guide*. Continuum.
Harrison, H., Birks, M., Franklin, R., & Mills, J. (2017). Case study research: Foundations and methodological orientations. *FORUM: Qualitative Social Research*, *18*(1), Article1. https://www.qualitative-research.net/index.php/fqs/article/view/2655/4079.
Hodge, J., Foley, S., Brankaert, R., Kenning, G., Lazar, A., Boger, J., & Morrissey, K. (2020). Relational, flexible, everyday: Learnings from ethics in dementia research. Paper presented at *CHI2020*. https://www.youtube.com/watch?v=IdXonkuVVTw.
Israel, M. (2014). Will all the ethical social scientists please stand up? *The Conversation*, 4 November. https://theconversation.com/will-all-the-ethical-social-scientists-please-stand-up-33508.
Israel, M., & Hay, I. (2006). *Research ethics for social scientists*. Sage.
Kohn, T. (2014). Ethics review and the limited gaze: A plea for an intervention. *The Australian Journal of Anthropology*, *25*(3), 379–381. https://doi.org/10.1111/taja.12109_3.
Mapedzahama, V., & Dune, T. (2017). A clash of paradigms? Ethnography and ethics approval. *Sage Open*, *7*(1). https://doi.org/10.1177/2158244017697167.
McAweeney, E. (2020). Who benefits from health misinformation? *Medium*, 30 March. https://points.datasociety.net/who-benefits-from-health-misinformation-8d094804058d.
Merriam-Webster Dictionary (2020). Coercion. https://www.merriam-webster.com/dictionary/coerce.
Miles, M., & Huberman, M. (1994). *Qualitative data analysis*. Sage.
Murray, L., Pushor, D., & Renihan, P. (2012). Reflections on the ethics-approval process. *Qualitative Inquiry*, *18*(1). https://doi.org/10.1177/1077800411427845.
National Health and Medical Research Council (2018). National statement of the ethical conduct of human research (2007) – Updated 2018. https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018.
National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html.

Posetti, J., & Bontcheva, K. (2020). Disinfodemic: Deciphering COVID-19 disinformation. Policy Brief 1. UNESCO. https://en.unesco.org/covid19/disinfodemic.
Quacquarelli Symonds (2023). QS world university rankings, 2024. https://www.topuniversities.com/university-rankings/world-university-rankings/2024.
Rogers, K. (2020). Trump's suggestion that disinfectants could be used to treat coronavirus prompts aggressive pushback. *New York Times*, 24 April. https://www.nytimes.com/2020/04/24/us/politics/trump-inject-disinfectant-bleach-coronavirus.htm l.
Ross, W. D. (2002). *The right and the good*. Oxford University Press. (First published 1930).
Schrag, Z. (2010). *Ethical imperialism: Institutional review boards and the social sciences, 1965–2009*. Johns Hopkins University.
Schuwirth, L., & Durning, S. (2019). Ethics approval for health professions education research: Are we going too far down the barrel? *Medical Education*, *53*(10), 956–958. https://doi.org/10.1111/medu.13942.
Stake, R. (2008). Qualitative case studies. In N. Denzin, & Y. Lincoln (Eds.), *Strategies for qualitative inquiry* (pp. 119–149). Sage.
Taylor, J., & Patterson, M. (2010). Autonomy and compliance: How qualitative sociologists respond to institutional ethical oversight. *Qualitative Sociology*, *33*, 161–183. https://doi.org/10.1007/s11133-010-9148-y.
Transparency International (2019). Corruption perceptions index. https://www.transparency.org/en/cpi/2019.
United Nations (2020). UN tackles 'infodemic' of misinformation and cybercrime in COVID-19 crisis. https://www.un.org/en/un-coronavirus-communications-team/un-tackling-%E2%80%98infodemic%E2%80%99-misinformation-and-cybercrime-covid-19.
University of Pittsburgh (2018). Purpose of the human research protection office and institutional review board. https://www.irb.pitt.edu/content/chapter-2-purpose-human-research-protection-office-and-institutional-review-board.
Walton, N. (2020). What is research ethics? https://researchethics.ca/what-is-research-ethics.
White, M. (2020). Why human subjects research protection is important. *Oshsner Journal*, *20*(1), 16–33. https://doi.org/10.31486/toj.20.5012.
Who failed (2020). *National Review*, April 7. https://www.nationalreview.com/2020/04/coronavirus-pandemic-world-health-organization-failed.
Wikler, D. (2017). Must research benefit human subjects if it is to be permissible? *Journal of Medical Ethics*, *43*(2), 114–117. https://doi.org/10.1136/medethics-2015-103123.
World Health Organization (2020b). Coronavirus disease (COVID-2019) situation reports. https://www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports.
World Health Organization (2020c). Novel coronavirus (2019-nCoV). Situation report 13. https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200202-sitrep-13-ncov-v3.pdf.
World Health Organization (2020d). Q&A: Hydroxychloroquine and COVID-19, Newsroom, &. Geneva. https://www.who.int/news-room/q-a-detail/q-a-hydroxychloroquine-and-covid-19?gclid=EAIaIQobChMIr-Wxur2K6wIVideWCh1UqgzoEAAYASAAEgKoXvD_BwE#.
World Health Organization (2020a). WHO Director-General's opening remarks at the media briefing on COVID-19–11 March 2020. https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020.
Yin, R. (2014). *Case study Research: Design and methods* (5th ed.). Sage.