2 ETHICAL ISSUES IN RESEARCH DESIGN

PURPOSES AND GOALS OF THE CHAPTER

In this chapter, we introduce and develop the idea of research ethics as an orienting idea framing and permeating the entire research design process.

We explore the thinking that you will need to do about ethics when developing your research design. We stress the point that thinking about research ethics, just like research design itself, is a constant process. When doing so, we distinguish between research ethics and gaining ethics approval from a research committee.

We take a close look at foundational concepts associated with research ethics such as the principles of participant confidentiality, anonymity, and consent. We focus on what we will need to think about when putting these ethical principles into practice when designing our research.

Ethical challenges and dilemmas arising from contemporary trends such as the repurposing and sharing of existing data, and the increasing rapid digitalization of many aspects of social life, are also explored. In addition, we discuss the role of **ethics committees**, emphasizing that they are more than simply regulatory authorities.

Throughout the discussion we highlight that thinking about ethics is an important part of the reflexivity[1] that underpins the entire research design process (see Chapter 1). Such thinking impacts on all aspects of the development of our research design, from the moment we have an idea about a possible research problem, to well after we complete our research including what we say, and how we write, about that research.

Having this discussion early in the book (the second chapter) is a deliberate choice made to emphasize the centrality of reflexive thinking with ethics when designing our research. We develop the ideas and issues introduced in this chapter throughout the rest of the book. In this way, we model and capture an iterative way of thinking with ethics when designing our research. This is important because ethical matters related to research design are multifaceted and dynamic—they do not keep still and often emerge as a research design develops and then is put into practice.

The goals of this chapter are to

- Introduce the idea of research ethics.
- Focus on the thinking that you will need to do about ethics when developing your research design.
- Explore participant confidentiality, anonymity, and consent as foundational, but at times problematic, concepts in research ethics.

- Consider the impact that sharing or repurposing data, using digital platforms when collecting data, or using nonresearch generated sets of digital data as part of our research design has on putting ethics into practice.
- Explore the role of ethics committees.
- Emphasize the centrality of reflexive thinking with ethics when designing research.
- Provide examples that illustrate the impact that thinking about ethics has on the way we design our research and put it into practice.

WHAT IS RESEARCH ETHICS?

From the minute we begin thinking about what we might study *and why*, and then how we will study it *and why,* we are constantly interfacing with ethical considerations. *Ethics* is a term that all readers will have come across at some stage. But what exactly are we talking about when we talk about ethics or research ethics? Answers to this question range from whole books, to a few sentences, and all places in between! Wiles (2013) provides us with a useful entry point and orienting framework for exploring this question. She writes, "Ethics is the branch of philosophy which addresses questions about morality" (p. 4). This then raises the question of what morality is, and how morality is linked to ethics. Morality focuses on the "personal set of values and beliefs which guide self-discipline (including respect for others). . . . Ethics is an attempt to codify and regulate morality by stipulating norms and principles for behaviour" (Duncan & Watson, 2010, p. 50). It is not always easy to distinguish between morality and ethics as types of reasoning. This is because they are so closely linked, and because they are often used interchangeably.

Research ethics are concerned with moral behavior in research contexts. Principles and issues often identified in relation to thinking with research ethics in the design and conduct of research include "respecting human dignity, respecting persons, and being concerned for welfare and justice" (van den Hoonaard & van den Hoonaard, 2013, p. 15). Therefore, you will often see research ethics discussed in terms of doing no harm to participants (nonmaleficence); having some positive benefit to participants or society (beneficence); and respecting participants' decisions about what happens to them in the research, including if they choose to participate in it (autonomy or self-determination). In addition, no participant, or group of participants, should be either advantaged or disadvantaged over others (Anderson & Corneli, 2018).

Putting ethical principles into practice when designing research will require us "to continually reflect on the ethical implications of researching people's lives" (Duncan & Watson, 2010, p. 52) throughout the entire design process. This includes thinking about and asking ourselves questions such as these: What will we tell our participants about our study and when? What will we write about what they tell us—how and why? What will we do if our research uncovers issues of abuse or illegality? How will we look after our data and who has access to it? What will we say about how and why we did our research in a particular way? What will we include in, and what we leave out of, the reporting of our research and why? Such reflexivity is central to developing what van den Hoonaard and van den Hoonaard (2013) refer to as a researcher's "inner ethical poise" (p. 13). In the discussion to follow, readers are encouraged to develop awareness of, and explore, both their inner ethical poise *and* why that awareness matters in terms of the way we think and act when designing our research.

Regardless of which research methods we intend to employ in our research design, we will be forced to consider and think reflexively about what van den Hoonaard and van den Hoonaard (2013) describe as "keystones in any ethical research" (p. 39), namely participant confidentiality, anonymity, and consent. They note that these keystones form a complex triangle of connected ethical related issues. This triangle is bent into various forms by the circumstances and context of each individual research project and design. For "[w]hile there are a number of 'common' ethical issues [such as **informed consent**, anonymity and confidentiality, and risk and safety] . . . research is always situated and contextual and the specific issues that arise are often unique to the context in which each individual research project is conducted" (Wiles, 2013, p. 9).

In the next sections of this chapter, we will take a closer look at what it means to put these keystones of ethical research into practice when designing our research.

PUTTING INFORMED CONSENT INTO PRACTICE

Before we begin collecting information from people in our study, it will be necessary to gain their consent to both collect and use that information. How to obtain that consent and how to ensure that it is *informed* consent must be a central part of our thinking from the outset when we are designing our research—not an afterthought. But what is informed consent? Informed consent is when participants agree or consent to participate in the research. It means that the participant understands *both* that they are giving consent *and* what they are consenting to. Such consent relies on full disclosure by the researcher of what participating in the research involves.

To make an informed decision about whether to consent to participate in a research study, potential participants must be given both transparent, and sufficient, information in an appropriate form about the study. This is so that participants know

- what the study is about;
- who designed the research and decided the way it will be done;
- what their role as a participant in the study will be;
- who will actually do the research or collect information from them;
- that they can decide whether or not they want to participate;
- that they have the right to withdraw, or withdraw any information collected about or from them, at any time from the study without having to give reasons;
- what benefit they may or may not receive from being in the study;
- who else might benefit from the research and how;
- any risks that they may encounter by participating in the study;
- any costs to them (including time) by participating;
- what will be done with the information that they provide to researchers;
- who the researchers are, their affiliations, and the source of any funding for the research received.

Each of these points should be thought about and addressed *as you are designing your research*. This means that you will be thinking with, and about, ethics at all stages of the development of your design. To be able to give clear information about each of them means making our research design, and our thinking about that design, as clear, honest, and transparent as possible to potential participants. This includes the actual research questions, the aims and the rationale for the research, the ways in which the research will be conducted, and what we will tell about the research and to whom, after it is completed.

For example, we cannot deceive people about aspects of our research by telling them that our research is for one thing when in fact it is for another. Nor can we imply some advantage to participate when that might not be the case, therefore raising false hopes and expectations on the part of our participants.[2] This is because an important part of informed consent is that the consent is given freely and not because the participant is offered inducements (such as financial gain) to participate in the study, nor because there are negative consequences for them if they do not participate.

Informed Consent—Who, What, and When

We will also need to think about how much information, in what form, to give, when and to whom (Wiles, 2013). For example, we will need to think about how to keep the language that we use when describing our study in information sheets and consent forms, for example, as concise and simple as possible. Thought will also need to be given to participant group appropriateness of that information in terms of the way that the information is presented, including the assumed level of literacy of the reader. A way of doing this is to ask "persons from the sample population of interest to review the consent form(s) prior to using it" (Lahman, 2018, p. 74).

PUTTING IT INTO PRACTICE

SEEKING CONSENT IN AN APPROPRIATE WAY

Lahman's suggestion to ask "persons from the sample population of interest to review the consent form(s) prior to using it" (Lahman, 2018, p. 74) could usefully be extended to include asking these persons from the sample population of interest to also review the way in which that consent will be sought. For example, is a written consent form the best means of gaining consent in the population or community of interest? There may be culture-specific considerations that we need to take into account that make the use of a written consent form inappropriate.[3] Persons from the sample population of interest could also be asked to comment on from whom that consent needs to be gained. For example, Duncan and Watson (2010) found, when researching in different cultural contexts, that in some communities it was necessary for them to obtain verbal community consent before attempting to get written consent from individuals in those communities.

Sometimes when conducting our research, the design of the research may change. For example, in many **qualitative research approaches**, aspects of the research design emerge as the study progresses. This can make giving information about exactly what participating in a study may mean problematic.[4] Therefore, in such cases we will need to consider

when and who we will need to get informed consent from and overtly incorporate these considerations into every part of our research design including constantly reviewing them as the design of our research evolves. The same consideration applies if our study design is some form of longitudinal study:

> In longitudinal studies or research with repeated stages of data collection it may be appropriate to provide information, and gain consent, for each stage of data collection. . . . This approach highlights the importance of viewing consent as a process that is ongoing throughout a project rather than as a one-off event (Wiles, 2013, p. 28).

Other issues related to informed consent arise if we intend to reuse data that has been collected in other studies. We return to this point in a later section of the chapter.

Informed Consent in Relation to "Vulnerable" Populations

There are some individuals and groups of people formally deemed "vulnerable" by ethics committees, government regulatory authorities, and professional associations. For example, the Declaration of Helsinki[5] explicitly states that "[S]ome groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm. All vulnerable groups and individuals should receive specifically considered protection" (World Medical Association, 2018, item 19).

In general, a group is considered vulnerable if there is good reason to believe that individuals in that group may, for some reason, have difficulty providing free and informed consent to participate in research. In the Declaration of Helsinki (World Medical Association, 2018), individuals incapable of giving informed consent, individuals likely to consent under duress, individuals with increased likelihood of incurring additional harm, and individuals that do not benefit from the results of the research are all considered vulnerable.

TIP

BE AWARE OF LOCAL UNDERSTANDINGS AND REQUIREMENTS RELATED TO WHO IS DEEMED VULNERABLE

Individual countries may also designate who vulnerable groups are. For example, in the United States, groups designated as **vulnerable populations** include "children, prisoners, individuals with impaired decision-making capacity, or economically or educationally disadvantaged persons" (Department of Health and Human Services, 2018). Therefore, it will be important to make sure when designing research that you are aware of the local understandings and requirements related to who is considered a vulnerable participant and what that means for gaining consent.

The use of the designation "vulnerable," while well intentioned, has been critiqued on a number of grounds. One ground is that this designation may actually work against the best interests of groups deemed vulnerable. This is because increased regulation and requirements for accessing participants may make research with these groups increasingly difficult and thereby reduce the amount and scope of research focusing on these populations. This can lead to the situation described by Markham et al. (2018) where "systems of

research and ethics governance do not facilitate and support social research that needs to be done, because it has been traditionally been [sic] prohibited" (p. 3).

Another criticism is that the designation of vulnerable may take away the right of individual participants in these groups to participate in research. They may be excluded on the assumption that they are vulnerable (predetermined by others' definition of that term), and therefore not competent (predetermined by others' definition of that term), to give informed consent (also predetermined by others' definitions of that term). The effect of this is that large groups of people deemed as being vulnerable such as children or those with cognitive disabilities "who all in various ways could stand to benefit from having their living conditions elucidated by research" (Juritzen et al., 2011) are in effect excluded and their rights and interests further marginalized.

All of this raises a series of questions around informed consent for which there are not clear-cut answers. These questions include who decides whether a person is competent to participate in a study. Particularly if the study is about something that the person has knowledge of and wants to participate in, who makes that decision? Whose rights predominate? Who is able to speak for whom and when? Reflexively thinking about these questions and their effect on the way that we design our research can help us avoid some of the taken-for-granted assumptions that we might otherwise make about informed consent that on the surface may seem quite reasonable. It can help us shift the focus of our thinking from whole of group vulnerability to vulnerability of individuals, or groups of individuals, within that whole of group designation. In so doing, it can shift the emphasis in our thinking to the idea of research participants as "*capable and competent yet vulnerable* at the same time" (Lahman, 2018, p. 13). This can open up possibilities for the inclusion of people in our research that otherwise may be excluded because of standardized and normalized understandings of what it means to be vulnerable.

PUTTING CONFIDENTIALITY AND ANONYMITY INTO PRACTICE

The ideas of confidentiality and anonymity are closely related. At times, you may even see these terms used interchangeably. While there is no doubt that they are linked, they are not the same.

Confidentiality is wider in scope than anonymity. Keeping a research participant's identity anonymous is part of confidentiality. However, confidentiality is not ensured by keeping the participant's identity anonymous. For example, it is possible to breach confidentiality if information from an anonymized participant is reported or used in some way in the research when that participant specifically requested that it not be used (Wiles, 2013). Confidentiality is more than just not disclosing the name, identity, or identifying features of participants. It is also about the way that any data that a participant has provided or is related to that participant is shared or not shared, and with whom.

Anonymity is used by researchers to protect the identity of the participants in their study. In research design, anonymity often involves using pseudonyms when referring to participants or sites in the study. A **pseudonym** is a fictitious name given by researchers to participants or sites in a research study. The pseudonym is used instead of their real name when reporting and discussing the research. However, even such a seemingly benign and simple process requires some careful thought when designing your research, and in itself should not "be confused as equal to ethical research" (Lahman, 2018, p. 83).

For example, one thing we will need to think about is what pseudonyms will be used and who will choose them and how. Will we ask participants to choose their pseudonym or will we as researchers do this? If we choose the pseudonym, what impressions, intended or otherwise, might be given about a participant by assigning them a particular pseudonym? Being able to rename someone involves the use of power (Hurst, 2008; Lahman, 2018).

PUTTING IT INTO PRACTICE

WHAT DO YOU DO IF IT IS IMPOSSIBLE NOT TO IDENTIFY THE SPECIFIC SITE OF A STUDY?

Sometimes, it may be impossible not to identify the specific site of a study. For example, a master's student, Christine Moe Grav (Grav, 2015), that one of us supervised wanted to study the effect on a group of middle managers in a specific government department of having to implement a government-mandated departmental structural reform that would result in them losing their position. In other words, these managers would have to manage themselves out of their jobs since the result of the reform would be that there was no more middle management. There were 15 of these middle managers in this specific department. Christine was interested in how these 15 managers experienced this process and what those experiences could tell us about the process of change management. The problem she faced was how to do this study in such a way that it ensured confidentiality and anonymity for this group of 15 participants even though it was impossible to do the study without identifying the actual reform and therefore the department that the reform affected and therefore the 15 managers.

Christine protected the confidentiality and anonymity of each *individual* manager in terms of what information they contributed to the study by making it impossible to identify which manager had said what. This was done by not linking any demographic data to individual participants or to the information they provided for the research. If Christine had linked the participant or the information they gave in their interview to demographic data collected about them specifically, such as length of time in the position, it would not have been difficult for a reader to cross-reference that information to the 15 managers and figure out who had said what. By providing ranges of length of time in the position rather than listing experience levels for each individual anonymized manager, Christine was able to provide a demographic snapshot of this group while preventing specific information being able to be linked to individual managers. When citing her participants, Christine did not include any demographic data about the participant in question.

Sometimes we may need to consider what we will do if a participant does *not* want to be given a pseudonym but wants their real name to be used or their identity to be linked to the data collected about them. In these instances, it is important to make sure that participants understand what having their real name used will mean in terms of the way that the information is presented in public arenas such as publications, presentations, and reports. It means making it clear that it will be possible to identify them *and* link the information that they gave, their data, to them.

The Use of a Pseudonym Does Not Necessarily Ensure Anonymity

We will also need to remember that in itself the use of a pseudonym for individual participants does not necessarily ensure anonymity for participants. For example, if you identify

the specific region or town or organization or sector that the study is located in, it might not be difficult for people to backtrack and identify who some of the participants might have been in the study. This is particularly so if we collect demographic data about our participants and directly link that data to other data collected in the study. An example of this would be if we report excerpts from qualitative interviews in the following way: "managers here are not good at explaining things" (Julia, Female, 38 years, 2 years' experience, mid-level manager).

While Julia is not the person's real name, the demographic data is real. Therefore, if the site of the study can be identified, it will not be difficult to work out who "Julia" is. This can also be the case even if the data are reported only using the pseudonym itself, for example, "managers here are not good at explaining things" (Julia). This is because if in a table of demographic data, each anonymized participant has been listed and their demographic data attached to their pseudonym, then it is a simple exercise to backtrack and connect that demographic data to the participant.

Consequently, Morse (1998) suggests reporting ranges of the demographic data of the entire participant group (e.g., age ranges), rather than specific demographic data of each individual participant (e.g., age). She also suggests that we "do not attribute each quotation to a particular participant, unless there is a compelling reason to do so" (p. 302), arguing that the researcher will have selected particular quotes as illustrative exemplars of their findings and so attaching a quote to an individual (even with a pseudonym) is not necessary.

This does not mean that demographic data about the individual participants in a study cannot be collected or used in a study. The key point is that specific demographic data, no matter what methods are used, must not be linked to individual participants in a way that it could identify those participants if the participants have been promised anonymity when participating in the study. It also protects the confidentiality of what that anonymous person has said.

PUTTING IT INTO PRACTICE

Navigating Ethical Issues Is Not Always Straightforward

Our discussion of putting confidentiality and anonymity into practice has highlighted that this is not always straightforward even if you have obtained informed consent and taken steps to ensure the anonymity and confidentiality of the participants and sites in your research. For example, some form of observation is often used by researchers as a way of obtaining information about a particular social setting of interest.[6] Different sorts of issues arise when making those observations, depending on what type of observations you make and where. Issues may also arise from your level of involvement in what is being observed.

Therefore, issues that you will need to think about include

- if you intend to make observations part of your study design you will need to consider in what capacity you will make those observations. For example, will you make those who are being observed aware that they are being observed or what is being observed or why? How does your decision about this impact on informed consent and also the privacy of those being observed?
- if you are going to research people in public places such as shopping centers or public streets, will you need to get consent from every person you observe?

Given that in a shopping center or public street it may not be possible to do this, does this mean that it is not possible to do this type of observational research?

- if when you are making your observations you observe an interaction or behavior that is concerning in some way— for example, bullying or sexual harassment— what will you do? What about if you observe what you consider to be inadequate or incompetent professional practice? Should you intervene or report that behavior? What about anonymity and confidentiality considerations in all this?
- if you are a student and then return to debrief your observations with others and your analysis of those observations, how will you ensure the anonymity and confidentiality of that observational data when you talk about it?

You will need to think through and take up your own inner ethical poise in relation to these types of dilemmas and justify what you choose to do as part of your research design.

Although we have used observations as the vehicle for the discussion here, the same sorts of considerations apply to other methods used to collect data from and about people, such as interviews and surveying. There is no simple answer to these types of questions. However, a good piece of advice is given to us by Ryen (2011):

> There are no standard answers to these dilemmas. . . . We need to be prepared for all these challenges, which demand that we put them on the agenda from the very start of our projects and ask ourselves how they relate to our own particular project.
>
> But what should we do? A good piece of advice is always to invite experienced researchers with particular knowledge in research ethics and in your field to discuss matters with you. (pp. 418–419)

WHAT YOU NEED TO THINK ABOUT WHEN REUSING, REPURPOSING, AND SHARING DATA

Some research designs involve "repurposing, reusing, combining, sharing and linking data in new ways" (Ballantyne, 2019, p. 357). Indeed, there are increasing calls that researchers *should* share their data (Meyer, 2018), resulting in pressure directly and indirectly being placed on them to do so. Some journals (see for example, *Nature Research* [2022] and *Science Journals* [2021]) and funding bodies such as the National Science Foundation (2014) and the UK Economic and Social Research Council (ESRC) are requiring some sort of data sharing as a prerequisite or requirement for publication or funding. The UK Economic and Social Research Council Data Policy, last updated in 2021, states that "[p]ublicly-funded research data are a public good, produced in the public interest, which shall be made openly available and accessible with as few restrictions as possible . . . for future research" (Economic and Social Research Council, 2021, principles 1 and 2).

One of the central questions that the reuse or sharing of data as part of a research design raises is who decides that is it OK to share and re-use that data, and what can or cannot be shared. As Flick (2015b) puts it,

> If we start interviews, for example, by asking participants for their (informed) consent—are such permissions for doing research or the informed consents obtained valid for re-use of data for all purposes and for every other researcher? What does this mean for clearances by ethics committees? (p. 604)

To address these important questions requires us to consider what implications the **repurposing of data** has for one of the keystones of ethical research, namely informed consent. A central consideration is whether a participant's consent for reusing, repurposing, and sharing their data can ever really be *informed*. When consenting to the reuse of their data, research participants will not necessarily know exactly what their data will be reused for, or by whom. This raises the possibility that participants' data could be used in a study that they would not have consented to their data being reused in, because of, for example, who is doing the study or who is funding the study or what the aims of that study are.

The potential difficulties of obtaining informed consent for the use of data from previous studies have led some commentators to suggest that the primary question for the reuse of such data is not "'[C]an we get consent', but rather 'Does the public interest in using the data outweigh individual interests in controlling access to the data'?" (Ballantyne, 2019, p. 358). However, this suggestion raises yet another set of questions related to informed consent that will need to be thought through and about. Questions such as, "Is there an upper limit to the risks that individuals should bear for the sake of the public benefit of data use? What legitimizes decision-making processes? Who should be held accountable for data misuse and how?" (p. 365).

To these questions posed by Ballantyne we can add even more related questions such as, What does an upper limit to the risks those individuals should bear for the sake of the public benefit of data use actually mean—is that harm OK in some instances? Who will decide what this upper limit is, will it be applied equally to everyone, and will we know that upper limit when consenting to our data being reused or repurposed? Similarly, who will decide what the public benefit of data use is? Will this be a legal or regulative or ethical, individual, or collective decision? How will it be enforced? Moreover, again, who will decide this, how, where, on a case-by-case basis or . . .?

Therefore, if when designing your research you are thinking about using data for which the original consent did not explicitly include a clause or statement about data sharing or reuse, then you will have even more thinking to do. This relates to whether the more "effective" and "efficient" use and reuse of data for some sort of greater public good should outweigh the rights of each individual participant to determine the way that their data are used and who has access to it.

How to Address These Types of Questions?

Beck (2019) suggests that using multiple **layers of consent** is one way of addressing, or at least beginning to think about, how to address the ethical issues that arise around informed consent when participants' data collected for one purpose is used for another. Such layered consent may make it possible for the participant to have more control in relation to the extent of, and purpose for, the reuse of their data. This is because multiple layers of consent would enable research participants giving informed consent for a specific study (the primary study) also being explicitly asked whether they consent to some or all of (1) participating in the primary study and only having their data used in that study, (2) the researchers in the primary study being able to reuse that data in later studies, and (3) the archiving/storage of that data which may then be accessed by other researchers and reused in other studies.

However, even if multiple layers of consent are used, the issue that still arises is how much information we need to give about each of these layers before we can say that any

"consent for reuse" (Bishop, 2009, p. 262) that is given really was informed? How explicit does information about each of these layers need to be about what data will (and won't be) shared, when and how, and with whom, as decided by whom, in order to be able to claim having informed consent for the reuse of that data and/or use of that data in a specific secondary study?

There are no easy or "correct" answers to questions such as these. However, if you are considering using a research design that involves data sharing and/or reuse and/or the archiving of your study's data for future researchers to access and use, you will need to think *through* these questions. You will also need to declare how you have designed your research with these questions in mind. This is not easy to do as "[b]alancing the rights and responsibilities of the primary researcher and the research team, secondary researchers who want to make use of the data, the data archivist, research participants, research funders and the general public may present significant challenges" (Wiles, 2013, p. 88). Thus when designing research that involves some form of data sharing or repurposing, it is important to think reflexively, not simply linearly, about the use of that data after it is collected. This includes after your research is concluded.

WHAT YOU NEED TO THINK ABOUT WHEN USING INFORMATION ON THE INTERNET AS DATA

The advent of the internet and the rise of digital data has refocused researchers' attention on concepts like "privacy" and "informed consent." It raises questions such as, "When should someone expect confidentiality on the internet? When should a researcher seek a participant's permission to conduct research on the internet?" (Lahman, 2018, p. 209). For example, if information on social media or social networking sites is "harvested," "mined," or "collected" in some way and used as data in a research study, does that mean that consent needs to be given for the collection and use of that data? If so, how might this be done?

For example, what if someone collects digital traces of our everyday activities, again without our knowledge or consent, and aggregates them into massive sets of digital traces known as Big Data?[7] Such digital traces can be in the form of text, videos, and images taken, for example, from social media (such as Facebook or Twitter), personal blogs, chatroom conversations, and other forms of internet communities. The digital traces also include data transmitted by microchips embedded in "clothing, products, credit cards, and passports" (Mills, 2018, p. 596), Internet of Things,[8] as well as records of some form of activity generated by activity bracelets and individual health monitoring devices. Then, what if that Big Data set is used as the basis for algorithmic analyses that are used to predict aspects of our behavior such as our political leanings or likely consumption patterns?[9] Who regulates or makes decisions about this? Who actually owns that data, and who can, and cannot, give consent for digital traces to be used for research and other purposes? If we are planning to use this type of data, these questions need to be thought through carefully.

Blurring the Boundary Between Public and Private

The accessibility of digital data, such as digital traces of our daily activities, forces us to consider what is public information and what is not? In the digital age, this is not so easy to answer given that "much of Internet behavior is both private (person in their home residence) and public (person is active in the Internet) simultaneously" (Lahman, 2018,

p. 200). For example, in a study designed to reveal the potential of large datasets, Danish researchers Emil Kirkegaard and Julius Bjerrekær (2016a, 2016b) obtained access to a large set of data by pretending to be looking for partners on a dating site. In fact, their intention in joining the dating site was to scrape[10] the data in the user profiles of members of the dating site OKCupid.com. From the information they obtained, they developed a publicly available dataset.

The researchers justified not obtaining informed consent to access this information by claiming they were merely presenting already publicly available data and hoped that other researchers would use the dataset to address other research problems. They stated that a dataset collected by researchers is too often "not used to its full extent" (Kirkegaard & Bjerrekær, 2016b, p. 1), and this slows down "the progress of science immensely because other researchers would use the data if they could" (p. 1).

The ensuing controversy was massive. OKCupid users, academics, online commenters, and others accused the researchers of making confidential and sensitive private-user information public. However, the researchers continued to argue that the dataset was presenting already publicly available data.

This case raises the question of whether an internet-related activity, such as becoming a member of OKCupid, is private or public or both private and public simultaneously. It also raises the question of even if something is public, does that mean that it is OK to use private information made public as research data.

The increasing use of data from the internet by researchers gives rise to many questions about what is public and what is private. For example,

- when someone posts information about themselves or others on social media such as in tweets or blogs or conducts a conversation in a social networking site such as Facebook, who can use that information and what for?
- when people post information about themselves and aspects of their lives on public domains on the internet, where the information is accessible by all, does that mean that this information can be used as data in our research studies without asking the people who posted it if they consent to this? In other words, does the fact that this information is being used formally as research data change the thinking about ethics we need to do?
- what about "public" data in a closed or private internet community, such as OKCupid?
- how do we make that decision?
- who makes that decision?
- given that digital traces have no geographical boundaries, what formal regulatory requirements will need to be met?

Further complicating matters when trying to address the issues that the points raise is the rapid rate of growth and change in both the development of technology related to digitization[11] and the use to which that digitization can be put. This includes commercialization of data such as the buying and selling of sets of digital traces.[12] Who should profit from that sale? Is this exploiting the people from whose activities the digital traces were harvested? Who owns the data? During the time that has elapsed between us writing

this chapter and you reading it, there is no doubt that many new and different questions will have emerged around thinking about ethics in relation to digitally based research and informed consent. It is not possible to predict where discussions of the issues already being raised by some researchers and scholars about the possible need for changes in our thinking about consent and privacy in a digital age will take us.

None of this means that the principles about the importance and centrality of the idea of informed consent and privacy (or any other ethically related matter) we have discussed previously in this chapter are outdated or no longer relevant in light of a fourth industrial revolution and increasing digitization more generally. Quite the opposite! Rather, all of this reminds us of, and returns our thinking to, a point made earlier: "Ethics is not a static event but a continual process" (Sparkes & Smith, 2014, p. 206). New and different issues constantly arise related to informed consent, anonymity, and confidentiality. This includes research that is driven by various forms and aggregations of digitized data.

WORKING WITH ETHICS COMMITTEES

In many countries, formally constituted ethics committees also known as **Institutional Review Boards**, or IRBs, regulate ethical matters relating to research design and conduct. When designing your research, you will need to find out what these formal regulatory requirements are, consider them when designing your research, and obtain the necessary ethics committee approval to proceed with your research. This should happen before you contact potential participants or commence collecting any data. In the case of multiple-site research studies, you will need to ascertain if you are required to submit your research design to several ethics committees if each site has its own ethics committee. You will also need to find out what form your submission should take. Is there a template that you are required to follow? Does the template vary from committee to committee?

Ethics committees, and their underpinning understandings of research, are often influenced by the traditions of medicine. This is because "the original focus of IRBs and the context from which they emerged was that of medicine and the scientific discourse that underpins medicine" (Cheek, 2008, p. 57). For example, in the United Kingdom, the Royal College of Physicians in 1967 recommended that all medical research be subject to ethical review. By 1991, every health district was required to have a Local Research Ethics Committee (LREC). In addition, Multi-centre Research Ethics Committees (MRECs) emerged as a means of helping streamline proposals that otherwise would have to go through numerous LRECs (Ramcharan & Cutcliffe, 2001).

Similarly, in the United States, the impetus for the initial development of IRBs also came from medicine and the science underpinning medicine. Increasing public and government concern over unethical research studies, such as the Tuskegee Syphilis Study,[13] ultimately resulted in the Belmont Report from the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1979. This report detailed fundamental ethical principles for the conduct of human research: beneficence, respect, and justice. These principles are what shape IRB standards in the United States today.

Ethics committees, such as IRBs, consider how a proposed research design puts principles such as beneficence, respect, and justice into practice. For example, they consider whether the research is worth doing in terms of producing useful and significant findings and outcomes. They also examine whether the proposed research design will enable

trustworthy results. This means that the methods to be used to collect data from participants need to have been clearly explained. This includes recognizing potential issues that may arise from those methods about informed consent, anonymity, and confidentiality *and* how they will be addressed.

Particular attention is often focused on information sheets or sufficient information in some form that participants in the research will be given about the research before they sign a consent form or give consent in some other acceptable way to participate in the research. Ethics committees are also interested in how data and information related to the study will be stored and who will have access to that data. This is important because it can be a seemingly "ordinary" thing such as storing data on a laptop that destroys the entire confidentiality and anonymity of a research project and compromises its ethical integrity if, for example, the laptop is stolen during the research.

Focusing on the Principles, Not the Requirements

When thinking about where research ethics "fits" into the research design process, many researchers immediately focus on what they must do in order to gain "ethics approval" from an ethics committee or review board. As a result of this sort of focus, a form of shorthand terminology such as "getting ethics" has emerged as part of the research design process. The danger in the consolidation of this type of shorthand terminology is that thinking about ethics is reduced to how to meet the requirements for ethics committees' approval. "What are the requirements, and have they been met?" becomes the focus rather than the ethical matters themselves. This type of thinking can lead to "checklist" type thinking about ethics. In checklist thinking, ethical thinking becomes focused on ticking the boxes by "passing" or "meeting" those specific requirements. Often the thinking that sits behind those requirements is lost, or at best becomes a secondary focus with the main goal being to get the approval.

Ethical matters and thinking *through* ethics throughout the research design process cannot, and must not, be confined or reduced to a static list of standardized steps to be followed that can be made into a checklist and then ticked off as complete one by one. For example, do I have a consent form, information sheet, and so on. In such thinking, the often unstated assumption is that if you address all the things on the list and get a tick next to each of them on some sort of literal or mental checklist, then your research design is "ethical," ethics "approval" has been gained, and your thinking about "ethics" is done. In fact, what actually has been gained is approval to proceed ethically. If the thinking about ethics when designing research is reduced to a focus on meeting the requirements of an ethics committee or checklist, the danger is that the focus on the ethical issues themselves, or ethics in relation to the particular research being designed and conducted, can be lost once the approval is gained.

Just complying with predetermined procedures, such as the format that an information sheet must take, may not necessarily ensure that the design and conduct of the research is ethical. Research design, the research process, and therefore the thinking through ethics that influences every part of that research process are not static but continually unfolding and developing—this is why your thinking about ethics is not finished when you have met the requirements of an ethics committee—in many ways it has just begun. New ethical issues may arise, or change during the life cycle of your research, forcing you to revise your initial research design.

The key point that emerges from all this is that there is much more to research ethics and ethics committees than regulation and procedures. To focus our thinking about ethical matters related to research design solely on meeting or "passing" the procedural requirements of an ethics committee runs the risk of standardizing and limiting thinking about both ethics *and* ethics committees, reducing them to matters of procedure—where ethics is "got" or the requirements "met." Such thinking reduces the role of ethics committees to an administrative focus and loses the important contribution that they can make as educational and scholarly bodies concerned with advancing conversations and understandings of ethical research *itself,* thereby developing researchers' "ethical literacy" (Wiles, 2013, p. 1) and inner ethical poise.

Activity

Finding Out About Professional Ethical Guidelines

Thinking with ethics with respect to your research design will also need to take into account relevant "[p]rofessional ethical guidelines and codes [containing] disciplinary norms of ethical behavior," but which "are not legally enforceable" (Wiles, 2013, both quotes from p. 6). Such a code identifies standards of behavior and conduct based on core ethical principles and values of a profession, organizations related to that profession, and those working in that profession.

Examples of such guidelines include the ICN Code of Ethics for Nurses (International Council of Nurses, 2021), the Code of Ethics of the Education Profession (National Education Association, 2021), and the Code of Ethics for Social Workers (National Association of Social Workers, 2021).

Find out if there are professional ethical guidelines or codes related to the area that your research will be conducted in and think about if, and if so how, these codes or guidelines may affect your research design and the way it is put into practice.

CONCLUSIONS

Thinking about putting ethics into practice is a reflexive part of the research design process and part of being a responsible researcher. It is irresponsible to design research without constant consideration of ethical matters from the initial idea until the conclusion of that research and sometimes even beyond that, for example, when we are considering reusing a study's data. When unexpected issues arise during the research, reflexive thinking provides a way of thinking through the issues and seeing them for what they are, making decisions related to that thinking, and being able to justify both to yourself, and others, why you made the decisions you did. These others include the participants in your study, your supervisors if you are a student, the readers of your research, and formal bodies such as ethics committees.

Thus, thinking about ethics cannot be reduced to a series of predetermined decisions about whether or not we meet certain predetermined criteria, and therefore can say that something is ethical. Such reductionist thinking reduces research ethics to techniques or points to be checked off on an "ethics to-do checklist." Checklist thinking loses sight of the fact that "to-do" requirements such as having a consent form or an information sheet,

storing data appropriately, and ensuring confidentiality and anonymity are outworkings of the ethical thinking that sits behind them. In themselves, they are not the ethics of the design. The thinking behind the requirements is lost.

Issues and uncertainties can arise when thinking about how to put research related ethical principles and issues into practice. For example, what happens if there is disagreement among researchers about what "ought to" or "ought not to" be done in relation to a proposed research design or what the "right thing to do" is, such as whether a dating profile site should be scraped or not. How do we decide, based on what, if our research design avoids "harm" or is "promoting good"? Grappling with such questions requires reflexive thinking on our part about ideas such as "ought," "ought not," "harm," "promoting good," and "the right thing" *themselves*. Why do we think the way we do about each of them; how does this affect the way we think about, design, and actually do our research, and what, and why, we say and report about that research.

Thinking about ethics in this way opens up to scrutiny all of the decisions and actions that we take when both designing and implementing our research. Such thinking extends the focus of our thinking *through* ethics beyond an individual study or research design, or meeting the requirements of a specific ethics committee. It can "push scholars to question the ethical stakes of what is *not* studied, the questions that are *not* asked, and the social groups and communities that are *not* the subject of research" (Blee & Currier, 2011, p. 404).

As Macfarlane points out, "[R]esearch ethics is rarely about headline-grabbing incidents of scandal and drama. There is an 'ordinariness' about the day-to-day decisions we face which is rarely recognized" (p. 24). Examples of such ordinariness include whether to exaggerate the significance of our research in order to attract funding (Chubb & Watermeyer, 2017).[14] Or it might be about being tempted to cut the odd corner, perhaps about the extent of our data collection or the detail we provide in the write-up of our research, or adapting the way we report our research to meet the requirements of a journal. Or it might be any or all of

> keeping the audio recording going for a few minutes after completing a formal interview in the hope that the interviewee might say something more interesting; promising to send someone their interview transcript to check and never doing so in the (almost) sure knowledge that there will be no consequences; referencing to sources that we may have found in the bibliographies of others but never actually read ourselves; or taking more authorial credit than we should do when working with other, perhaps less powerful or experienced, researchers. (Macfarlane, 2010, p. 24)

This ordinariness can also include seemingly benign practices such as cultivating trust, or even friendship, with those participating in our research. What is the motivation for cultivating such trust or friendships? Could it be to get people to participate in our research and give us the information we want from them?

We have raised many issues in this chapter that you will need to think about when developing your research design, when putting that design into practice, *and* after you have completed your research. Therefore, this chapter is not the last word on ethics in relation to research design. Rather it is a first word in an ongoing discussion that aims to provide a platform for the thinking that will need to be done *about* ethics at all stages of the

development of your research design. It provides the foundations for you to develop your own "inner ethical poise" (van den Hoonaard & van den Hoonaard, 2013, p. 13).

In this way, the chapter has set the scene for discussions in later chapters of the book about putting ethical principles into practice in the various areas that make up what we call a research design such as choices about research questions, methodology and methods, and what we write, and how we talk, about our research.

SUMMARY OF KEY POINTS

- Research ethics are concerned with moral behavior in research contexts.
- Ethics, and thinking about ethics, is a process that impacts on all aspects of designing research.
- Ethical matters related to research design are multifaceted and dynamic.
- Three core principles of research ethics are the concepts of informed consent, confidentiality, and anonymity.
- Repurposing, reuse, and sharing of research data pose particular issues about informed consent and who has the right to share, or use shared, data.
- Emerging forms of digital data create new and different ethical challenges when designing research.
- Ethics committees have an important contribution to make in advancing conversations and understandings of ethical research.
- Getting ethics approval from ethics committees is not the same as designing and conducting ethical research.
- Reflexivity is central to developing a researcher's "inner ethical poise" (van den Hoonaard & van den Hoonaard, 2013, p. 13).

KEY RESEARCH-RELATED TERMS INTRODUCED IN THIS CHAPTER

anonymity
confidentiality
ethics committees
informed consent
Institutional Review Boards (IRBs)
layers of consent – repurposed data
pseudonym
qualitative research approaches
repurposing of data
research ethics
vulnerable populations

SUPPLEMENTAL ACTIVITIES

1. **Doing your homework and being prepared for interacting with, and learning from, Ethics Committees**

   Find out which IRB or ethics committee(s) you may need to receive formal ethics approval from before you could begin your research. When doing so, take into account that this may vary depending on from where, and in what capacity, you will submit your research proposal. For example, will it be as a student in a

higher education institution, or will it be as an employee of an organization or both? Remember, if your proposed study involves multiple sites, you may be required to obtain approval from each site.

Next, obtain a copy of the guidelines and requirements of those ethics committees. Think about what kind of information they request from you, and what design decisions will you need to have made to address those requests.

- Why do you think that this information is requested?
- Do the forms all request the same information?
- If there are differences between them in terms of the information they request, what are they and why might this be?

If you are in the process of developing your research design, begin drafting your application for the relevant ethics committee(s) as you develop your proposal.

2. Thinking about if the means justify the ends when we design our research

Thinking about whether the means justify the ends is a central ethical consideration when designing our research. We will explore this point by looking at the example of researchers exaggerating the "impact" of their proposed research when writing an application for research funding in order to improve their chances of attracting funding.

Chubb and Watermeyer (2017) studied how researchers wrote the section of their application for funding that required them to identify and demonstrate the "impact" of their proposed research by stating "how they will ensure economic and/or societal returns from their research" (p. 3). They interviewed researchers about what they did and why when writing this section about impact. Answers they received included

- ". . . telling a good story as to how this might fit into the bigger picture. That's what I'm talking about. It might require a bit of imagination, it's not telling lies. It's just maybe being imaginative." (p. 8)
- "If I want to do basic science I have to tell you lies." (p. 5)
- "It's virtually impossible to write one of these grants and be fully frank and honest in what it is you're writing about." (p. 5)
- "I don't think we can be too worried about it. It's survival. . . . People write fiction all the time, it's just a bit worse." (p. 6)
- "People might, well not lie but I think they'd push the boundaries a bit and maybe exaggerate!" (p. 9)

Here we see academics justifying what is at best exaggerating, and at worst lying, when writing this impact statement. Justifications such as they were just being imaginative or creative, or this is just part of what one has to do to get a grant.

This raises a dilemma for researchers when funding is needed for the research to be able to proceed. If the funding is not gained, then the research cannot proceed. Therefore, how far are researchers prepared to go to get that funding? Does gaining the funding and therefore being able to actually do the research outweigh exaggerating the impact of the research? This is an ethical matter and consideration.

Think about and discuss the following dilemma that arises from this situation:

- As a researcher, do you write the impact statement (or any other part of the proposal for that matter) "to fit the requirements of funders . . . on the surface a seemingly commonsensical or ordinary position to adopt if winning the funding is the goal" (Cheek, 2017, p. 31)? After all, this is something everyone else is doing anyway.
- Or do you choose not to write your proposal in line with those requirements and therefore effectively make yourself and your research uncompetitive in the funding competition? Therefore, your project which may have significant benefits to the population of people in it, will not proceed.
- Is there a middle course of action in all this?

FURTHER READINGS

Cheek, J. (2010). Human rights, social justice, and qualitative research: Questions and hesitations about what we say about what we do. In N. K. Denzin & M. D. Giardia (Eds.), *Qualitative inquiry and human rights* (pp. 100–111). Left Coast Press.

Lahman, M. K. E. (2018). *Ethics in social science research: Becoming culturally responsive*. SAGE.

Wiles, R. (2013). *What are qualitative research ethics?* Bloomsbury Academic.

NOTES

1. See Chapter 1 for an extended discussion of reflexivity.
2. For example, when participants are consenting to be part of a research project testing the effects of a certain drug, one group of participants will be given the drug being tested and the other group a placebo. Informed consent requires us to tell participants that the design of this research involves some of the participants in the study being randomly allocated to the group being given the placebo and not the active drug. This might be them. In this way, potential participants are not deceived into thinking that by participating in this study there will necessarily be the chance of any benefit to their individual health. This is especially important if the participants are in poor health and looking to participate as a chance of improving their health status. Further, it is equally important to make clear that even if they are randomly allocated to the active group, and receive the drug, the drug may have no, or even adverse, effects.
3. See Lahman 2018, pp. 79–81, for a good discussion of this.
4. See Chapter 5 for more about flexible and emergent study designs associated with qualitative research approaches.
5. The Declaration of Helsinki is "a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data" (World Medical Association, 2018, item 1).
6. In Chapters 6, 7, 8, and 9 we take a closer look at what observations are and can be used for in your research design.
7. Defining exactly what *Big Data* is, is not easy as there is much confusion around the use of this term. Most often Big Data is associated with the combination of many digital traces. It is this combination of digital data traces which is "big"—in terms of the amount and diversity of sources of those digital traces.

8. "The internet of things, or IoT, is a system of interrelated computing devices, mechanical and digital machines, objects, animals or people that are provided with unique identifiers (UIDs) and the ability to transfer data over a network without requiring human-to-human or human-to-computer interaction" (IoT Agenda 2016).
9. See for example Tubbs (2018, paragraphs 6–7) for a discussion on big data and marketing:

   > Publishers are gaining more data on their visitors and this allows them to provide more relevant advertising. Google and Facebook are already doing it with their amazing targeting options but third party vendors will soon have the same array of choices. You could target people based on their recent searches, articles they read, lookalike audience and so on. There is no limit to the impact big data is making in the marketing world.

10. "Web scraping, also known as web data extraction, is the process of retrieving or 'scraping' data from a website. Unlike the mundane, mind-numbing process of manually extracting data, web scraping uses intelligent automation to retrieve hundreds, millions, or even billions of data points from the internet's seemingly endless frontier." Furthermore, "A web scraper is a specialized tool designed to accurately and quickly extract data from a web page" (both quotes from scrapinghub, 2020).
11. Digitization is the process of converting information from a physical, analog format (for example, paper based medical records, or scientific articles in printed editions of a journal) into a digital format (Gartner IT, 2018).
12. See the discussion of this in relation to the 2016 U.S. presidential election and the use of big data (specifically, Facebook profiles) by the company Cambridge Analytica to individualize and better target political advertisements (Cadwalladr & Graham-Harrison, 2018; Detrow, 2018).
13. In 1932, the U.S. Public Health Service, working with the Tuskegee Institute, began a study to record the natural history of syphilis in hopes of justifying treatment programs for syphilis. Initially, 600 African American men were put in the study—399 with syphilis, 201 who did not have the disease. They were not aware that they were in the study or that the study was about tracking the progression of untreated syphilis. The men with syphilis received no treatment needed to cure their illness. Instead, they were told that they were being treated for "bad blood" and received free medical exams, meals, and burial insurance. The untreated men died, went blind, developed mental illness and other severe health conditions arising from having syphilis. The duration of the study was originally intended to be for a period of 6 months, but actually continued for some 40 years (https://www.cdc.gov/tuskegee/timeline.htm).
14. This example is explored further in supplemental Activity 2 at the end of this chapter.