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Internet Research Ethics

– Resources and Challenges

A qualitative study

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I hope this thesis will be as enjoyable for you to read, as it has been for me to write.

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Abbreviations

Abbreviation	**Definition**
AoIR	Association of Internet Researchers
DME	Digital Media Ethics
GDPR	General Data Protection Regulation
ICE	Information and Computation Ethics
IRE	Internet Research Ethics

(…) normally when you do a study... The ethics is agreed, It's all very clear cut. You know, like you've done today, you gotta get the consent. You've gotta do things with the data. It's all fairly obvious...But with this... We just kept looking at it very regularly and having meetings just checking that we weren't crossing any ethical boundary, even though there are none, because there are no boundaries (…)

Social media researcher interviewed in the present study

Abstract

Internet sites such as blogs, discussion forums and Instagram is prevalently used for a variety of purposes, including communication about personal illness, and there is no sign that this usage will decrease anytime soon. This present study explores research ethical challenges qualitative researchers may face when employing communication on illness from these internet sites as data. Searches in various databases indicates that issues pertaining to internet research ethics typically have been explored in e.g., researchers' personal reflections on their own research, and in literature reviews. Previous research has shown that qualitative researchers have experienced a lack of resources for ethical decision-making in internet research. Additionally, previously conducted research indicates a gap in how ethical decision-making blueprints address pseudonymity, an example of a challenge presenting novel ethical challenges for qualitative researchers. This present study builds on, and further extends these results. The methods which are employed for this exploration are qualitative interviews with a small selection of participants, and thematic analysis.

The results of this present study show that the interviewed researchers experience uncertainty and confusion in meeting with internet research ethical challenges. Furthermore, the researchers express a perceived lack of resources for internet research ethics, and desire guidelines for internet research ethics which include more tangible and clear advice. Through presenting these results, this present study contributes to the important discussion on how to best support internet researchers in conducting ethically sound research.

Abstract in Norwegian (sammendrag)

Diverse nettsider, slik som diskusjonsforum, Instagram, og personlige blogger, brukes i dag til en rekke ulike formål, deriblant kommunikasjon om opplevelser knyttet til personlig sykdom, og det er ikke noe som tilsier at denne typen bruk vil avta med det første.

Masteroppgaven i hende utforsker forskningsetiske utfordringer kvalitative forskere kan møte når de anvender kommunikasjon om sykdom fra disse nettsidene som data i sin forskning. Søk i ulike databaser tyder på at problemstillinger knyttet til internettforskningsetikk typisk har blitt utforsket gjennom f.eks., forskeres personlige refleksjoner omhandlende egen forskning, og i litteraturgjennomganger. Tidligere forskning har vist at kvalitative forskere har opplevd en mangel på ressurser for etisk beslutningstaking relatert til internettforskning. Tidligere forskning indikerer også et gap i hvordan pseudonymitet, et eksempel på en unik etisk utfordring, blir adressert i etiske retningslinjer for internettforskning. Studien i hende bygger videre på, og utvider disse resultatene, og anvendte metoder for utforskningen er kvalitative dybdeintervjuer med et lite utvalg deltakere og tematisk analyse.

Resultatene av studien i hende viser at de intervjuede forskerne opplevde usikkerhet og forvirring i møte med forskningsetiske utfordringer knyttet til internett som forskningsarena. Videre uttrykker forskerne en opplevd mangel på ressurser for internettforskningsetikk, samt et ønske om retningslinjer for internettforskningsetikk på som inneholder mer håndfaste og klare råd. Gjennom disse resultatene bidrar denne studien til den viktige diskusjonen om å støtte internettforskere i å utføre etisk forsvarlig forskning.

Chapter 1 - Introduction

The topic under study in this project has been research ethics, and more the branch of applied ethics internet research ethics (IRE) within *qualitative* social media research.

Internet research ethics is a relatively novel field and has had a continuous development since the early 2000's. Guidelines for IRE (NESH 2019; Markham & Buchanan, 2012) is built on foundational and recognized norms and values for internet research. The emphasis on the importance of a processual, case-based approach to ethics, manifested in question-based guidelines that is, ideally, free of rules and codification of norms, has been important from the early stages (Markham & Buchanan, 2012).

Internet research, and more specifically social media research, has its own set of particularities that require specific attention from researchers, not least related to ethics. Exploring how researchers have approached salient IRE challenges in their own practice, with specific attention to resources has been an important aim of this thesis and has been explored through in-depth interviews and thematic analysis (Braun& Clarke, 2006). Three researchers were interviewed about their experiences with specific challenges related to internet research, in the context of their research on illness communication involving notions of sensitivity and vulnerability[1], and mediated on social media sites: forums, personal blogs, and Instagram.

1.1. Previous research

Explorations of IRE matters are typically done by researchers reflecting on their own practice, and through literature reviews. Via searches in a range of databases, in collaboration with expert librarians at Inland University of Applied Sciences, one study was identified that overlapped in design and scope with this thesis, and, while many articles were found that had similar topics as this present study, were also significantly different in terms of perspectives and methods.

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[1] The term sensitivity and mentions of vulnerability in this thesis is used interchangeably. The author of this thesis has also made a choice to refer to vulnerable subjects as people in a vulnerable situation (and other similar terms), in an attempt to disconnect the term from negatively charged connotations.

1.1.1. Identifying previous research literature

In the work to identify relevant literature, the author of this thesis collaborated with expert librarians at Inland University of Applied Sciences. We conducted searches in Psych Info, Academic Search Complete, Medline, Oria, Google Scholar and CINAHL. We got varied amounts of hits, depending on the combination of search words and –phrases (see attachment one for further details on the search): while some texts were relevant, a wide range of articles, book chapters and more, were not.

The more we narrowed the search down to not only include ethical challenges faced by qualitative researchers in internet research, but to also include ethics resources and the method of interviews (with researchers), the less relevant the hits became. Examples of scholars who have written such reflections on challenges met in their own research, are Ross (2019), and Rensfeldt et al. (2019).

1.1.2. Topics of previous literature

Previous research has identified a lack of consensus within managing various internet research ethical issues and challenges, and it has been proposed that development of guidelines for IRE is important, e.g., for journal editors: the article 'The ethics and editorial challenges of internet-based research', by Harriman & Patel (2014) discuss this, and the Association of Internet Resarchers (Markham & Buchanan, 2012) has highlighted the importance of researchers to continue to contribute to building upon the knowledge related to best approach research challenges and issues in internet research.

A range of contemporary scholars discuss relevant topics within qualitative internet research, e.g., Burles & Bally (2018), Rensfeldt et al. (2019), and Ess (2014; 2017), and a range of scholars also discuss ethics more specifically related to sensitive topics, e.g., Gao et al. (2022), Sipes et al. (2020), and Ross (2020). Further, many scholars have specifically focused on ethics in social media research, such as Ross (2020), Ess (2020), and Rensfeldt et al. (2019). Some scholars also include mentions of a 'best practice' for research ethics in their discussion, e.g. Rensfeldt et al. (2019), Burles & Bally (2018) and Perez Vallejos et al. (2019): typically discussing rule based versus context sensitive approaches to IRE. Contemporary literature on IRE typically discuss the concern for humans involved in research: issues related to how to ensure anonymity and confidentiality for involved parties, e.g. Elgesem et al (2016), challenges related to use of direct quotations& the potential risk of participants being reidentified through online searches, e.g., Roberts (2015).

However, there are not a large number of research publications where social media researchers' negotiation of central IRE challenges with specific attention to the use of resources has been explored.

1.1.3. Internet research ethical issues and challenges: explored through personal reflections and literature reviews

A big part of the publications that was found through these searches were personal reflections of researchers, written in the wake of published research. The author of this present study found that dilemmas and challenges connected to IRE have also typically been examined through literature reviews, as done by e.g., Gao et al., (2020), and Roberts (2015). Some of the studies that that the author of this thesis identified through searches in various databases had also discussed internet research ethics having ethics review board members as informants, as in the article by: Buchanan & Ess, (2009), and many articles were case articles based on researchers' own experience with internet research and ethics.

The researcher is a central piece of the puzzle on how best to approach and solve ethical issues as they are in close contact with the field, as well as IRE-resources, hence their perspectives and insights are valuable, and interviews can be a fruitful way of gaining insights into researchers' reflections and experiences.

1.2. A researchers' personal reflections on an internet research ethical challenge

One example of a typical article that was found related to IRE and qualitative internet research, is Gerrard's (2021) article, 'What's in a (pseudo)name? Ethical conundrums for the principles of anonymization in social media research. The article by Gerrard (2021) touches on many of the same points as this thesis, although it also has a different angle from which to explore the informant's experiences with ethical decision-making challenges and ethical resources. The article by Gerrard (2021) is based on the author's answers to questions which had been received when seeking ethical approval: these questions concerned changing notions of public and private online, identification of underage (and therefore vulnerable) participants, changes to processes of informed consent and risk to the researcher when conducting this type of research.

Gerrard (2021) had conducted research involving adult fan communities on social media, and had faced ethical challenges, particularly related to the use of pseudonyms, anonymity and issues related to the identity of the participants. Gerrard (2021) highlights that it can be complex to approach challenges related to pseudonymity, and especially at the start of a project, since there are many complex reasons for the use of pseudonyms, and the researcher may not learn about these before later stages of research. Sensitivity is not specifically discussed by Gerrard (2021).

1.2.1. Critique raised regarding addressing pseudonymity in guidelines

In the article, Gerrard (2021) directly addresses the Association of Internet Researchers (AoIR)[2] and similar bodies: the criticism is directed at a perceived lack in how these guidelines does not address pseudonymity as an individual ethical challenge. However, guidelines for IRE and other IRE resources are not further addressed. The article concludes with a call for researchers and Ethics Review Boards to consider ethics throughout the research project, and ongoing informed consent is highlighted as a simple way of considering ethics in a processual manner. Re-obtaining consent and checking in with informants throughout the projects, is recommended by the author (Gerrard, 2021).

1.3. Previous research exploring ethics related to images of body as data

One article that was identified through searches, is an article that is more similar to this present study in terms of aims and methods: ‘Pics, Dicks, Tits, and Tats: negotiating ethics working with images of bodies in social media research’ by Warfield et al. (2019).

The authors of this article interviewed 16 internationally situated researchers using in-depth interviews: the interviewed researchers had conducted research that covered a variety of demographic areas, including areas outside of Europe. The interviewed researchers had conducted research on social media that involved the use of images as data. All the interviewees had obtained ethical approval for their projects. The interviewees had been interviewed on processes related to their methodological choices, experiences with getting ethical approval from Research Ethics Boards, and research ethical challenges that was encountered post ethical

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[2] The Association of Internet Researchers is an academic association based on membership, with the aim to promote “critical and scholarly internet research independent from traditional disciplines and existing across academic borders” (AoIR, n.d.).

approval. In the article, Warfield et al. (2019) did not emphasize the topic of the interviewees research.

Even though the research article by Warfield et al. (2019) discusses ethical challenges related to the use of visual communication, and more specifically images of bodies as data, the discussion is presented as relevant for challenges faced in social media research ethics more widely:

> Digital images of bodies also implicitly confront some core and complex areas of digital research ethics like (…) issues around identifiability and confidentiality, topics related to intimacy and identity, and determinants of publicness and privateness within social media platforms and cultures. (Warfield, 2019, p. 2069).

1.3.1. Internet research ethical challenges and resources

The authors of the article by Warfield et al. (2019) discuss different ethical challenges that the interviewed researchers had encountered throughout the research process, and how these challenges had been negotiated. Warfield et al. (2019) found, amongst other things, that all their informants attended to the concept of contextual integrity (Warfield et al., 2019): which refers to the context in which the communication takes place (NESH, 2019, p10). And that juggling different considerations had been a challenging balancing act, tinted with uncertainty (Warfield et al. 2019).

All the researchers that had been interviewed by Warfield et al. (2019) confessed to a lack of resources: both for writing the application for ethical approval, as well as for managing the ethical challenges encountered in the research process. Other results were that Ethics boards was reported to be both under protective and overprotective: some had given automatic exemption from Research Ethics Board approval because online photos were considered pure data (thus not research involving human subjects), and others were had been overly concerned with consent and privacy. Also, the interviewees said that it had been a lack of support after the ethical approval had been granted. The interviewed researchers had sought out a *range of informal and formal advice.* The authors refer to this range of advice as ‘protocol assemblages’ (Warfield et al., 2019). The interviewees admitted to having contacted other scholars, taken cold calls to reviewers. One informant had even received a “magic folder” from another researcher, with ethical protocols collected when conducting similar research (Warfield et al., 2019). Warfield et al. (2019) states that seeking out a wide range of formal and informal advice is rooted in the recommendations from the Association of Internet Researchers to consult as many resources as possible. Warfield et al. (2019) further argue that contacting other scholars for ethical advice is not new. However, what is new is the sheer quantity and variety of sources that had been consulted (Warfield et al.,2019, p.2075), and was seen as a response to a lack of relevant resources for ethical decision-making (Warfield et al., 2019).

1.3.2. Employed strategies

Warfield et al.'s (2019, p.2083) Interviewees had practiced different ethical strategies, such as ethical fabrication of images, and the authors discuss the way the informants of their study had negotiated factors pertaining to contextual integrity and balancing personal identifiable information with research (p.2076). They found that balancing different factors related to technology and settings with possible interpretations of what constituted privacy, had been challenging for the informants (Warfield et al., 2019, p. 2076). One of the interviewees had checked in with the owners of the photos, to make sure they were comfortable with the use of the image in research (Warfield et al., 2019, p.2076).

All the participants that had been interviewed in the study by Warfield et al. (2019, p.2080) had also stated that ongoing consent, as opposed to obtaining one-off written consent, was a strategy that were practiced when conducting research within contexts where the frames for, and understandings of, ethics may change. Verbal consent, and consent via text, e-mail and online messaging had been applied by the interviewees (Warfield et al., p.2079).

1.4. Research question, interim goals, and aims of the study

Previous research has shown that researchers face novel ethical challenges in internet research, met with a variety of strategies, and even if researchers are from various fields, many challenges and strategies overlap amongst researchers. Previous research also shows that researchers have experienced a general lack of resources on internet research ethics, while at the same time drawing on a uniquely wide range of resources. Previous research also indicates a gap in how pseudonymity, as an example of a novel ethical challenge are addressed in guidelines on internet research.

There is a gap in existing literature pertaining to ethical challenges faced by researchers using textual communication as data involving notions of sensitivity and vulnerability, within a Western European research context, that is not conveyed directly by researchers themselves.

Moreover, there is a gap in research that exploring internet research ethical issues and challenges faced by social media researchers, with specific attention to guidelines on internet research ethics. In this present study, this gap will be addressed through in-depth interviews with three researchers that have utilized communication on personal illness, obtained from social media sites, as data. The interview data will further be analyzed and discussed, with relevant theory on internet research ethics as backdrop.

Internet research ethics is still evolving and will continue to evolve, as long as technology rapidly evolves and keeps changing the ethical landscape of the Internet. Many ethical challenges in internet research have currently *no defined answers.* As early as 1996, Storm King (1996, p.119) (cited in Buchanan & Zimmer, 2021) took note of the internet as a research arena, and warned caution:

> When a field of study is new, the fine points of ethical considerations involved are undefined. As the field matures and results are compiled, researchers often review earlier studies and become concerned because of the apparent disregard for the human subjects involved.

This warning mirrors a main concern in the contemporary discussion on how to best develop ethically sound research practice, when the research is conducted online, and, per definition, involves a need for considerations of people. Storm King's warning (1996, p.119) (cited in Buchanan & Zimmer, 2021) sets the tone for the exploration of this present study: a risk is that human beings are being negatively affected, either now or at a later stage, if the fine grains of ethical decision-making is not fully explored, and if researchers and others are left to much to their own devices in figuring out what sound ethical practice in internet research may entail.

Developing sound ethical judgment is often seen as best done through reflexive and context sensitive approaches (Markham & Buchanan, 2021). At the same time, there is a need for insights into various research contexts, as each context may bring to the forefront novel ethical challenges. Important questions thus appear: which ethical challenges in internet research appear in specific contexts? How may guidelines for internet research best continue to support researchers and others in their everyday ethical challenges, in a variety of contexts?

Currently, literature pertaining to ethical decision-making challenges and solutions related to internet research offers little consensus on how to solve various internet research ethical challenges. Little consensus is offered also in central documents for ethical decision-making.

This can be seen as a natural and inevitable consequence of the variety and ever evolving nature of internet research. Emily Ross (2020, p.46) points to the advocated deliberative approach to ethics as a cause for disparity in ethical approaches within social media research. Citing Samuel & Derrick (2017) Ross (2020, p. 46) further highlights that this disparity stemming from a lack of consensus may facilitate ethically problematic practices, thus also confirming the warning of Storm King (1996, p.119) (cited in Buchanan & Zimmer, 2021). And, once again referring to Samuel & Derrick (2017), Ross (2020, p.46) argue that it is important that researchers share their reflections, in order to develop a more consistent and solid approach to ethical practice.

An aim of this present study has been to contribute to the pool of knowledge pertaining to challenges faced by social media researchers, and their use of ethics resources, when using social media data where social media users' have revealed sensitive personal data[3]. Notions of sensitivity and vulnerability pose additional ethical challenges to an already complex research context, and implications of this for researchers practice is therefore interesting to further explore. Exploring this, responds to the call by e.g. the Association of Internet Researchers, one of the most prominent international organizational bodies involved in the development of internet research ethics to this day, for researchers to continue to reflect upon and develop the field of internet research ethics, and also to add their experiences to a continually updated online compendium of various cases (AoIR, n.d.).

The main research question for this exploration has been:

> "How do researchers, who employ publicly accessible communication about personal illness as data experience, use, and evaluate resources for internet research ethics, in particular guidelines?"

The interim goals have supported the research question, and further defined the study. The interim goals for this thesis are:

A) Map how internet specific challenges related to internet research ethics are negotiated by the researchers, when employing textual communication about illness obtained from social media sites as data.

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[3] Health-related data, such as data about illness, are classified by the GDPR (europa.eu) as sensitive personal information.

For this present study, it was decided that the focus would be on textual data, and not include images. The researchers’ perspectives on internet research specific ethics resources’ perceived strengths and weaknesses are addressed by the second interim goal:

B) Map the researchers' experiences with, and perspectives on, guidelines for internet research ethics. [4]

Moreover, the research question and interim goals has been the “leading stars” for *contextualizing* a discussion of guidelines for internet research, by both exploring the researchers’ specific research context and the researchers’ perspectives pertaining to IRE-guidelines.

The research question has been altered slightly from the initial research question, which aimed at including an exploration of the researchers’ experiences with using online unobtrusive observation as a method, related to research ethics. However, over the course of the interviews, it became clear that the theme about the method of unobtrusive online observation, was not being sufficiently backed up by data. All the informants had used online unobtrusive observation as a method for obtaining data, however, this was not something that they had reflected in-depth about, and thus relating this method to ethics through analysis, would be thinly founded. During the interviews, it was rather found that the researchers had explicit perspectives and thoughts related to ethics resources, and guidelines in particular: going more in-depth into resources, and in particular guidelines, the became important.

This present study is not an attempt to give exhaustive or in-depth descriptions of the philosophical tradition of ethics, nor the subcategory of research ethics itself. The aim has rather been to, with a base in the current and very real need for producing knowledge pertaining to understanding more about internet research ethics within the social sciences and humanities, contribute to the knowledge production on how researchers and others best can continue to develop professional and ethically sound practice, and what this may entail. As internet research is varied and homogenous, and takes place in a wide variety of contexts, context-specific knowledge is needed. Therefore, instead of aiming at producing generalizable results,

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[4] As part of this, it was of course also important to map which IRE resources that had been utilized by the researchers.

it has been an aim to say something about a specific context of research, focusing of depth rather than width.

1.5. Theory in brief

The main theoretical background for this present study is ethical theories, namely applied ethics within the social sciences and the humanities. Within this context, the present study focuses on research ethics related to qualitative research and more specifically internet research ethics, manifested in international and national guidelines.

Ethics is reflection on what is good, based on values and what is right, based on principles. As such, ethics can be a tool for making reflective, good, and right decisions. Ethics can be divided into various subcategories, such as metaethics, normative ethics and applied ethics. Applied ethics is about examining issues pertaining to specific situations, e.g., research: research ethics thus belongs under the umbrella of applied ethics. Research ethics is about ensuring that research is conducted in alignment with current values, norms and ideals. Four ethical principles are internationally recognized, and these are mainly beneficence, nonmaleficence, autonomy and justice.

‘A Guide to Internet Research Ethics’ by the National Committee for Research Ethics in the Social Sciences and the Humanities (NESH, 2019), are used as foundation for the discussion of the ethical challenges the researchers faced throughout the process of research. The document by the Association of Internet researchers, ‘Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)’, is used for discussing the widely advocated bottom-up approach to IRE. While the guidelines by the AoIR (Markham & Buchanan 2012) have an International and multidisciplinary scope, and is directed at internet researchers in general, the guidelines by NESH (2019) have a more specific disciplinary scope, namely the social sciences and the humanities. While the guidelines by NESH (2019) are national, they have also been internationally recognized, and is cited outside of a Norwegian context.

1.6. Research methods in brief

For this present study, a qualitative approach, and more specifically in-depth interviews. has been taken in order to explore the topic under investigation. The interviews were conducted digitally.

In this present study, three informants who had conducted research on social media sites (forums, Instagram, and personal blogs), involving health- related, sensitive data, pertaining to different illnesses, are selected. The interviewees for this present study had obtained ethical approval for their projects, and thus ensured that basic ethical standards for the research had been met.

Through interviewing researchers, using in-depth interviews, the aim has been to gain insight into reflections on ethical decision-making, within the context of their own research. In dialogue with a specific research question, interviews can be a tool for answering specific questions, while allowing exploration of different topics that come up in the process. The transcript data were further analyzed, using thematical analysis in a six-step process, as formalized by Braun & Clarke (2006).

The interviews for this present study were conducted in Zoom. All data were securely stored in OneDrive with restricted access, compliant with requirements by Inland University of Applied Sciences. These safety related concerns, and other general ethical concerns will be more thoroughly explained in the method and methodology chapter.

1.7. Structure of this present study

In the following section, the outline of the structure of the thesis is presented.

Chapter 2. The aim of this chapter is to provide the theoretical foundation for the discussion of the results. The theory is based on internationally recognized guidelines for ethical decision making in internet research, supplemented with arguments and perspectives from contemporary publications, which serves to enhance the understanding of what is outlined in the guidelines, as well as further contextualizing the theory. The theoretical background was in part predetermined, as it was known from the start of the project that the topic would center around internet research ethics: challenges and resources. Although the theoretical background in part was chosen prior to the start of the project, the themes/ categories within the main topic of internet research ethics were left open.

In this chapter, the history of internet research ethics is outlined, as this provides an important backdrop for the theory, and terms such as ethics, internet research ethics and personal information are elaborated. Further, considerations pertaining to internet research ethical challenges such as assessments of publicness and privateness, the protection of people in vulnerable situations and the typically advocated approach to internet research ethics, the ‘bottom-up’- approach, is outlined. The theoretical background is presented prior to the methodological choices and considerations, as this may ease the reading of this thesis, by providing important contextual and background information about the study.

Chapter 3 presents how the research has been conducted, specifically related to data collection and analysis methods. This chapter goes in depth to describe these methods and the research design and presents the background for selection of participants. The research- methods that are used for this present study are semi structured qualitative interviews. The interviews have been transcribed and thematically analyzed. Ethical and safety-related considerations related to carrying out the research for this thesis, as well as the validity of the study, are also discussed in this chapter.

The categories within the overarching topic of internet research ethics were left open for the thematical analysis as a methodological choice, and the transcript data were analyzed with the aim of considering all relevant information pertaining to the research question.

Chapter 4 presents a description of key results from the analysis, where results from the interviews and the thematic analysis are presented. Firstly, the main contents of key findings are outlined in Table 1, and the three informants are presented. Thereafter, the results are presented based on a thematic structure, in other words: according to the themes that came up as a result of interviewing and thematical analysis, and centers around ethical challenges related to unclear boundaries between publicness and privateness online, such as user expectations of privacy, informed consent, and also includes results pertaining to the use of ethics resources.

Chapter 5 In this chapter, the results from the study are set in a wider context in a discussion alongside relevant theory, as well as the research question. The discussion follows a, roughly speaking, similar structure as the presentation of results.

Chapter 6 This chapter summarizes the study and briefly summarizes the results of the study. It also provides critical reflection over how this was achieved. Lastly, it presents an outline of the possible implications of the project, and possible directions for future research.

Chapter 2 - Theoretical background

The aim of this chapter is to present the theoretical perspectives underpinning the study. The theoretical perspectives presented here lay the foundation for the discussion of results later in this present study and provide important contextual and background information for the thesis' main topic and research question.

Firstly, an introduction to ethics, and more specifically internet research ethics is provided, including different perspectives on, and definitions of 'internet research ethics', this is followed by an introduction to the history and development of IRE, provided in order to further contextualize the topic under investigation. Next a clarification of the term 'personal information' is provided, as it in this present study is included in discussions on notions of sensitivity and vulnerability and has a distinct meaning.

Following this, two internationally renowned documents, consisting of advice and guidelines about internet research ethics are outlined, with specific attention to, respectively, ethical considerations and the widely advocated approach et IRE: the bottom-up approach. First in line is the document issued by the Norwegian guidelines, 'A Guide to Internet Research Ethics' (NESH, 2019). Second in line is the ethical blueprint issued by the AoIR, 'Ethical Decision-making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)' (Markham & Buchanan, 2012), is outlined. The guidelines are supplemented by arguments and perspectives from contemporary literature and research on IRE, e.g., perspectives on vulnerability and sensitivity.

2.1. Ethics and internet research ethics

Ethics is a central area within philosophy and is centered around how people should act, and more specifically which actions are good or bad, right or wrong, and what the conditions for right and good decisions are. Ethics differ from, but also overlap with morality and law. The law typically tells us what *not* to do, and as humans we are obligated to follow the law. The law can be object to ethical scrutiny. Morality is based on norms, values and culture, and is a set of standardized and currently accepted ways of behaving. Typically, breaking with accepted norms will result in social sanctions. Ethics, on the other hand, is also built on values, norms and principles, and constitutes a system for reflection and decision-making. Ethics are not bound by law and require more thinking and reflection than in-built norms normally do.

While *good* decisions are based on values, the things that are important to us, e.g., family or justice. In order for a decision, or act, to be *ethical* it does not only need to be good, but also right. Principles are what guide us in mapping out acceptable, right, ways of obtaining our goals.

Ethics can be subdivided into areas such as metaethics, normative ethics and applied ethics. The latter subdivision is about examining issues related to specific situations, as in e.g., research. Research ethics is hence an area within applied ethics. Research ethics is about making sure that research is conducted according to current ethical norms, values and ideals. What is regarded as ethical to a great degree is culturally dependent, however some international standards, based on basic principles, have been agreed upon. These principles are primarily *to do good (beneficence), to avoid harm (non-maleficence, to respect autonomy* and *to be fair (justice).* The four basic principles are described in detail by e.g., Beauchamp & Childress (2001) and are prevailing within medical ethics, but also within research ethics in general.

Research ethics within the social sciences and the humanities is developed from research ethics for medicine and health sciences and uses the four basic principles and the same model to think about ethics. Within medical research ethics it has been central that human beings should not be utilized as a means for something else, but also be seen as a means in themselves. This mindset is mirrored in central documents, such as the Helsinki declaration: in paragraph 8 is it stated that "While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects" (World Medical Association, 2013). General research ethical guidelines can be seen as a codification of the constituting elements and scientific moral more generally.

Internet research is an area that belongs under the umbrella of research ethics, and the term internet research is composed of *internet* and *research* and is used in different ways in different contexts. The word internet can be used to describe a global network of computers for decentralized spreading of information (Markham & Buchanan, 2012; NESH, 2019)The term is more broadly used to describe the devices that we use and a space where information and interaction is situated (Markham & Buchanan, 2012, p. 3; NESH, 2019, p. 3). The term internet research can be applied for different types of research that involves the Internet: use of the Internet as a way of obtaining data, research on how people use communicative spaces such as blogs and fora, and research on the communication contextualized in these spaces (Markham

& Buchanan, 2012, p. 3). The term also encompasses different analytical approaches: content analysis, multimodal analysis, semiotic analysis, and so forth (Markham & Buchanan, 2012, p. 4). The heterogenous and interdisciplinary nature of internet research means that researchers must specify the content of the term for individual research projects (Markham & Buchanan, 2012, p. 3).

Ess' (2017) term 'digital media ethics' is relevant to mention in relation to internet research ethics, as digital media ethics is a branch of applied ethics that directly addresses ethical issues related to digital media. Ess (2017) is one of the "founding fathers" of IRE, states based on the uniquely interdisciplinary background of internet research ethics, that a wide range of peoples' knowledge and expertise may be relevant to discussions about ethical challenges related to digital media. Technological engineers, users of the technologies, as well as social scientists, philosophers and others may all have a saying when it comes to digital media ethics. (Ess, 2017). Since the early 2000s, Digital Media Ethics (DME) has emerged as a relatively stable subdomain of applied ethics. DME seeks nothing less than to address the ethical issues evoked by computing technologies and digital media more broadly, such as cameras, mobile and smartphones, GPS navigation systems, biometric health monitoring devices, and, eventually, "the Internet of things," as these have developed and diffused into almost every corner of our lives in the (so-called) developed countries. DME can be characterized as demotic—of the people—in three important ways. One, in contrast with specialist domains such as Information and Computing Ethics (ICE), it is intended as an ethics for the rest of us—namely, all of us who use digital media technologies in our everyday lives. Two, these manifold contexts of use dramatically expand the range of ethical issues computing technologies evoke, well beyond the comparatively narrow circle of issues confronting professionals working in ICE. Three, while drawing on the expertise of philosophers and applied ethics, DME likewise relies on the ethical insights and sensibilities of additional communities, including (a), the multiple communities of those whose technical expertise comes into play in the design, development, and deployment of ICE; and (b), the people and communities who use digital media in their everyday lives. (Ess, 2017) Digital media ethics, according to Ess (2017), is defined by people's everyday practices and use of media, and this definition is a narrowing that is in alignment with the argued demotic nature of digital media ethics: digital media ethics is ethics that concern all of us. In other words, digital media ethics is relevant to users of social media, students, supervisors, researchers and others. Ess is also the author of the 2014 book

'Digital Media Ethics', that goes in-depth in describing ethical matters related to digital communication and has recently been issued in a third edition.

In the foreword, Luciano Floridi-a scholar with a background in philosophy, descriptively says about the book and its topic that it addresses the ethical challenges related to the entanglement of various technologies with our everyday lives and refers to Schrödinger in writing that the book gives a sharp picture of a fuzzy object (Ess, 2014).The way of thinking about ethics that Ess (2014; 2017) presents, is also represented in the guidelines on IRE by the AoIR (Markham & Buchanan, 2012), that more specifically address the fuzzy area of internet research ethics.

Other scholars that have written about ethics related to our digital environment, although not specifically related to digital media, are Bergsjø & Bergsjø (2019), who uses term 'digital ethic*s':* a term that is also related to the meshing of technology with our everyday lives. Digital ethics is described by Bergsjø & Bergsjø (2019). as a tool for minimizing harm and ensuring that technology is used in the service of the good, now and in the future, reflecting the four ethical principles mentioned previously in this present study.

The term 'Internet research ethics' as used in context of the research that undertaken for this thesis, builds on the frames these definitions provide, and is further used to point to certain *specifics* of internet research ethics and –ethics resources.

2.2. The history of internet research ethics

Internet research ethics (IRE) emerged starting from the early 2000's, and has had a rapid development, from its humble beginnings. IRE has an extensive interdisciplinary background, and is rooted in computer and technology science, both in a historical sense and in terms of specific issues: such as privacy (Buchanan & Zimmer, 2021). IRE encompasses a range of academic disciplines and traditions (Buchanan & Zimmer, 2021). Ethical frameworks, such as deontology, feminist ethics, virtue ethics and utilitarianism has all been part of the forming of this subdiscipline (Buchanan & Zimmer, 2021). IRE as a (sub) discipline emerged in the early 2000's. At this time the time the Association of Internet Researchers published a first set of ethical guidelines for internet mediated research in 2002, (Ess & the AoIR ethics working committee, 2002), followed by the (Norwegian) National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) in 2003 (Ess & Hård af Segerstad, 2019, p. 179).

After this initial stage, the digital environment evolved, and most profound was the emergence of *social media sites*, that presented new challenges. With this, the second phase of internet research ethics emerged, and the AoIR issued a second set of guidelines in 2012 (Markham & Buchanan, 2012). These two documents advocated and presented a bottom-up, reflective and question-based approach to ethical decision-making. The development of technology and the digital environment continued to evolve and resulted in a third phase of IRE, and the AoIR issued an additional set of guidelines in 2020 (Franzke et al., 2020).

This last set of guidelines builds on the first two documents, and the question-based and context sensitive approach is continued in this document. The third document has greater focus on the stages of research, and the issue of informed consent , especially in relation to big data approaches, approaches that utilize very large amounts of data in analysis and collecting data with a wide variety of techniques (Franzke et al., 2020).In 2019, a set of National Norwegian guidelines were also issued: "The guide supplements and refers to the Ethical guidelines for research in the social sciences, humanities, law and theology (2016) published by NESH, and is based on NESH's Guidelines for Internet research ethics (2003)" (NESH, 2019).

The first set of guidelines issued (2002) by the AoIR, aimed at providing guidelines specific for research in the digital environment. The philosophy behind the guidelines was to provide researchers with tools to approach IRE from the bottom-up. This is an approach that starts at the bottom with the practitioners and their ethical practice, instead of top-down approach, that presents as a more rule based and universalized approach (Ess & Hård af Segerstad, 2019, p. 181). It has been argued that careful consideration of each specific case is necessary (Ess & Hård af Segerstad, 2019, p. 181). The following set of guidelines issued in 2012 (Markham & Buchanan, 2012) builds on and expands the first document (Ess & Hård af Segerstad, 2019, p. 182). The same focus on a bottom-up approach was kept, with an emphasis on providing a list of guiding questions (Ess & Hård af Segerstad, 2019, p. 182). The third document has more focus on stages of research, as well as the challenge of informed consent, specifically related to research that includes using large sets of data (Franzke et al., 2020). *The same focus on a reflective, processual, case- by case approach is found in the Norwegian guidelines on internet research, issued by NESH (2019).*

The field of internet research is still exploratory and rapidly evolving, and this is used as an argument for providing guidelines that are overarching, free rules, and ideally an aid for reflection for the researcher (Markham & Buchanan, 2012). It is acknowledged that novel research contexts and –challenges place a greater demand on researchers and the research community to conduct and develop ethically sound and responsible research approaches and -practices (NESH, 2016).

2.3. Personal Identifiable Information: a clarification of the term

The term 'personal identifiable information' is used in this present study, both directly and indirectly and a description of what the term encompass is needed and will therefore be provided in the following paragraphs. The description provided below relies on the definition by The Norwegian Data Protection Authority (Datatilsynet, n.d.).

Personal information is all information that can be tied to a person, and personal information can potentially be personally identifiable information, which means that it can be used to identify a person.

Typical examples of this type of information are various forms of contact details, such as a phone number or an email address. Photos can also be personal identifiable information if people can be recognized in them, and audio recordings can be personal identifiable information even if no names are mentioned.

Including personal identifiable information in research has both legal and general research ethical implications, however the focus in this thesis is not on the legal aspects, it is directed to the personal ethical assessments of researchers, and more specifically the ones interviewed for this thesis. The General Data Protection Regulation (GDPR) article 4, states that personal identifiable information is all information that can be tied to an identified or identifiable person. More specifically, this is a person that directly or indirectly can be identified by different identificators. These identificators can be names/ identification number, and one or more indicators of a person's identity, such as: social, physical, physiological, psychological, cultural and/ or economic identity (Datatilsynet, n.d.).

By law, some personal identifiable information is categorized as sensitive personal identifiable information. Information that falls under this category requires more to be processed than other information. There are ten categories of information classified as sensitive by the GDPR (Article 9 and 10), amongst them are *health information* (Datatilsynet, n. d.). The informants of this present study had conducted research about personal health communication on social media. This meant that they had encountered both personal identifiable information as well as sensitive personal identifiable information in their projects. The researchers interviewed for this thesis had made assessments on how to approach this, both related to informed consent, assessments of publicness/ privateness and user expectations of privacy.

2.4. ‘A Guide to Internet Research Ethics’

NESH’s ‘A Guide to Internet Research Ethics’ (NESH, 2019) is mainly aimed at researchers within the humanities and social sciences, focusing on peoples’ encounters with digital networks. ‘Encounters’ is described as “dissemination of information, communication, and interaction via the internet” (NESH, 2019, p. 8). The document builds on general ethical guidelines within the social sciences, humanities, law and theology (NESH, 2016), that emphasize human dignity as a founding principle, and is further built around norms, values and principles, such as verifiability, openness, human dignity, confidentiality, privacy, free and informed consent and the responsibility to avoid serious harm (NESH, 2016).

In the guidelines (NESH, 2019), Key ethical considerations in IRE are outlined, and *a situated, context sensitive approach to IRE* is emphasized. Challenges related to the public/ private divide is outlined first, then concerns for children and groups labelled as vulnerable, followed by the consideration of informing participants and obtaining consent, the responsibility of the researcher for ensuring confidentiality and anonymity, and lastly: the sharing of data, open data and what is referred to as ‘big data’. The last considerations are only briefly discussed in the guidelines (NESH, 2019), and are not included in this presentation. The reason behind this exclusion is the results from the analysis (see theme 1: ‘encountered challenges’, in the discussion of results).

In the document by NESH (2019), ‘Internet Research’ as a term is used in a manner neutral to technology and includes the involvement of various devices, and encompass different communication networks (NESH, 2019, pp. 7–8). In the guidelines, it is further emphasized that the document is *advisory*, and an aid in research ethical reflection and judgment, as well as being a resource that can assist in solving ethical dilemmas, throughout the research process. The document builds upon and expands the guidelines for general research ethics within the social sciences, law and theology by NESH (2016). As this document (NESH, 2016) is referred to throughout the document, specific cross-references will not be included in this presentation.

In the subsequent sections, various internet research ethical considerations, as found in the guidelines by NESH (2019), will be outlined, starting with the distinction between public and private, and challenges related to unclear boundaries between public and private. The topic of ‘reasonable expectations of privacy’, that falls under the umbrella of distinctions between public and private in the NESH guidelines (2019), will be supplemented by contemporary literature. Following will be an outline of the considerations for children and vulnerable groups, also presented alongside arguments from contemporary publications, the responsibility to inform and obtain consent: likewise supplemented with contemporary literature, and respect for confidentiality and anonymity as found in the NESH guidelines (2019). Supplementing with contemporary literature on three of these areas of considerations outlined by NESH is included for reasons apart from just these topics being widely discusses in relation pertaining to IRE in contemporary literature and research publications: the contemporary literature aids in expanding the understanding of the IRE considerations outlined by NESH (2019), and also further contextualize the theory.

Following this, the typically advocated bottom-up approach to ethics is outlined, with a main foundation in the discussion by the AoIR (Markham & Buchanan, 2012). For the same reasons as mentioned above, this discussion is also presented in conjunction with contemporary literature on the topic.

2.4.1. The distinction between public and private

In internet research, the distinctions between what is public and what is private is often unclear. Assessment of publicness and privateness is important for ethical decision-making and ethical reflection, hence challenges related to these unclear boundaries are described in the guidelines by NESH (2019), and here the main rule regarding information and consent is reiterated, namely the researchers’ responsibility to inform participants, and if personal information is processed, to obtain consent (NESH, 2019, p.8).

IC is related to the research ethical principle of autonomy. There are several requirements related to an informed consent for research: the participant needs to be capable of consenting, the participants must be provided full disclosure and understands the disclosure, participates voluntarily and consents to what the participation entails (Varkey, 2021).

Specific attention is given to potential exemptions from these rules, one of them being when research is conducted in open and public arenas (NESH, 2019, p. 9). While determining what is public and open arenas in offline research is typically not challenging, the blurred boundaries between what is public and what is private on the Internet typically makes this more of a challenge. Therefore, it can prove challenging to define when the main rule applies and when to apply exemptions to the rule.

NESH (2019) states here that even when information is disclosed publicly and is openly available, this doesn't necessarily give "green light" for research to proceed without informing and obtaining consent from research participants (NESH, 2019). Here, NESH (2019) address a core issue of ethical assessments in internet research involving data from social media: even if the arena is not restricted by access, and the users actively communicate towards an audience, additional assessments of the publicness or privateness of the data is required, before the data can be used for research purposes (NESH, 2019).

Additionally, seemingly public communication can involve considerations related to notions of vulnerability and sensitivity, as it may involve people requiring additional safeguarding. Thus, the material needs to be evaluated carefully, to determine if the use of the material in research is suitable (NESH, 2019, p.9). NESH (2019) advises that researchers assess the degree of *sensitivity* of the information, as well as how *accessible* the information is in the public sphere. Research ethical challenges typically surface in cases where sensitive information is disclosed in arenas that are not clearly public (NESH, 2019, p. 9). It is further suggested that researchers visualize publicness and privateness as two ends of a spectrum, meaning that *either/or assessments of publicness and privateness will typically not suffice* (NESH, 2019, p.9).

NESH (2019, p.10) introduce the concept of 'Reasonable expectations of publicity', as a concept that can aid in assessing to what degree a user may expect that information and communication can be available outside of the context where it is found (NESH, 2019, p.10). This concept is advised to be applied when it is uncertain whether a statement is public or not and may be appropriate to apply in relation to what NESH (2019) names the "grey zone". The grey zone typically involves sensitive communication, disclosed in open arenas which can be unclear for the participant (and researcher) whether they are public, or private (NESH, 2019, p.10). NESH (2019) puts emphasis on the researcher's individual responsibility to identify and assess necessary criteria for 'reasonable expectations of publicity' (NESH, 2019, p.10). Rules of sites are mentioned as an indicator of user's reasonable expectations of privacy: "The rules of the forum may provide some indication of the user's reasonable expectations of publicity, i.e., the extent to which the users expect that the information published in the forum will be public (…)" (NESH, 2019, p.15-16). Additionally, even if social media users communicate in open spaces, that does not necessarily mean that they will accept that this information will be used for research purposes (NESH, 2019). The concept of reasonable expectations of publicity can help ensure that as less harm as possible is inflicted on users of social media and is thus referring to the general research ethical principle of non-maleficence, which is also crucial to be upheld if the principle of beneficence is to be fulfilled.

The concept of ‘reasonable expectations of publicity’ is also referred to as ‘user expectations of privacy’ in contemporary literature, and factors such as user's agency and choices, as well as technological settings are discussed:

Users who are interested in safeguarding their online persona and content often set their profile to private, where this is an option (Burles & Bally, 2018, p. 6), users thus can be seen to have made an autonomous decision regarding protecting their privacy. When people share on publicly accessible sites without password protection, it is reasonable to assume that they will be aware that readers outside of the communicative context can read what they have written (Burles & Bally, 2018, p.4). Furthermore, social media users may have varying expectations of who constitutes the audience for what they write, such as in blogs, where the purpose of the blog may be to access support through challenging times (Kim & Gillham, 2013, cited in Ross, 2019). Ross (2020) points to further implications reaching an unintended audience, through research dissemination, may have for a social media user/author: a blog author may not have intended for genetic relatives to read what they have written about their illness on social media, and thus being made aware of the potential for carrying the gene themselves. Genetic relatives can be burdened by the responsibility this knowledge may entail, for e.g., testing and surgeries to reduce risk, as argued by Hesse-Biber (2014) (cited in Ross, 2020), as well as negative feelings connected to potentially passing on faulty genes to children (Hallowell et al., 2006, cited in Ross, 2020). This example furthermore illustrates how internet research may actualize novel challenges related to the principles of confidentiality and anonymity, which evokes the responsibility of maintaining the principle of non-maleficence.

Some social media sites also require users to take measures to remain anonymous, and group settings can be set to either private or public: users of these websites have *choices* regarding how to protect their privacy, through settings, not revealing their personal identifiable information and using pseudonyms instead of real names, as noted by Kurtz et al. (2017) and Miller, Pole & Bateman (2011) (cited in Burles & Bally, 2018, p.4). On the other hand, pseudonyms can be a means to conceal one’s “real”, offline, identity, by portraying only one’s online identity. Hence, the use of pseudonyms may imply expectations of anonymity and privacy.

Another concept is introduced in the 2019 NESH guidelines, namely ‘contextual integrity’. NESH (2019) states that this context may be of relevance to research ethical considerations. Contextual integrity refers to the importance of the context of communication as a factor in assessing whether material should be seen as public or private, especially related to social media and blogs (NESH, 2019, p. 10). According to NESH (2019, p.10), contextual integrity refers to the context that is the form of communication and the design of the technology, in other words: the context where communication takes place and highlights that this context is crucial for assessments of what is public and what is private.

2.4.2. Concern for children and vulnerable groups

This section is mostly directed towards concern for children, with more general mentions of concern for groups that can be labelled vulnerable. Additionally, considerations for vulnerable groups and sensitive topics are mentioned in different sections of the document.

Under the heading ‘Concerns for children and other vulnerable groups’, the second area of consideration in the NESH document (2019), it is advised that, in research, it may be necessary to assess the vulnerability of participants, and that this specifically relevant for the protection of children, adolescents and what is referred to as vulnerable groups, such as patients (NESH, 2019, p.12). It is further stated that children, adolescents, and other vulnerable groups are entitled to special protection (NESH, 2019, p.12). Challenges related to the inclusion of adolescents and children in research is then further discussed, before the need for researchers to respect the values and opinions of research participants, such as minorities and political sub-groups, and that communication with other cultures require special attention to dialogue, and discuss limits to cultural recognition (NESH, 2019, p.13).

Then, at the very last end of the section, the thread on the inclusion of third parties is again taken up, and it is described that: when of information about third is collected, either directly or indirectly, through for example comment threads or photos, then researchers must assess and take into consideration what could be possible consequences for those people (NESH, 2019, p.13). Such information can also be sensitive, or potentially sensitive, and the information must be treated the same way as sensitive information related to the primary informants. The concern for third parties becoming included in research makes up the last section of considerations for children and so-called vulnerable people in research. The entanglement of notions of sensitivity and vulnerability with other contextual factors in social media research, which may present a novel challenge in itself, is not further discussed or described in this section.

Further advice on this therefore ought to be found elsewhere, e.g., in general research ethics guidelines, other documents and resources, or on the basis of the description of the other ethical considerations that are outlined in the document. However, contemporary publications also discuss challenges related to the inclusion of sensitive topics and people in vulnerable situations in internet research, and also further narrows down the definition of what notions of vulnerability and sensitivity may entail:

Contemporary literature highlight that qualitative research on communication on social media can provide novel opportunities for deep insights (Burles & Bally, 2018, p. 3; Ross, 2020, p.46): online venues such as blogs and social media platforms can be a rich source of data related to personal experience with illness (Ross, 2020, p. 46), as well as a rich source of knowledge about how people communicate with others about experiences related to being ill. Nevertheless, the inclusion and assessment of vulnerability and sensitivity may also be challenging, and not made any less challenging by the fact that vulnerability discussed within the context of research ethics often leaves out any clear definition of the term.

However, some distinctions have been agreed upon, e.g., people that have difficulties protecting their own interest are often classified as being vulnerable (Tiidenberg, 2020, p. 572). Hurst (2008, p.192) (cited in Solbakk, 2015) refers to three subcategories to what we may label as "vulnerable groups": those who are unable to provide consent, those who are at risk for harm, and those who may lack understanding. Solbakk (2015) refers to three sub-groups of so-called vulnerable groups, with emphasis on absence of the ability or competence to consent, risk of harm and lack of understanding, respectively.

So-called vulnerability is not necessarily directly corresponding with the offline situation of participants. A report from the UK Council for Child Internet Safety (2012), (cited in Tiidenberg, 2020, p.572) shows that vulnerability can also directly correspond with participants risky behavior on the Internet and the utilized service. Notions of sensitivity and vulnerability are intertwined, as sensitive practices, or risky behavior online can put practitioners in a vulnerable position: their risky behavior may for example expose them to face social stigma, and/ or legal consequences (Tiidenberg, 2020, p. 573).

Not to forget, *Interaction in the online environment can easily put people from all walks of life in a vulnerable situation***.** This means extra responsibility for the researchers in the ways ethics and the researcher- role is negotiated (Tiidenberg, 2020, p. 573).

It is agreed in academic communities that the categorizing of vulnerable and not vulnerable into separate groupings can have unfortunate effects (Tiidenberg, 2020, p. 572). As an example, a study by Egan et al. (2006), (cited in Tiidenberg, 2020, p.572) has shown that participants in research with brain injury was not positive to the label vulnerable being used on them, and they found it patronizing.

2.4.3. Publicness/privateness and Informed consent

NESH (2019) specifically discusses the potential exceptions from the general rule of informing participants and obtaining informed consent if sensitive information is included (NESH, 2019). NESH (2019) refers to various examples of exceptions, such as research involving public persons, and research in open arenas. It is however emphasized that, in similarity with offline research, sensitive information disclosed in an open arena should not uncritically be used for research purposes (NESH, 2019).

According to NESH (2019), there are various factors that informs the negotiation of the principles of information and consent, such as assessments of the accessibility of the material in the public sphere, the sensitivity of the information, the vulnerability of the participants and interaction with participants (NESH, 2019, pp. 13–14). NESH (2019) emphasize that the researchers' responsibility to inform and obtain consent is not bound to regulations alone, but is a matter of personal judgment and assessment:

> In other words, this does not refer to the statutory requirement for consent to the processing of special categories of personal data or the statutory entitlement to information and transparency, but to the ethical responsibility that invariably rests with the researcher, irrespective of whether personal data are involved or not, or whether the information is sensitive or not. *(*NESH, 2019, p. 14).

Practical challenges related to contacting informants are mentioned, such as challenges related to those that no longer are active, participants without contact information, and challenges related to contacting large numbers of participants (NESH, 2019, p.14). It is further noted that, in situations where obtaining consent of good quality is severely problematic, then the researcher may consider not carrying out the research at all (NESH, 2019, p.15). In other situations, it may be sufficient to provide open information about the project, and to obtain consent from participants that will be directly included in the data (NESH, 2019, p.15), for example in the use of verbatim quotations.

Additional considerations and suggestions pertaining to informed consent, complicated by unclear boundaries between public and private, are presented in contemporary scholarly publications, some of which's arguments are outlined in the next paragraphs.

Assessments of the grey areas between public and private spaces have implications for the principles of information and consent (Elgesem et al., 2016). Even though these areas can be challenging to navigate, the literature offer some suggestions: when sites are *password protected and involves sensitive information*, it would be quite clear that informed consent should be obtained, while in cases where non private information is disclosed in a public space, this would not be as clear (Elgesem et al., 2016). Additionally, the practicality and feasibility of seeking informed consent is dependent on a variety of factors, such as group size, available contact information, and if there is a space for public or private postings (Burles & Bally, 2018, p. 7). Contacting informants can sometimes be more intrusive than foregoing this (Burles & Bally, 2018, p. 7).

In a scoping review on online ethnography for people with chronic conditions, it was recommended that researchers need to obtain informed consent from users before using both public and private data, as a precautionary measure (Gao et al., 2022). The principles of informed consent and confidentiality in internet research is said to require extra attention when involving people sharing their personal stories (Burles & Bally, 2018, p. 2), as potential harm can occur to participants by revealing identifiable information. Roberts (2015) refers to the potential harm of reidentification of persons or groups via online searches.

Contemporary literature also highlights additional factors related to consent: obtaining informed consent can also present an opportunity for the researcher to *involve participants in setting the boundaries for the use of their data*. (Burles & Bally, 2018, p. 7): hence, it can also be additional benefits related to obtaining consent, apart from obtaining the consent itself. Ross (2020), in her reflection on involving blog-material about cancer in her research, found that contacting users/ authors of blogs for informed consent, provided additional benefits to approval for material to be used in research, such as more insight into the illness and reasons for writing (Ross, 2020). Ross (2020 also notes that most blog authors had been positive about being included in research and saw this as a welcome opportunity to raise awareness. In the same article, Ross (2020, p.52) reiterates the benefits of involving users in ethical considerations in the concluding part of her article, referring to Samuel & Derrick (2017) when stating that her article "echoes call for a more collaborative approach to social media ethics for individual research projects involving not only research ethics committees and researchers".

Apart from being tied up to the principle of non-maleficence, Informed consent is also largely tied to the principle of autonomy: for participants to have a real choice, they need to be capable of consenting, otherwise the choice of participating in research is not realistically their own choice. Also, as Ross (2020) and Burles & Bally argue (2018) using the consent process as an opportunity to involve users in ethical decisions, and more specifically deciding on how their own data will be used, is an act that explicitly takes social media users' autonomy into account.

2.4.4. Respect for confidentiality and anonymity

Burles & Bally (2018, p.8) states that evaluations regarding maintenance of confidentiality hinges on details such as the disclosure of PI, and the sensitivity of the topic and subjects. Regardless of various assessments, in internet research, it can be hard to promise participants real anonymity and confidentiality (NESH, 2019), as factors such as the nature of technology and public accessibility can make it possible to reidentify individuals or content, even when information has been stripped of PI. It is advised that the researcher take these limitations into account when informing and obtaining consent (NESH, 2019, p. 16).

The use of pseudonyms does also not guarantee that a participant will not be identified, since pseudonyms are oftentimes used across platforms and venues, and a collation of various data can nonetheless lead to reidentification (NESH, 2019). Heilferty (2011b) (cited in Burles & Bally, 2018, p.6), argues that confidentiality has heightened importance when sensitive topics are involved in research, since a possible reidentification of participants can lead to harm or exacerbated vulnerability. Means for minimizing risks related to identification of informants have been suggested. Roberts (2015) (cited in Burles & Bally, 2018, p.6) suggests that slightly altering quotations can be one way of minimizing risk.

Barker (2018) (cited in Burles & Bally, 2018) argue that, if data is produced on a site such as a forum and by a large group of people, it can be more difficult to trace the data back to individual persons, and thus the researcher can be less stringent about preserving confidentiality. It is however noted that it is up to individual researchers to decide on the level of precaution (Burles & Bally, 2018, p. 8). The NESH guidelines (2019) emphasize researchers' personal responsibility for informing informants about potential limitations to professional secrecy and confidentiality. However, since the condition for confidentiality is that information is stored and can be searched, disclosing limitations to what actual anonymity and confidentiality that can be promised to informants, becomes important (NESH, 2019).

2.5. A bottom-up approach to Internet Research Ethics: in contemporary literature

How to best approach ethics has been, and is, a hot topic in contemporary literature, and the most often advocated approach is the 'bottom-up' approach to ethics: a term that is used interchangeably with terms such as a 'processual-approach', a 'context-sensitive'-approach, and so on, *and thus seems to be a rose that smells just as sweet, regardless of its name.*

A bottom-up approach to ethics, starting with researchers' day-to-day practices, typically expressed in question-based guidelines, is a widely advocated approach to internet research ethics. Ess (2020, p.285) further refers to this approach, as seen in both the guidelines by NESH and the AoIR, as internet research's' "primary ethical style (as process- and dialogically oriented)", and further turns the attention to "the primary questions both sets of documents have used to foster the ethical reflection and judgment seen to be central to effectively coming to grips with the ethical challenges evoked by Internet research, including research on social media", as a part of this style, or this approach.

Burles & Bally (2018, p. 1) notes that, despite an emergence of research ethical guidelines over the years, discussion about many issues concerning IRE are an ongoing event In the center of this discussion is how best to approach ethical challenges in internet research. Challenges in internet research are approached and solved in a vast variety of ways, reflecting the dynamic and transient nature of the internet (Burles & Bally, 2018, p. 10). The discussion of ethics is seen as important to continue to develop a *best practice* (Markham & Buchanan, 2012). It is argued that best practice can be achieved through a situated approach to IRE (Burles & Bally, 2018, p. 10).

Rensfeld et al. (2019) argues that seeing ethical considerations as situated means viewing ethical considerations as intertwined with the context of the research (including the participants), the methods used, as well as the aim and objectives of the research (Rensfeldt et al., 2019, p. 198). Ross (2020, p.52) also points to the importance of a social media researcher to stay context sensitive, by consulting existing literature and research. To account for all the different aspects of context, the researcher must use judgments and reflect throughout the process of research (Rensfeldt et al., 2019, p. 198). Through approaching ethics in a processual and context sensitive manner, researchers can acquire knowledge that may be transferable to other, similar cases, as argued by Rensfeldt et al. (2019, p. 198). And, if not directly transferable, the lessons can be utilized as examples in altered versions, for similar cases (Rensfeldt et al., 2019, p. 198). It is also suggested that a processual and question-oriented approach is the best suited approach for research involving sensitive topics (Perez Vallejos et al., 2019).

Top-down decision-making can prove less flexible than situated approaches in meeting with the novel contexts of internet research. Top-down approaches are more rule based compared to a reflexive and context-based approach. This is less desirable from an ethical point of view as discussed by Markham (2006, p. 44). Burles & Bally (2018, p. 1) argue that the wide spectrum of available methods for use in differing internet environments means that a top-down approach to ethical decision-making can be problematic.

A reflective and bottom-up approach to IRE- matters can be illustrated by the high-level questions by Chris Mann (2008) (cited in Markham,2006, p.42), made for assisting in internet research ethical decision-making and reflection. Typical areas suited for their application are cases complicated by issues surrounding privacy, anonymity and informed consent (Markham, 2006, p. 42). The questions are related to *magnifying the good, not doing harm, and recognizing other human's autonomy and worth.*

Central features of the two approaches have been visualized by the author of the present study, in the following two figures. In Figure 1, illustrating a top-down approach to IRE, norms, values and principles are at the bottom of the pyramid, and thus makes up the core foundation of the approach. In this approach, a priori decisions can be seen as the expression of this foundation. In practice, this typically results in rules. In Figure 2, norms, values and principles are also the foundation, but here context specific decision is the expression. In practice, this typically means questions and other tools for reflection.

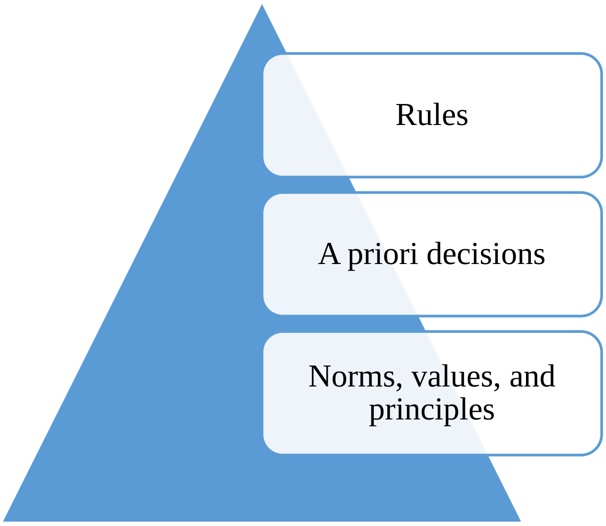

Figure 1. A simplified illustration of key components of the top-down approach to IRE.

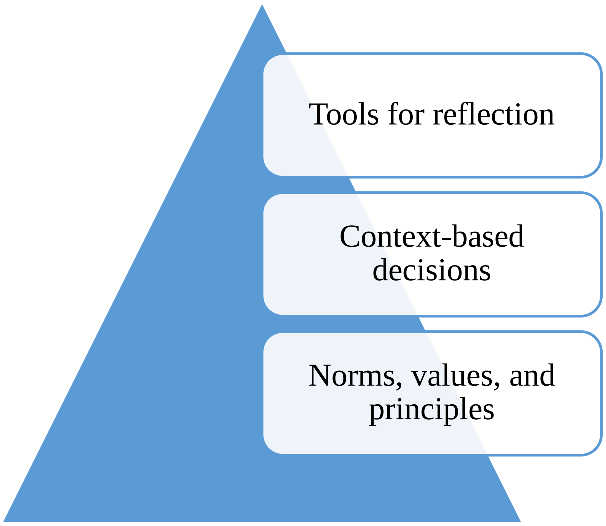

Figure 2. A simplified illustration of key components of the bottom-up approach to IRE.

2.6. The bottom-up approach: as advocated by the Association of Internet Researchers

The increase in access to the Internet on a global basis, the expansion in communication technologies, and an increasing meshing of online and offline life, were some of the factors that sparked an evolvement of the first set of guidelines that had been issued by the AoIR in 2002 (Markham & Buchanan, 2012, p. 2). The result was a second set of guidelines on ethical decision-making in internet research: “Ethical Decision-making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)”. The pool of literature pertaining to internet research and internet research ethics had also grown alongside these socio-technological developments, and some of this literature has also been utilized in this set of guidelines from 2012 (Markham & Buchanan, 2012, p.2). The document from 2012, also provides a thorough discussion of the advocated bottom-up approach, and is followed by another document, the provisional last in line, issued in 2020 (Franzke et al., 2020).

In the document, a list of key guiding principles for ethical decision making in internet research is proposed. It is recommended that these key guiding principles are consulted throughout the research process (Markham & Buchanan, 2012, p. 4). In the document, various overarching, as well as more specific, questions for ethical reflection are provided. In addition, a set of key guiding principles are outlined, as well as key considerations in internet research. And combined, the questions, key considerations and key guiding principles are meant as guidelines for researchers and others in processes of research ethical decision-making and –reflection. These are provided instead of rules or more specified guidelines per se. Summarized, the key guiding principles takes these factors into account: the need for protection of participants according to their level of vulnerability, contextual definitions of harm alongside the need to make processual decisions based on practical judgments, the involvement of humans in nearly all types of internet research and balancing of rights and interests. Also emphasized is the importance of consulting a range of resources related to ethical decision-making:

> Ethical decision-making is a deliberative process, and researchers should consult as many people and resources as possible in this process, including fellow researchers, people participating in or familiar with contexts/sites being studied, research review boards, ethics guidelines, published scholarship (within one's discipline but also in other disciplines), and, where applicable, legal precedent» (Markham & Buchanan, 2012, p. 5).

The AoIR suggest that regulations, originally intended for ensuring sound ethical practice, can bere a potential hindrance for researchers, by enforcing predefined and universalized determinations about what may constitute harm and risk, as in the following examples: defining certain people as vulnerable, or by seeing informed consent as sufficient for mitigating harm (Markham & Buchanan, 2012, pp. 7–8). It is however acknowledged that, typically, it will be a need to predict ethical consequences, in order to be granted ethical approval for projects (Markham &Buchanan, 2012, p.8). It is argued that the requirement to make predefined decisions and assumptions will have to be balanced with the necessity of being open and responsive to ethical challenges throughout the process of research (Markham & Buchanan, 2012, p. 8).

The personal responsibility that lies with the researcher in such a reflective processual approach process is stressed (Markham & Buchanan, 2012). This individual responsibility is however being nuanced with the suggestion of consulting as many resources as possible (Markham & Buchanan, 2012), and as it is further described in the latest guidelines by the AoIR: dialogue, as in discussions with friends and colleagues, is described as an essential ethical technique. Further, the importance of discussion and dialogue when reflecting on ethical dilemmas and making ethical judgments is emphasized (Franzke et al., 2020, p.23)

A flexible bottom-up approach to matters in IRE is foregrounded throughout the document. Codes and rules are seen as an inappropriate fit for approaching IRE (Markham & Buchanan, 2012, p. 5). This approach is labelled variedly as, for example: a "bottom-up", "case-based", "processual" and "context specific" approach in the guidelines, and no specific guidelines or rules are provided, as this is seen as counter to what is desirable for approaching IRE related challenges. Here, norms, principles and questions for reflections serve as guidelines.

In the AoIR document, the seemingly endless variety of contexts, and the wide variety of fields of research, are used as arguments in support of the bottom-up approach. It is argued that making rules or universalizing and predefining any set approach to IRE would not be practically possible, nor would it be desirable (Markham & Buchanan, 2012, p. 7). What is considered as harm. To take an example, what is considered as harm may hinge entirely on the specifics of the contexts (Markham & Buchanan, 2012, p. 7), and therefore predefined decisions or rules would not suffice.

It is stressed that different stages of research may need different ethical considerations (Markham & Buchanan, 2012), and that therefore a processual approach, instead of an approach where ethical decisions and assessments, e.g., related to harm, are predefined, or reduced to a "tickbox" for ethics. Additionally, the guidelines place emphasis on the risk related to thinking that by e.g., obtaining consent, this alone mitigates harm.

It is further noted that considerations of obtaining informed consent typically are most salient in the beginning stages of a project, while challenges pertaining to for example the use of verbatim quotations typically arise at later stages (Markham & Buchanan, 2012, p.5-6).

Chapter 3 - Methods

In this chapter the methods that were used in this present study are presented. The methods that have been chosen has been chosen for their suitability in answering the research question: qualitative approach has been taken, involving in-depth interviews, and more specifically, digitally conducted in-depth interviews, with a selection of three informants. Conducting interviews involved designing an interview guide, and various ethical and safety-related considerations. The criteria for inclusion will also be outlined in this chapter.

3.1. Qualitative interviews

The qualitative interview as a method is well suited for gaining valuable insights and rich descriptions of experiences and perspectives on given topics (Thagaard, 2013). By taking this approach, one can collect comprehensive and extensive data on an informant's perspectives and experiences (Thagaard, 2013). As for choosing this method for a project, it should be chosen on the foundation of the method supporting the overall aim of the research project (King et al, 2019).

How fitting a method is for a particular project depends on what the purpose of the research is. In this project, direct communication with informants was seen as a good way of obtaining data stemming from the experiences and perspectives of participants. This data could be missed using for example a text-based approach, relying on the research articles only for data and analyzation (Seidman, 2006). Triangulation of methods: combining these interviews with a textual analysis could also be analytically interesting. However, taking the constrictions of time and length of this thesis, as well as the research question, interviewing was deemed sufficient.

Three researchers were interviewed for this present study. Albeit a small number, three interviews provided enough data to be able to answer the research question. Additionally, ensuring broadness in terms of perspectives and insights was not the aim of conducting these interviews: conducting three interviews allowed the author of this present study to focus on obtaining in-depth information, and to conduct a thorough analysis of the data.

3.1.1. Semi structured interviews and the interview guide

In this project, semi structured interviews were used. This form of interviewing is the one most utilized in qualitative studies, and it can be referred to as "the" qualitative interview (Thagaard, 2013, pp. 90–91) Qualitative interviewing is also the most applied method within qualitative research (King et al, 2019, p.6; Thagaard, 2013).

In a semi structured interview, the researcher is guided by an interview schedule, mostly referred to as the interview guide. The interview guide is a list of questions prepared before the interview takes place (Clark et al., 2021; King et al., 2019). The questions of an interview guide are related to a project's topic, or collection of topics. For a semi structured interview, it is important that the guide allows room for some flexibility regarding both the order in which the questions can be asked, as well as in the formulation of questions and which questions can be asked. The objective of the interview is to gain access to the informant's perspectives and experiences; the interview guide should make it possible to delve deeper into topics of interest (Clark et al., 2021) For this project, the interview guide was structured around three loosely defined themes, with related questions under each theme. The interview guide was in English; however, interviews were conducted in a way that allowed informants to speak in their first language. No major challenges were found in translating the relevant terms used in the interview guide.

A total of 16 questions were prepared beforehand, including follow-up questions. The guide was made in such a way that it would not be necessary to keep the exact order of the questions, and there was not a need to formulate every question in the same way to obtain satisfactory answers. A certain looseness of structure is needed to obtain desired fluency and flexibility in the interview, allowing room for reflection and exploration, notes Thagaard (2013) While keeping the interview guide flexible and not too rigid in structure, it should also secure that the topics under investigation, as well as the research question itself, are in fact being held central to the conversation (Clark et al,2021, p.428). The structure of the interview guide crafted for this thesis followed these important steps, aiming to formulate the questions in an open-ended fashion, and allowing space for the questions to be posed in the order that is most natural and beneficial, throughout the interview. This also allows for deviations, into other potentially relevant and interesting themes.

Different forms of questions were included in the interview guide to gain in-depth and detailed answers. The main questions were supported by follow-up questions, with the purpose of gaining more in-depth knowledge on a specific topic. Probes are questions that create flow in the conversation. Probes can be anything that provides response and encouragement to the participant, both verbal and non-verbal cues, such as nodding, hand gestures and more

(Thagaard, 2013). Main questions and follow-up questions were partly included in the guide, and partly coming up in the actual interview, while making sure that the important main questions were answered. The informants oftentimes answered questions without the interviewer having to articulate them. Possible probes were considered before conducting the interview.

When conducting interviews with researchers as informants, it might be reasonable to expect that the tolerance for theoretical jargon might be at a higher-than-average level. Still, it is sensible to use theoretical jargon related to internet research ethics with care, as some of the specifics of the jargon may or may not be well-known (Clark et al,2021, p.428).

In order to put the interview guide to the test, and to gain experience with interviewing, a pilot interview with one of the supervisors of this thesis was conducted. The supervisor had herself conducted internet research on forums and had used textual communication about a sensitive topic as data (Nacey, 2020). The interview situation thus mimicked the actual interviews, and constructive comments and feedback were provided by the supervisor. The interview guide was adjusted according to the experiences elicited from the pilot interview.

3.2. Qualitative interviews conducted online

For this project, the semi structured interviews were conducted via the video-conferencing software Zoom. Online video interviewing has been chosen for this project as the best option after making various considerations. The video interview is the type of interview that most resembles the traditional face-to-face interview. Both visual and verbal clues can be observed from both parties (Saarijärvi & Bratt, 2021, p. 393). Facilitating good verbal and non-verbal communication is desirable for this project, which aims is gaining access to the perspectives of the interviewees within a limited time frame. There are drawbacks and benefits related to conducting digital interviews, as well as certain safety concerns. This will be discussed in the following sections.

3.2.1. Benefits and drawbacks of online video interviews

Online video interviews, resembling everyday interaction, can be effective in facilitating communication that flows with desirable ease (Lobe et al., 2022).

To be able to have a similar kind of flow as when using in- person interviewing was desirable for the semi structured interviews aimed at accessing the views of informants. The use of online video interviewing also enables recruiting participants that fit the criteria for inclusion, without having to worry about location (Lobe et al, 2022, p.6; Carter et al, 2021, p.713). Regardless of this, it is still important that the research is informed by the research questions. This is the basis

for determining which participants to include, and as such, methodological concerns outweigh the mere practical ones (Carter et al., 2021, p. 731).

In this present thesis, the informants were chosen on the basis of the type of research they had conducted, in other words: they were selected based on their relevance to the study. The choice of conducting interviews digitally helped facilitate the inclusion of participants living abroad.

Another benefit of choosing digitally conducted video interviews is that it can more comfortably be fitted into busy schedules, and participants can attend them from their office, or even in the comfort of their own homes. Opting for conducting interviews digitally also means less carbon footprint, compared to interviews where either participant or researcher may have to take a flight. Additionally, the object of study is research conducted in the virtual world, thus the use of digital interviews for this project thus adds another dimension to the topic under investigation. On some points this could be an aid in better understanding the informant’s experiences.

Some drawbacks associated with online video interviewing are potential fluctuations in quality of internet connectivity and other technological issues, such as poor quality of video or audio recordings. This can negatively affect the interview (King et al, 2019, p.120-121; Clark et al, 2021, p.440). Such disruptions can negatively impact recording, and result in difficulty when transcribing the interviews (Clark et al, 2021, p.440). There might also be a higher possibility that participants withdraw from the interview at the last minute, than for in-person interview (Clark et al, 2021, p.441). To lessen the impact of these issues, some measurements were taken prior to the interviews, such as ensuring that the interviewer had stable internet connection in the space where the interviews would be carried out, checking in and confirming the scheduled interviews with participants, as well as following up with information about the project. It could also have been possible to collect the informant’s telephone number, for use in case of a disruption of the internet connection. This would, however, did mean that desirable aspects of in-person interviews, including the physical proximity that makes reading non-verbal and environmental cues easier, would have been lost. Another possibility that was considered was re-scheduling the interview, if disruptions would have forced the interview to an unfortunate end.

3.2.2. Online video interviewing: software and safety

When opting for online video interviews for research purposes, it is important the researcher assesses the safety of the platform that is used. For this project, the guidelines for research given by Inland University of Applied Sciences were followed: the choice of platform needed to be secured with access granted through the university. Access to the platform Zoom was provided by the university. This was the paid version of Zoom, which is important, since the free version is associated with certain risks, such as uninvited people gaining access to meetings (Lobe et al,2020, p.3, 5). In paid versions of Zoom, extra levels of safety are provided, and privacy is better secured (Lobe et al, 2020, p.3).

Prior to the interviews, an invitation link was sent to the participants, and an additional measure of safety was added by enabling the ‘waiting room’ function: the participants had to wait until accepted into the meeting. This ensured that the interviewer had a high level of control of who was accepted into the meeting.

3.3. Participants

The participants that were chosen came from different fields within social sciences and human sciences, and all had performed their research on different diseases, and different social media sites. This turned out to be enriching for the research, as all had some different perspectives on the same subject of internet research ethics. The informants chosen worked within a Western European context.

The criteria for inclusion were:

- The informants had done research using non-interactive online observation.
- Informants should work within a (Western) European context.
- The research had to involve social media sites, and communication about illness on these sites.
- Research could only involve participants over the age of 18.
- The researchers had ethical approval for their project.

The reason behind choosing participants with one similar, qualitative, method in common, is that methodology and ethical considerations typically are meshed, and a common ground between informants in terms of data-collection method and level of interaction with participants, can be an important factor when gathering data for this thesis. It was also important that the informants had experience with social media research in particular. The

background of choosing informants conducting research within a Wester European context, was that it should be some common grounds for the context which the researchers were working within. The legal aspects may not be the same in the three countries the informants are working in, but there would be more common ground in terms of values and principles than if the researchers had come from more disparate parts of the world. Although it was a small number of participants that were selected, it was considered that adequate saturation of the data could be achieved with three in-depth interviews, in alignment with the research question and aims of the study. Interviewing a larger number of researchers may have added more perspectives, but also a larger material, and the author of this present study has prioritized depth, instead of ensuring width. Also, the aim has not been to make claims that can be generalized to include all researchers working within similar contexts.

Another inclusion criteria were that the informants had conducted research on illness communication. Illness is chosen as a category, as it requires specific research ethical attention from researchers. The diseases under research were either under researched/ stigmatized and chronic in nature. Reasons for not choosing researchers that had conducted research involving the same illness, was in part practical. I was not able to identify and/ or recruit a sufficient number of participants within either illness category that also met the other criteria for inclusion. Including researchers which had included data pertaining to different diseases can nonetheless be an asset. Having included only one illness category might have elicited more in-depth knowledge pertaining to a particular disease. However, including different illness-categories can help highlight any coinciding factors which may apply more widely to research involving communication about illness as material.

The reasoning behind the requirement for the research of the informant’s should only include persons be over the age of 18, is that research on minors requires additional specific attention, and a discussion of this falls outside of the scope of this thesis. Ethical approval for the informant’s research projects was the last criterion for inclusion. That the projects had been granted ethical approval meant that basic ethical and legal standards had been met. This was important, since the scope of this thesis is not to directly discuss the formalities or legal aspects of ethical decision making in internet research, as this has been thoroughly described elsewhere.

3.4. Issues related to ethics, privacy and safety

Before the interviews were conducted, the project was notified to Norwegian Agency for Shared Services in Education and research (SIKT, previously known as NSD). SIKT stated that they had assessed that there was a lawful basis for processing the personal data.

Interviewees were contacted by e-mail, and informed consent was obtained by the author of this present study, and stored on OneCloud, away from the other data. The consent form was based on a consent form provided online (SIKT, n.d.) The form was further adjusted by the author of this present study: it was distributed in Norwegian and English, and the was designed to sufficiently and clearly inform the participants about the purpose of the study, what participation would entail, and to use clear and easily understandable language in doing so. In the consent form, the author of this thesis also further clarified that digital interviews would be conducted, and that all audio recordings would be safely stored. Participants were further ensured that they would not be identified in the dissemination of the study, as refers to the respect for confidentiality and anonymity of participants (NESH, 2016). The author of this present study also sought to make it clear that participation was voluntary, and that participants could withdraw at any time. Voluntary participation is an important research ethical principle (NESH, 2016). Sufficient information also lays the foundation for enabling participants to determine for themselves whether they want to be included in research, or if they would like to abstain (Varkey, 2021).

As language is also an important factor in anonymization, the benefits of using verbatim quotations conveyed in the informants’ mother tongue, in addition to English translations, was weighed against potential harms of doing so. After careful consideration, it was decided that the research presentation would benefit from using quotations in the original language, as in translation, quotations may lose some of its meaning, and thus presenting both original and translated quotations, may ensure accuracy. The risks of potential harm were also considered low, as other personally identifiable information has been stripped from the data.

To ensure anonymity, identifiable information was altered and/ or left out, to anonymize the informants in the transcripts. As part of this process, transcripts were returned to informants for comments, who provided valuable feedback, including helpful comments regarding additional anonymization of the transcripts. All data was stored securely on OneDrive, and both data storage method and the various software used for in this present study, was approved by Inland University of Applied Sciences. The researcher has an obligation to store data properly (NESH, 2016), as safe data storage is also important for maintaining anonymity and privacy.

When informing informants and obtaining consent via e-mail, as in this present study, NESH (2019) states that it is important to make sure that information is sufficiently conveyed to informants. In this present study, this challenge was met by thoroughly informing about the study in the consent form, opening for questions from informants regarding the consent form, and to reinform about the study at the beginning of the interview.

There are additional ethical and safety related issues to consider for digitally conducted video interviews, as compared to in-person interviews. To ensure privacy e.g., it is recommended to advise the informant to take the audio call in a private setting, and the same goes for the researcher (King et al, 2019, p.122; Lobe et al,2020, p.2). In this present study, the informants were sent a set of instructions regarding attending the interview in an environment where they will not be disturbed, and to close other applications, as recommended by Lobe et al. (Lobe et al., 2020, p. 2). It was also recommended that informants used the 'blurred background' function, to better protect their confidentiality (Lobe et al, 2020, p.6).

Krumsvik (2014) writes about the importance of following rules and routines for research ethics. At the same time, he highlights the importance of the ethical awareness of the researcher throughout the process of research (Krumsvik, 2014, p. 167) The ethical awareness of the researcher relates to integrity and trust: the researcher should be not misusing what informants have said and should meet all informants with the same intention (Krumsvik, 2014, p.167). The wellbeing of informants was also considered. Avoiding unnecessary strain, and to minimize harm to the informants, is a research ethical obligation (NESH, 2016). Even if the nature of the topic of the interviews did not necessarily warrant any special precaution to be taken, the interview situation could nonetheless potentially be stressful for the informants. Interviews conducted online can be an intense experience for both researcher and informant, and the conversation can, for one reason or another, potentially be stressful for the informant. A plan was set up to inform participants at the start of the interview about the timeframe of the interview, and the outline of the content. The interviewer also made it clear that the informants only had to answer the questions that they felt comfortable with. Throughout the interview the interviewer paid attention to nonverbal cues, checked in with informants if they needed breaks, and confirmed the timeframe. It is easy to become blind to ethical issues, especially as a novice researcher (Krumsvik, 2014, p.167). Therefore, it was important for the author of this thesis to be aware, and to be made aware, of potential adverse effects of the research. However, with all measures in place, and with careful attention to treating informants with respect and care, the benefits of conducting the study appeared as greater than any potential harm to the participants.

3.5. Ensuring quality: validity and reliability

It is well known that the terms for assessing quality in quantitative research, validity, reliability and generalizability, do not apply to qualitative research the same way, although they are also used here. Validity, as used in quantitative research normally is related more specifically to the data-material (Drageset & Ellingsen, 2010), but refers to whole research process in qualitative research. Krumsvik (2014, p.141) further notes that validity in qualitative research is related to the question if what was intended to be investigated, has in fact been investigated, as opposed to in quantitative research, where it is related to the question if what was intended to be measured, has in fact been measured (Krumsvik, 2014).

Validity in qualitative research hinges on the researcher; accuracy and execution are factors that can enhance or threaten the validity of a study (Drageset & Ellingsen, 2010). In this present study, it has been important to strengthen the validity by being accurate in the reproduction of what was said by the informants during the qualitative research interviews and by carefully designing the interviews, including the wording of the questions asked. During the interviews, the author of this present study also made sure to confirm with informants if what they had said was understood in the way that they had meant. Validity can be strengthened by asking clarifying questions, such as “did I understand you correctly?”, to ensure a common understanding between researcher and informant (Drageset & Ellingsen, 2010). The author of this present study emphasized asking clear and unequivocal questions. Unclear questions, or questions that can be interpreted in a variety of ways can lessen the reliability, and thus also the validity (Krumsvik, 2014). Another step in enhancing the quality of how the interviews were conducted was piloting the interview prior to conducting the actual interviews.

Accuracy, also important for strengthening the validity of a study, is related to the congruence of the results in relation to reality (Krumsvik, 2014). In this present study, the audio recordings of the interviews were transcribed with due care and attention in order to, as accurately as possible, reiterate what the interviewees had said during the interviews. Inattentiveness when transcribing can be a threat to validity (Drageset & Ellingsen, 2010). The analysis was also conducted in a thorough and systematic manner, something that, in addition to ensuring an adequate level of accuracy, according to Krumsvik (2014) is important for ensuring the transparency of a study. The author of this thesis also sought to provide a rich and detailed representation of the data, and to include quotations that provided adequate contextual information, to further strengthen the validity of this present study.

Transparency relates to the term reliability in qualitative research (Krumsvik, 2014), and refers to good planning of the research project (Drageset & Ellingsen, 2010). The reliability of this present study was strengthened through attention to planning and matters such as how to securely record and store data were considered early in the process. The ‘Diktafon’, and the external digital recorder, was tested prior to the interviews, resulting in overall satisfactory recordings. There were only a few instances where words or sentences got “lost”. This could have been lessened with the use of an external speaker been used. Returning the transcripts to the informants also ensured transparency and accuracy in this present study. This can thus be seen as having strengthened both the validity and the reliability of this present study (Krumsvik, 2014).

It has been an aim of this present study to obtain in-depth knowledge, and not to produce generalizable results that can be transferred to a wide variety of contexts. Krumsvik (2014) describes transferability and is typically not feasible to obtain in qualitative studies, that often involve a non-representative, and small selection of participants (Krumsvik, 2014), such as this present study. However, results from qualitative studies may have relevance for broader theory. In this present study, the field of internet research was assessed by reviewing existing guidelines specific for IRE, and by consulting contemporary literature discussing IRE related issues. This was an important step towards producing results that may be relevant for broader theory.

That another study, utilizing similar methods, has shown similar results, can also be an indication of the validity of a study (Krumsvik, 2014). In this present study, a systematic search for previous research was conducted, to identify potential gaps in previous research. One study was identified, through searches in various databases that mirrored the methods of this present study, and that also shared a similar scope and aim (Warfield et al., 2019).

3.6. Thematic analysis

When analyzing the data in this project, a six-step procedure, as described by Braun & Clarke (2006) was applied. The proposed six-step process is noted as not described as rules, but rather as guidelines that can be used in an iterative process of analysis (Braun & Clarke, 2006, p. 86).

Braun& Clarke (2006) argues that this method should be viewed as a foundational method of analysis within qualitative research (2006, p.78), on the basis of its benefits of being a flexible and nuanced method, as noted by Holloway & Todres (2003) (cited in Braun & Clarke, 2006, p.78).

Thematic analysis is a method that can be used both to describe and to interpretate data, in conjunction with relevant theory, and the method can be used across a wide range of theoretical foundations (Braun & Clarke, 2006, p. 78). Thematic analysis is a well-suited route to take in order to get a hold of the experiences, viewpoints, values and knowledge in the possession of people made subject to research (Caulfield, 2019).

In this thesis, the informant's various personal experiences with navigating the landscape of IRE, including the use of ethics resources, was the starting point for the analysis of data, and it has been important to further explore emerging themes that appear in analyzation and interpretation of the data.

3.6.1. The six-step process

An inductive approach to the data was taken, meaning that the data formed the basis for the themes, instead of the data being approached with a set of preconceived ideas (Braun & Clarke, 2006, p. 89). The themes that were formed during the analysis of data, can be seen as having been formed through a negotiation between the author of this thesis, theoretical background, and the data itself: The themes were developed bottom-up, meaning firmly grounded in empirical data, while still being informed by previous research in the field.

4.3.2. Conducting the analysis

The six-step process is illustrated in Figure 3:

Step 1	• Transcription. • Immersion in the data.
Step 2	• Assigning codes to excerpts.
Step 3	• Assigning themes.
Step 4	• Revising themes.
Step 5	• Further definition of themes.
Step 6	• Writing up the analysis.

Figure 3. This figure illustrates the six-step process of thematic analysis, as described by Braun & Clarke (2006).

Step 1

In the first step of the six-step analysis process, the aim is that the researcher gets familiarized with the data. This means getting immersed in the data, which in this case were transcripts from the three interviews that were conducted. Initial ideas for codes and themes were formed while transcribing the interview, which were transcribed in a close to orthographic manner. The aim was to represent what had been said by the informants in a way that conveyed the content of meaning sufficiently. During the process of transcribing the interviews, the audio files were revisited several times, to ensure the transcripts came out as accurately as possible. This process was a lengthy process, especially considering the informants spoke in three different languages, but it was a good way of getting to "know" the data at hand. According to Braun& Clarke (2006, p. 87–88), transcripts should be adequate and verbatim representation of the audio. Non-spoken utterances can also be included where relevant. It is also noted that the process of transcription is a good first step in getting familiar with the material. When finished, the transcripts were read, then re-read, as it is recommended by Braun &Clarke (2006, p. 87) to read through the material at least once.

Step 2

The interview- data was considered as whole, while acknowledging the differences between the individual transcripts. The process of applying initial codes, step 2 in the process began with the first transcript being considered individually, and preliminary codes were assigned to excerpts that might be of interest (Braun & Clarke, 2006). There are many ways one can code data, either manually or by using software (Braun & Clarke, 2006, p. 89). In this project a manual approach was taken.

Codes identified in the first transcript were then again applied to excerpts in the second transcript, following into the third transcript. New codes appeared in each transcript. These new codes were then applied to excerpt in the other transcripts. Codes appeared both within individual transcripts, as well as across the data: in thematic analysis the researcher seeks to identify patterns across data, instead of within individual transcripts (Braun & Clarke, 2006, p. 81). The identified codes were then revised. Revising the codes involved checking that the data included in the codes were fitting with the code, and were sufficiently supporting the code (Caulfield, 2019). The transcripts were then read again to make sure that all relevant data was accounted for, and all excerpts were assigned fitting codes (Braun & Clarke, 2006, p. 89). It is important to pay attention to every finding equally, when assigning initial codes, to not miss potential themes in the data that may be of interest (Braun & Clarke, 2006, p. 89)

It was important to keep some of the contextual data in the excerpts assigned to the data where relevant, to avoid the pitfall of rendering the data too narrow (Bryman, 2001, cited in Braun & Clarke, 2006, p. 89).

Step 3

After initial coding came the process of assigning theming to the data. This is the third step in Braun& Clarkes six-step process (Braun & Clarke, 2006). Generating themes from the data meant that codes that were relevant to each other were collated together into themes and subthemes (Braun & Clarke, 2006, p. 89). In this process, some codes were discarded because they did not have enough support in the material, while others were kept as themes (Braun & Clarke, 2006, p. 89).

Step 4

The process continued in step 4 of the analysis- process, with revising the themes (Braun & Clarke, 2006)**.** The aim here is to make sure that the data adequately supports the themes, and that the themes were in fact central in the data (Braun & Clarke, 2006, p. 91). This is a two-level process, and at the first level, coded extracts were checked to see if they fit the themes coherently. (Braun & Clarke, 2006, p. 91). At the second level it was checked if the themes fit with the overall meaning conveyed in the data (Braun & Clarke, 2006, p. 91). In this process several themes were discarded, while others were combined.

Step 5

In step 5, the themes were assigned names, and further defined (Braun & Clarke, 2006, p. 92).). In this step, each theme was considered and scrutinized to find the essential meaning, and it was made sure that the themes had separate, though related "identities". A part of this step is deciding whether themes within themes are present (Braun & Clarke, 2006, p. 92), and in this data set, subthemes were mainly kept as belonging within the 2 resulting themes. Figure 4 illustrates how a final thematic map can look like, after going through the different steps of the analysis. The final results are here categorized into themes and subthemes.

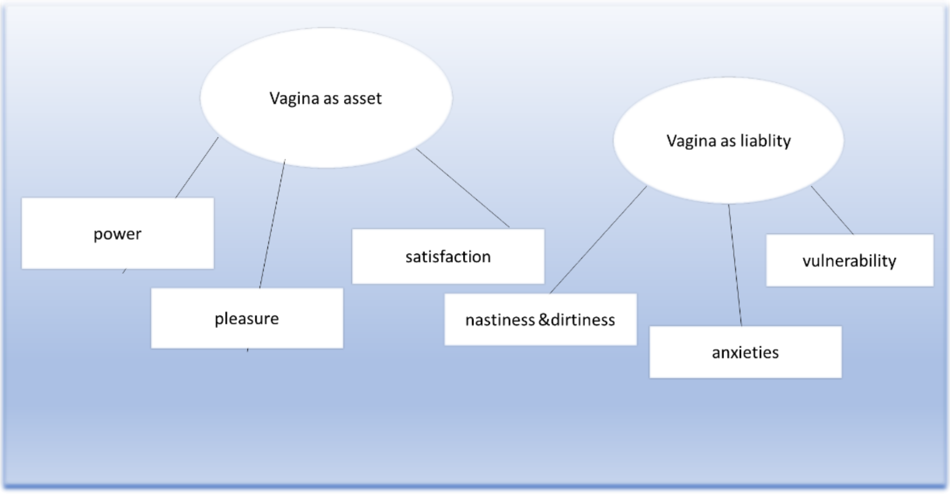

Figure 4. A reconstruction of the final thematic map originally presented by Braun & Clarke (2006, p. 91).

Step 6

The 6th step in the process is writing up the analysis (Braun & Clarke, 2006, p. 92), and the writing up process in this thesis consisted of writing out the results, as well as the discussion of these results. The aim was to present the storyline of the data in a coherent way, and to illustrate this with quotations from the data (Braun & Clarke, 2006, p. 92). The theory chapter was written in conjunction with writing the analysis, and the process of analyzing the data consisted of fluctuations between the different stages of analysis. Notes were written whenever thoughts and ideas came to mind and getting familiarized with the data was an ongoing event. Codes and themes were assigned and reevaluated throughout the whole process.

Chapter 4 - Presentation of results

In this chapter, informants will be introduced, and key results from the interviews and the thematic analysis will be presented. Three informants were interviewed for this present study. The researchers had conducted research involving illness communication used as data, within various social media sites (forums, blogs and Instagram). Key themes resulting from the interviews were ethical challenges encountered in the research process, and utilization of ethics resources.

4.1. Introduction to results

The results presented in this chapter are based on two key themes discovered through thematic analysis. The first overarching theme is challenges related to the researchers' negotiation of encountered research ethical challenges ('encountered challenges'). The other main theme relates to the utilization of resources for making ethical decisions in internet research ('resources').

These themes correspond with the interim goals of this thesis, that is

A) Map how internet specific challenges related to internet research ethics are negotiated by the researchers, when employing textual communication about illness obtained from social media sites as data, and **B)** Map the researchers' experiences with, and perspectives on, guidelines for internet research ethics. Not included in the results, although discussed by informants, is **1)** variations in ethical requirements for researchers and e.g., journalists when disseminating potentially sensitive information obtained from social media, and **2)** the benefits related to being an "insider" of a social media community when conducting research. These themes are discarded, as they are not directly related to the research aims and the research question.

The themes were formed with a foundation of related codes discovered during the process of thematically analyzing the interview material. No predetermined set of codes were applied, neither was any theory chosen beforehand: the data was approached in a bottom-up and inductive manner. This lets the data, to a greater degree, decide what is important, and thus better reflects what came out as important themes from the interviews, and not from a predetermined theory. A simplified chart of key content of themes is presented below. This simplified chart presents key content of the two main identified themes from the three individual interviews, providing an oversight of key results.

Table 1. A simplified presentation of the key elements of the results.

	Forum-researcher	**Instagram-researcher**	**Blog-researcher**
Considerations of publicness and privateness & user expectation of privacy	Considered user expectations an important factor in determining the publicness of data. Involved users of forums (patients) in deciding about boundaries. Forum owners were contacted: they confirmed the publicness of the site: the researcher nevertheless adopted a strategy of being cautious.	Considered user expectations an important factor in determining the publicness of data. Referred to visualizing used publicness and privateness as two ends of a continuum as a tool for ethical decision-making. Expressed challenges related to balancing sensitive and personal communication with the publicness of the account under study.	Considered user expectations an important factor in determining the publicness of data. Expressed challenges related to balancing sensitive and personal communication with the publicness of the account under study.
Main resources for ethical decision making in IRE	Discussion, peer literature, colleagues, (patients/ users of fora), and co-researchers.	Guidelines from the Association of Internet Researchers, various texts including peer literature, anthologies, and other texts.	Guidelines on IRE by NESH, research groups, senior researchers, colleagues, and peer literature.

Main challenges identified with resources/ guidelines	Disparity in use of criteria for ethical decision-making in existing peer literature, little knowledge in the researcher's field about IRE. A lack of clarity and consensus. Makes a call for standardization of guidelines, as well as for specific advice on how to approach salient issues in IRE.	Little advice in guidelines on how to handle sensitive material (apart from the legal aspects). Not enough knowledge and discussion about IRE. Calls for guidelines and discussions more relevant for the field of study and the topic (human sciences/ linguistics and illness narratives), outside of legalities and general principles. Lack of advice on how to manage the inclusion of sensitive topics and people in vulnerable situations in internet research.	Would have appreciated more knowledge in deciding organs (for ethical approval) and place of work, as well as an overview of researchers carrying out similar research. Did not identify a great number of peer researchers carrying out similar research.

4.2. Introduction of informants

The blog-researcher

One researcher used the text in personal blogs as material for her research. These blogs can also be referred to as "weblogs", online sites where the authors can share their experiences and perspectives. In the blogs that this researcher had used as material, the authors wrote about their illness experiences. The blog writings were communicative, informal in style, episodic, and involved the sharing of personal narratives related to the variants of the disease. These diseases can be seen as "taboo" diseases and therefore difficult to talk about. This informant also had some experience with IRE, through her role as a lecturer, and her work with research ethics and privacy at the University where she works. For this researcher, at a time when the GDPR had just been implemented, getting ethical approval became a lengthy and somewhat frustrating process. Getting access to seemingly public was not as easy as first thought.

> På en måte så trodde jeg at det kanskje var litt enklere enn det var sånn i, i praksis, faktisk ...Fordi at det helt fra starten av var en tanke om at man skulle forske på data som var veldig åpent-tilgjengelig. (…) Jeg følte at jeg skulle liksom slippe litt unna det trodde jeg da. Fordi at jeg skulle bruke materiale som nettopp ligger veldig åpent-tilgjengelig, og veldig bevisst delt (…).
>
> In a way, I thought that it was perhaps a little easier than it was, like in practice, actually ... Because of that right from the start there was a thought that one was going to conduct research on data that was very openly available. (...) I felt that I was going to somehow get away from that, was what I thought at the time. Because I was going to use material that is very openly available, and very consciously shared (...).

Although the long process of getting ethical approval was an important consideration for the researcher, this topic will not be discussed in the discussion part of the thesis, as it falls outside the scope of this project. The topic is nevertheless included as part of the context and conditions for the researchers work with ethical decision-making. The blog-researcher also mentions how the material online can be time-consuming to find, and that there were challenges related to the temporariness of the material. The material could be there one day, and then the site could have been taken down the next day. Although these are interesting and relevant to IRE, these aspects also fall outside of the scope of this thesis.

The forum-researcher

This informant conducted research on forums where participants communicated with peers about having a common, under- researched and widely misunderstood disease. On the forums people exchange advice and experiences for support and validation purposes. She had her debut in research about 15 years ago, and thus has solid experience. Her first encounter with internet research was about six years ago. The reason for going online was to get a different perspective, or more specifically, a different insight on patient’s views and thoughts about their disease and received healthcare. The material gathered from online observation was thematically analyzed by the forum-researcher and co-researchers, with the aim of getting patient perspectives. The forum-researcher was active in the forums under investigation even before it was decided to do research on the forum/s. Observation based internet research presented an opportunity for providing information not necessarily found elsewhere: "(…) just because it was, it was, it seemed to be a different, ahh...not necessarily better, but a different way of obtaining data (…)".

The Instagram-researcher

This informant conducted research on an Instagram account "owned" by five informants. On this account, the users communicated openly about various experiences related to having a disease that is seen as under researched and talking about this disease involves elements of taboo. The aim of the account seemed to be informative and communicative: a place for followers and others to seek support and knowledge. This informant had experience with conducting internet research from previous academic achievements, a few years back in time, and had thus had already made some reflections on IRE.

4.3 Theme 1: Encountered challenges

This theme is about the ethical challenges that the social media researchers had encountered in the process of their research, and how these had been met and managed. Many of the challenges the researchers had met, were related to assessments of publicness and privateness of social media environments, which is a characteristic challenge of internet research. Hereunder, informed consent, assessing various contextual factors- including technology, user expectations of privacy and sensitivity/vulnerability were discussed. Included in the theme were also considerations related to privacy and confidentiality, and more specifically the potential risk of reidentification. Challenges related to confidentiality and privacy are another characteristic challenge in internet research ethics.

For the researchers interviewed for this present study, it was important that the social media-site and the data gathered from it was openly accessible. None of the researchers had considered conducting research on sites that were not openly accessible. However, it can be a challenging task for researchers to determine whether data that are seemingly public should be treated as such, as this depends on factors other than just accessibility. The blurring of boundaries between public and private means that the researchers have to assess a number of different factors, such as user expectations of privacy, the sensitivity of the topic, the amount of personal information that is shared, and more. In assessing publicness and privateness, the researchers used different parameters, and spoke about this implicitly as well as implicitly.

4.3.1. Parameters as a tool for assessing publicness and privateness

The Instagram-researcher was the one out of the three researchers that most explicitly spoke about using different parameters for determining the privateness or publicness of site/ data, than the other two researchers did. This researcher sees using parameters as a useful tool for ethical decision making in internet research that are complicated by unclear boundaries:

> Ett bra sätt att tänka kring det, att man kan ställa upp olika parametrar som säger att ja, men det här tyder på att det är...är ja, men mera öppet eller mer privat, och sen får man liksom göra olika etiska val efter det»
>
> A good way of thinking about it, is that you can set up different parameters that say that yes, yes this indicates that it is, well, more open or more private, and then you have to make different ethical choices according to that.

The researcher also finds that the boundaries in internet research do not seem as clear as the boundaries in offline research: “...ja, men det blir aktualiserat liksom andra gränsdragningar tycker jag... En i liksom offline där vi kanske har en bättre liksom..Ja-men, det här är privat, det här är inte privat”. "...Yes, but it actualizes other boundaries, I think.... Then in sort of offline where we might have a better sort of... Well, this is private, this is not private".

The researcher uses the visualization that publicness and privateness are two points on a continuum. Taking user expectations of privacy into consideration when determining which end of the continuum material belonged to, was important also for this researcher, and determining levels of publicness and privateness was a balancing act of different parameters.

> (…)sammanhang som som är liksom utifrån sett öppna... (…) det är inte säkert att användarna ser på dem på samma sett, så det måste man ju väga in... och där... Har jag i alla fall ofta tänkt att ja, men det är ganska bra att tänka på det som ett liksom kontinuum.
>
> (...) contexts that are sort of open seen from the outside... (...) it is not certain that the users look at them in the same way, so you have to take that into account... and there...I have often thought that, well, it is quite good to think of it as a kind of continuum.

4.3.2. User expectations of privacy

Users' expectations of privacy were an important consideration for all the researchers in determining the level of publicness or privateness that were to be assigned to the material.

Assessing factors such as instructions for use and declaration of purpose posted on the social media sites, intended audience and user's active participation and -sharing, as well as the desire to be cited, was part of the overall assessment.

The forum-researcher, who had collaborated with other researchers, had made various assessments of the publicness/ privateness of the forum. One of the parameters that were suggesting that the material on the forum was public, was that *the owners of the forum made it clear that the forum was in fact public*: "Yes, so we.. I wrote to the owners of the, so the *Illness Related*, to the owners of the forum and they clarified it was public. So anyone can access that data.". It was thus clear for the researchers that the site itself was public, and in that respect, that it was also unproblematic to conduct research on the site.

The forum researcher further highlights user expectations as an important parameter for assessing publicness and privateness, emphasized the importance of assessing expectations users might have had related to their privacy, when carrying out research on discussion forums:

> Expectations, I think, is a big one... and perceptions of the people on those, the perception might be actually... that it's private, even though officially it's public, so... I think you just have to be very careful and very open about it all. And you really consider the ethics... (…).

The users of the forums could have different expectations of what was private than the researcher did. This suggested that a level of privacy might be expected, even if the forum was open to everyone with a wish to access it.

For the blog-researcher, the instructions for use, posted on some of the blog sites, indicated that it was reasonable to expect that blog-authors would expect publicness. The instructions were recommendations for users to be careful when sharing. The instructions acted as a reminder of the public nature of the site: friends, family and strangers could openly access and read the blogs. The way users actively shared their narratives, and the personal control of the blog, were other factors pointing towards publicness for this researcher. Additionally, the blog-researcher found that many bloggers *wanted to be cited and referred to.*

> (…) og du har makt til å slette den, slette hva du vil, legge den ned. Mmm...så tenker jeg at det er på måte er mest..Ja, den er såpass, veldig...aktivt delt da- fra deres side… (…) Noen av disse bloggerne ønsker jo helst å bli sitert, eller delt.

> (...) and you have the power to delete it, delete what you want, shut it down. Mmm... so I think it's kind of most... Yes, it's so much, very... actively shared - on their part... (...) Some of these bloggers would prefer to be quoted or shared.

That the writers of many of these blogs wanted to be referenced explicitly, and for many of them this was also a source of income, was something that this researcher had given much thought.

The researcher's overall assessment was that the nature of the blogs was public- as they were openly accessible, and it was reasonable to expect that the bloggers were aware of this. Not only did the bloggers actively write and construct their own blogs, on one of the central platforms users were even reminded of the possible consequences of writing in a public digital space. These factors pointing towards publicness, were then balanced with other factors, such as the vulnerability of patients, and th**e** intended audience of the blogs, that typically do not include researchers, when including material in the research.

The Instagram-researcher points to certain parameters clearly indicating a public purpose of the account. A parameter clearly suggesting publicness of the material, was the informative and "activist" purpose of the studied Instagram account. This had been stated explicitly in 'bionotes', a feature of Instagram accounts, where users can write about themselves and the purpose of the account. This strongly indicated that writing publicly had been a *deliberate decision* by the users of the account. This was not something that was meant to be locked up in privacy. At the same time, the informant balances the clearly outward- directedness of the account with the amount and type ofPERSONAL IDENTIFIABLE INFORMATIONthat the users of the Instagram- account revealed.

> (…) så det finns ju en sånn liksom... «Nu ska vi berätta för er». Det finns en sådan kunskapsbyggande liksom ambition med kontot och dom berättar ju liksom öppet för en ganska stor publik i meningen att dom ska synas. (…)

The Instagram-researcher also reflects on the fact that the audience of an open Instagram account may or may not be familiar followers, and thus it should be expected that followers and non-followers alike will be able to view the contents of the account, further indicating publicness.

The blog-researcher notes that, although there were many parameters that suggested publicness of the blogs, the blogs were not written with the purpose of being researched. In other words, researchers were not an intended audience for the people that had been authoring these personal blogs. *This suggested to the researcher that the publicness had boundaries*. Disclosure of personal and sensitive information also indicated to the researcher that, even if the blogs were essentially open for everyone to access, there were certain factors that indicated a level of privateness. The researcher kept this in mind when reflecting on how to represent the participants, and she expressed utmost respect for what had been shared in the blogs.

For the Instagram-researcher, the deliberate decision of the Instagram-users to write actively outwardly, in a sort of "activist" manner, was balanced with the amount and type of personal identifiable information that the users of the Instagram- account revealed:

> (…) Och så, så det tänker jag att liksom måste ställas mot att man samtidigt berättar väldigt mycket om sig själva. Att dom deltar väldigt mycket som, liksom, individer...
>
> (...) so there is sort of a kind of... "Now we are going to tell you". There's a kind of knowledge-building ambition with the account, and they talk openly to a fairly large audience with the intention that they shall be visible. (...) And so, I think that has to be set up against the fact that they tell a lot about themselves at the same time. That they participate very much as, kind of, individuals ...

This researcher also points out that users have a *choice* in setting their Instagram account to either public or private: "Ja-men...Att det är...ett offentligt konto på Instagram...så har man möjligheten att välja privat konto.. Att det finns ett sådant liksom alternativ gör ju att man i alla fall tänker sig att de som har ett konto har vald antingen privat eller offentlig."

"Yes, but...The fact that it is...a public account on Instagram...and you have the opportunity to choose a private account... The fact that there is an option like that means that you at least think to yourself that those who have an account have chosen either private or public."

4.3.3. Ethical strategies: erring on the side of caution, and involving participants in ethical decisions

The forum-researcher had employed an overall strategy of erring on the side of caution as a way of ensuring that the research was ethically sound. The forum-researcher had also employed another strategy of involving participants in decisions about their own data, as the only one out of the three researchers.

The forum-researcher mentioned repeatedly throughout the interview that it was important for her to stay on the cautious side when it came to making ethical decisions, when carrying out the research. This was a strategy that she had used in response to different factors, such as the novelty of the research, and a lack of resources, such as specific advice or relevant peer literature.

> (…) normally when you do a study... The ethics is agreed, It's all very clear cut. You know, like you've done today, you gotta get the consent. You've gotta do things with the data. It's all fairly obvious…But with this... We just kept looking at it very regularly and having meetings just checking that we weren't crossing any ethical boundary, even though there are none, because there are no boundaries (…)

The researcher's overarching strategy, to stay cautious, helped ensure that no vital boundaries were crossed, even if it seemed to be no boundaries. The participants in the forum that this researcher was interested in, was found to be positive towards be included in research, and participants were actually consulted as a part of this research, and together the researchers and participants negotiated what was acceptable boundaries:

> (…) and then it was just talking to a lot of patients about how they would feel about it, whether they supported it and actually this patient group really wants research. They're very research- friendly so. They were, they were invariably very supportive, so different from my last job that was *----*.

4.3.4. Informed consent and verbatim quotations

Searchability of research material presents a challenge in internet research, that is not found in the offline counterpart. When researchers include verbatim quotations from users on social media in research, it comes with the risk of potentially reidentifying the informants via online searches, which can possibly cause harm to the informant. At the same time, using verbatim quotations in presentation of research is seen as an important aspect of adequately and transparently representing data in many research fields.

All the researchers interviewed for this present study had obtained informed consent from the participants that would be quoted in their research. As a natural consequence of balancing various factors, where notions of sensitivity and revealing of sensitive personal information heavily weighed in, made this an easy choice for all researchers, and stood out as somethings that was the right thing to do.

One of the researchers, the blog-researcher, had to exclude participants that had written under pseudonyms, as it was regarded as potentially intrusive to contact authors that had written under a pseudonym. This had been decided in the process of obtaining ethical approval. The forum-researcher, on the other hand, indicated that the use of pseudonyms was an extra protection layer of participants.

The responsibility related to conducting research involving people struggling with ill health can sit heavily on the shoulders of a researcher. The weight of responsibility is also not made any less heavy by complex contexts and unclear boundaries. This was no less true for the blog-researcher, who had felt this load of responsibility on her shoulders, and used **quotations** with care and respect:

> Jeg har veldig respekt for..det jeg deler, -når jeg siterer det for eksempel. Og jeg føler jo at. Jeg føler jo et ekstra...jeg føler absolutt et ekstra liksom ansvar... Ja. Som... Et personlig ansvar kanskje innimellom, fordi jeg ikke vet, ikke sant, de slutter jo å skrive, så vet du ikke hvorfor for eksempel de slutter å skrive.. -Er det fordi de har fått det bedre, eller fordi de har fått det dårligere? Sant... -og det vet jeg jo ikke, så det er klart at det... det det har jeg tenkt på mange ganger.
>
> I have a lot of respect for... what I share - when I quote it, for example. And I feel that. I feel an extra...I definitely feel an extra sort of responsibility... Yes. Like... A personal responsibility maybe sometimes, because I don't know, right, they do stop writing, so you don't know why, for example, they stop writing. -Is it because they've gotten better, or because they've gotten worse? You know... -and I can't know that, so of course... That’s something I've thought about that many times.

This researcher conducted research on the most acutely ill of the three researchers and was attentive to respectfully represent her informants throughout the study. Informed consent was obtained for everyone that was quoted, as part of what had been decided in the process of ethical approval for the study. The blog-researcher decided that she would not obtain informed consent from informants that had written under a pseudonym. It was decided that seeking to obtain informed consent from these writers could be intrusive, as the use of pseudonyms in this particular context indicated a desire to remain anonymous. Material from pseudonymous informants was included as part of a more general analysis.

A main ethical challenge for the forum-researcher was the use of direct quotation Even if the forum was deemed openly available to all, searches via online search- engines can make it possible to search for, and trace back to principally anonymized informants and possibly reidentifying them. The users of the forums had used pseudonyms, which for this researcher made it an easier decision to use direct quotations, than had real names been used.

> The ethical consideration with that is if I directly quoted somebody in the paper, somebody could type that into Google and then that would take them into the forum, and they could **possibly*** identify the patient. But because it was pseudonyms, we decided to still use the exact quotations. And because anyone can get onto the forum anyway (…).

(*When speaking, the researcher seemed to stress the word ‘possibly’, something that seem to indicate that this was a possibility, albeit not something that was certain)

For the sake of accurately representing the patients, the researcher preferred to quote verbatim. Official permission was obtained for each quote, while the rest of the material was included in a general analysis. Users of forums that she quoted directly were contacted individually for obtaining informed consent. The researcher did not want to abuse the trust of the patients on the forum: “(…) I always like to quote verbatim, so we had an agreement that the administrator would write to each person who I wanted to quote. And say what is this...And...and get official permission for each quote. The rest of it was just done as a general analysis.”

A possible harm of people feeling an abuse of trust, if finding out in hindsight that they had been researched, is mentioned by the informant. This was one of the reasons behind being diligent with contacting informants that would be quoted in the final article, even if it was found to be unclear what could be considered either public or private.

> So, people think they're talking privately and then suddenly it gets published in the paper and they feel...An abuse of trust... So that's why we made sure anyone we were quoting...-We went to them and said: can...can we quote you? But yeah, I think the whole public private divide is a very dodgy line at the moment isn't it...you can't always tell.

At the time of obtaining informed consent, the Instagram-researcher clarified what the study would cover, and what this would entail for the participants. In the presentation of results, all identifiable names were excluded as part of anonymization of the participants. This researcher also points out that data can be traced back to individuals via searches. This was another challenge (in addition to the unclear boundaries between public and private) that separates internet research ethics from its offline counterpart. The researcher specifically relates the searchability to the use of direct quotations. For this researcher, interested in language and meaning, it was relevant that the material, including quotations, was sufficiently presented to the reader. Using quotations had to be balanced against not revealing too much about the users, and the need to avoid harm:

> (…) När det gäller det här Insta kontot så behöver jag ju ge liksom en en tillräckligt rättvisande bild för att man ska förstå vad det är för typ av konto utan att förstå exakt vilket konto det är...hur många konto kan det finnas ...alltså? Man har ju liksom den här **sökbarheten*** och att det är liksom. Öppet tillgängligt och det sättet, det.. Blir ju någonting att förhålla sig till.
>
> (...) When it comes to this Insta account, I need to give a sufficiently accurate picture so that one can understand what type of account it is without understanding exactly what account it is, how many accounts may there be ... well? You have this **searchability*** and that it’s like. Openly available and the way it ... becomes something to relate to.

*In the interview, the informant stresses the word ‘searchability’, which can seem to indicate that it was an important consideration

4.3.5. Benefits of social media research

Using openly existing material comes with both challenges as well as benefits, and even if it the research itself was challenging, the data collection time-consuming, and complex ethical considerations, as well as formalities, added extra layers of complexity, the blog-researcher emphasized the benefits of online observation:

> Og det nettopp fordi, da vet du...du kan på en måte med hånden på hjertet si at...jeg har ikke påvirket det her datamaterialet i det hele tatt...Det er klart at når jeg måtte be om samtykker, så kunne man jo kanskje si at de jeg ba om samtykke fra..kan jo endre måten de skriver på etterpå? Det de skriver i bloggene sine etterpå, for nå vet de at de blir observert. Men for det meste så har jeg jo brukt data som var.. som var..som lå der allerede.
>
> And that's precisely because, then you know... you can sort of say with your hand on your heart that... I haven't influenced this data material at all... Of course, when I had to

> ask for consents, you could perhaps say that the people I asked for consent from... can change the way they write afterwards? What they write in their blogs afterwards, because now they know they are being observed. But mostly I have used data that was... that was... that was out there already there.

4.4. Theme 2: Resources

The second theme includes the researcher-informants use of, and reflections on, different available resources for ethical reflection and decision-making. What is not included in the theme, are reflections that were more related to formalities and legalities. Related to this, a paradox was also mentioned by two of the informants, that could have been interesting to include, if the aims of the thesis had been different: the researchers noticed that many of the patients were writing very openly about sensitive matters, but this did not seem to be regarded as sensitive to them, and many users wanted to be cited and referred to, but it was not permitted for the researchers to cite them directly in their articles. Thus, the theme excludes some topics that were of importance to the informants.

The informants were found to use a range of resources for IRE. Some resources, such as discussion, consulting peer literature and colleagues were used by all three informants, while two informants used specific guidelines for IRE: the blog-researcher used the NESH (2019) guidelines, and the Instagram-researcher used guidelines by the AoIR.

4.4.1. A lack of ethics resources

When the forum-researcher was asked about her thoughts on making ethical decisions in internet research versus in offline research, the answer was that it was different with the ethics in internet research. A main concern for this informant was the lack of advice, and when consulting peer literature, a plethora of differing approaches to ethics was found:

> I think it's different with the ethics because. A) it's a new area, so there's not much advice. I did look before we did this and try and get ethical advice and even our ethical approvals committee. You're the first person who's asked this, so I looked at other papers and everyone seemed to do it in different ways.

The informant in this case did not have much readily available in terms of advice for ethical decision making and, as a direct consequence of this, decided to stay on the *cautious side*.

> I did a literature review and found different people used different methods... And yeah, our Ethics Committee didn't really have any advice when I first went to them, so I just sort of wrote our plan out and because we went on the cautious side, I think everything was OK.

The blog-researcher used discussions with senior researchers, other colleagues and literature, as well as drawing on her own knowledge of and experience with research ethics, as important resources. The informant had also used the NESH guidelines for IRE as a resource at the beginning of the project. It was found that this was a helpful resource, one that she had also used in her lectures. The informant did not use other guidelines except guidelines by NESH, and these were mostly used the first year.

Talking to senior-researchers and using research/ project groups were two important resources for ethical decision making and -reflection. When the researcher felt unsure about ethical matters, these resources were often consulted. Having people to go to for ethical advice and discussion was important for the blog-researcher, either formally or informally, such as stopping by the office next door, or attending meetings. The researcher also used peer literature as a resource for ethical reflection and -decision making: the researcher felt that she was *alone* in much of the ethical decision making, and consulting peer literature was a means of filling this void: peer literature also proved valuable for the researcher in handling sensitivity and vulnerability. A catch was that not much directly relevant literature was available.

> Fordi at jeg var jo litt alene her om å drive med akkurat dette. Ja, det er jo ingen på avdelingen her som hadde drevet med internettforskning fra før. Det var egentlig.. jeg var jo ganske mye alene. Det vil jeg jo si... og så brukte jeg selvfølgelig disse retningslinjene fra NESH også...Ja, men disse kjente jeg jo til fra før...så de de brukte jeg jo aktivt i de første månedene av.... (…) Ja...for å forberede godkjenningen min og sånn så.

> Because I was quite alone here in doing this. Yes, there's no one in this department who had done internet research before. It was actually... I was pretty much alone. I would have to say... and then of course I used these guidelines from NESH too... Yes, but I knew about these from before...so I used them actively in the first months of... (...) Yes...to prepare my approval and such, so.

When being asked what could have been different concerning IRE in her specific field, the informant highlights that while the general research ethics- resources at the university where she works are good, there is a lack in resources on IRE specifically. The researcher thus found herself feeling alone in making complex ethical decisions in her project. This researcher would gladly have seen more competence about IRE in the different organizations she had been in contact with, so that the process could have been shorter and smoother. She also would have wanted a person to turn to for advice on specific IRE questions, or an oversight of people conducting the same type of research, facing similar ethical issues. The researcher points out that this would have been especially of help in the starting phase of the project.

4.4.2. Benefits and drawbacks of having to make predefined ethical decisions

For the blog-researcher, one of the challenges was having to make *predefined decisions* when in the process of getting the project ethically approved:

for hvis du er opptatt av informasjonen uten individene.. altså, ja helt anonymisert informasjon, for eksempel, så er det jo ikke så... det var liksom de der...de der overgangene der, altså som sagt gjorde det vanskelig for meg også **-før***du er i gang med materialet ditt, å ta stilling til da..

because if you are concerned with the information apart from the individuals... well, yes, completely anonymized information, for an example, then it is not so... it was kind of those...those transitions there, as I said, made it difficult for me also – **before*** you start with your material, to take a position on, right...

*Here it seemed that the informant put emphasis on the word ‘before’, as to accentuate that it was difficult to anticipate ethical challenges, before the project had started

The informant also refers to this in another comment: “Så er det jo nettopp å ha en litt åpen holdning til...Hva skjer her? Det er jo veldig vanskelig å skulle predefinere hva du skal finne i materialet ditt når du skal ha en åpen holdning til hva du ikke vet hva du finner”.

> "So it's just to have a somewhat open attitude towards... What's going on here? It's very difficult to predefine what you're going to find in your material when you have to have an open attitude towards what you don't know you're going to find."

Despite challenges at the start of the project, for the blog-researcher, the lengthy and at times frustrating process turned out to be an asset when continuing the project. In the process, useful and specific working- frames had been set in place:

> ehh...i tillegg til at jeg har jo på en måte, nettopp fordi jeg måtte gå gjennom den prosessen, så.. i så lang og grundig...grundig runde i starten, så har jeg jo på en måte en

> ganske grei ramme da, for det hva jeg skal gjøre til forskjell fra kanskje mange andre.. så har jo jeg det enda mer konkretisert.ehh...in addition to the fact that I in a way have, precisely because I had to go through that process, so... in such a long and thorough...thorough round in the beginning, I in a way have a pretty good framework for what I should do, unlike perhaps many others... I have it even more concretized.

Thus, even if predefining ethical challenges had been difficult, it nonetheless provided the researcher with a beneficial ethical framework to work within.

4.4.3. Involving forum users in ethical decision-making

The forum-researcher employed a strategy of involving forum-users in her ethical decision-making. Users were consulted by the researchers regarding setting up boundaries for the use of their data in the research. Communication with various charities was also a resource for this researcher, as they had good knowledge about the patient group. Consulting peer literature was a step towards getting an overview of how things could and had been done. As the forum-researcher had mentioned earlier, the disparity of approached made it difficult to have any real role model, so bits and pieces that could fit the research were selected:

> (…) so some of the things I would make sure I did anyway- as a matter of research ethics I did, but then obviously there was some with that like you said, the blurring of boundaries and ah... transferring it online, I did then have to look at other people’s online research and think...but they were all so different, everybody used different criteria at that time, so I just picked the bits that I thought actually suited our study and were ethically cautious.

4.4.4. A call for clear, specific and relevant ethics guidelines

When asked if something could have been different, to ease the work with making ethical decisions in internet research, a wish for more clarity is expressed: “(…) It'd be useful to have a sort of standard checklist that you go through that you considered for it, because I Think it is…It could be quite standardized.” The researcher thinks that the ethics of this kind of social media research could be more standardized, like in a sort of checklist.

At the same time, a need for flexibility is expressed, and it is emphasized that each case of research will be different, but that having more specific advice would nevertheless be helpful: “Each researcher has got to have the flexibility and each research group, and each patient-group is going to be different, so yeah... I think it's coordinating all of that with some sort of specific advice, is also useful". From the perspective of this informant, the ethics shouldn't be completely rule based, but rules should exist, to avoid potential harms from occurring:

> Ahh...I think... It's useful to have that, but not to have to ...To have them as guidelines rather than rules. But to probably have a few rules within that, and then everything else can be adapted as long as everybody is ethically aware, because you could have some people going into it without* ethics approval and then ruining it, -not just for the patients in that group, but for the researchers in the future.

The Instagram-researcher, when assessing these specific challenges for IRE surrounding what is public and what is private, consulted guidelines for internet research ethics by the Association of Internet Researchers**,** as well as read various texts about the topic. The researcher also specifically consulted research situated within the same demographic context and compared her project's ethical challenges with the ones found in these. The Insta-researcher would like to see more discussion on IRE. The researcher also makes a call for building more real knowledge on IRE- matters, although she has noticed a positive change from when she started this project.

> När jag påbörjade det här så var det väl liksom lite osäkert, men vad, vad.. hur ska man tänka? Och det var ju då därför jag liksom började titta, ja, men hur har andra tänkt? Kan jag tänka så liksom?- För att på något sätt bygga en en grund att stå på
>
> When I started this, it was a bit uncertain, but what, what... how should one think? And that's why I started to look, yes, but how have others thought? Can I think like that? - To somehow build a foundation to stand on.

The Instagram-researcher also emphasizes the importance of guidelines that are *relevant to* the specific field of research she belongs to. The informant also points out that much of discussion on ethics in general is related to the natural sciences and is not directly transferrable to the human sciences and linguistic studies:

> Jag kan tycka det är väldigt mycket av de etiska diskussionerna ofta handlar, eller dom handlar liksom om naturvetenskaplig forskning ofta.(…) Det är inte aktuella frågor att ta ställning till om jag har en biobank eller om jag gör djurförsök
>
> I can think that a lot of the ethical discussions are often about, or they are sort of about natural science research. (...) It is not relevant questions to take a position on whether I

> have a biobank or whether I do animal experiments. Apart from general ethical guidelines and the law, this researcher sees the need for having resources more specific to different fields of study, including internet research.
>
> Men en del av de överväganden som vi gör som forskare s ser u väldigt olika ut beroende på i vilket **fält*** vi är. Vad innebär det att behandla, liksom personuppgifter och känsliga personuppgifter liksom ha vad ingår i att behandla dem? Alltså hur..Hur ska vi hantera dem?
>
> But some of the considerations we make as researchers look very different depending on which **field*** we are in. What does it mean to process, like personal data and sensitive personal data, and what is involved in processing them? So how... How should we handle them?

*When speaking, the informant emphasizes the word ‘field’, and in relation to the context, this may indicate that she thinks that general ethical advice is not adequately covering ethical challenges in her field of research.

When being asked what more ideal guidelines for IRE would look like, the researcher is at first not sure, and needs a moment to reflect on the question. The researcher acknowledges that a set of guidelines that cater to a very wide range of fields might not be feasible. The informant nevertheless mentions that more clarity in advice on how to approach and solve sometimes sticky ethical matters online would likely be welcomed by most researchers, and does echo the call for more clarity made by the forum-researcher:

> Det är klart att, jag tror att de flesta forskare skulle nog vilja ha något mer handfast och liksom peka på, att jag gör så här. Och det hade säkert varit bra om man etablerar...ja-. Men en mer sånn... "så gör man så här gör man inte”. (…) Det kan vara svårt att få ihop det, men jag tror att de flesta skulle vilja ha en tydligare svar, att: kan jag göra så här? Borde jag göra så här? Och det tror jag att alla hade uppskattat.
>
> Of course, I think that most researchers would probably want something more tangible and sort of point out, that I do this. And it would certainly be good to establish...yes-. But a more like... "you do it this way, and not that way”. (...) It can be difficult to get that together, but I think most people would like a clearer answer, that: can I do this? Should do this? And I think everyone would have appreciated that.

This researcher also emphasized the importance of a case by case and flexible approach, and even if clearer guidelines would be appreciated, this does not mean that strict rules for IRE would be of benefit:

> Det är ju positivt att ha något att hålla i handen som någon typ av riktlinje, men ibland, eftersom alla olika digitala sammanhang har olika förutsättningar.. Jag tror att det ofta kommer krävas väldigt specifika överväganden när man dels tittar på olika faktorer, att det blir lite mer case-by-case, snarare än att du ska alltid göra så här. Det är väl något man kommer behöva fortsätta hantera även om man utvecklar tydligare riktlinjer för hur man ska hantera materialet
>
> It is positive to have something to hold in your hand as some kind of guideline, but sometimes, because all different digital contexts have different conditions... I think that very specific considerations will often be required when one in part is looking at different factors, that it will be a little more case-by-case, rather than that you should always do it this way. This is probably something one will have to continue to deal with even if clearer guidelines for how to handle the material are developed.

4.4.5. A gap in ethics resources on how to approach sensitivity and vulnerability in internet research

When considering how to approach sensitive topics, the Instagram-researcher did not find much advice in the available resources, outside of the frameworks of the law on handling sensitive PI. When it came to managing sensitive information not directly related to legalities, the researcher found support in peer- literature from the demographic context which she conducted research within**:**

> Ja, det finns ju inte riktigt med just det här, liksom att den typ av sårbarheten hos gruppen och liksom att det är känsligt...Det finns ju inte med alla dom här, liksom guiderna och riktlinjer riktigt...ehh..så där tog jag väl mer stöd i...tidigare,liksom, forskning i en *-* kontext och ett liknande material.. hur det hade hanterats..Så att när det handlade om.. Någonting som...inte bara i sjukdomen, liksom någonting som faller inom ramen för det som, enligt lagen klassas som känsliga personuppgifter.
>
> Well, it's not really included this, like that the type of vulnerability of the group and sort of that it's sensitive...It's not included in all these, sort of like guides and guidelines really...ehh...so there I sought more support in...earlier, like, research in a *-* context,

> and a similar material...how it had been handled..So that, when it was about.. Something that...not only in the disease, like something that falls within the frame of what, according to the law is classified as sensitive personal data.

While the Instagram-researcher mentioned that she had utilized the guidelines on internet research ethics by the AoIR as a resource in her ethical reflection (Markham & Buchanan, 2012), she did not mention this document as resources from which she had found advice on approaching notions of vulnerability and sensitivity.

Chapter 5 - Discussion

In this chapter, prominent results of the study are discussed in light of relevant literature. Previous research has also been included in the discussion, in order to compare the results of this present study with those of previous research.

The researchers that were interviewed for the present study had assessed and managed various challenges related to the context of their research. The main challenges that were of concern for the researchers, are also challenges that differ from challenges in offline research. These challenges included defining boundaries between what is public and private on social media sites, assessing user expectations of privacy, and the use of verbatim quotations. Notions of vulnerability and sensitivity were intertwined with these considerations and added layers of complexity. The informants had identified and managed many of the same challenges, negotiated by the informants in differing and overlapping ways by the individual researchers. The informants had used a range of ethics resources when approaching these challenges. Nevertheless, the informants conveyed feelings of being alone, a lack of available and relevant resources, as well as inconsistency in contemporary literature.

The results that stemmed from interviewing researchers, and from thematic analysis, have been influenced by the role of the interviewer. In preparing for the interviews, guidelines and theory related to internet research ethics were consulted. This laid some premises for the types of questions that were asked, which in part were directly related to resources and guidelines for internet research ethics. Additionally, follow-up questions regarding certain answers could have been asked by the interviewer, in order clarify answers, and gain additional insights. Additionally, it is important to recognize that multiple realities exist, and the results of this present study are but one snippet of that multiplicity.

Some, if not all, ethical challenges encountered in internet research are internet research specific. Moreover, the searchability of data online makes ethical challenges in internet research differ, and **c**ertain challenges related to privacy and protection of data are also different in internet research, compared to offline research (NESH, 2019).

5.1. Theme 1: Encountered challenges

The informants of this present study had faced a variety of IRE challenges in their research, and in this section, the results pertaining to the theme 'encountered challenges' is discussed.

5.1.1. Uncertainty pertaining to open accessible data: public or not?

The guidelines on IRE by NESH (2019) highlight that “Ethical considerations in Internet research may be complex as well as counterintuitive” (NESH, 2019, p.7). That internet research is complex and can escape intuition is also confirmed by the researchers interviewed for this present study: at first sight one may think that communication on a site or platform is public, and that users should expect this, while at second glance one may come to contest this initial assumption.

Many challenges in internet research are tied up to a blurring of boundaries, where it is not necessarily clear what is public, and what is private. Various factors need to be balanced by researchers in order to make appropriate distinctions between what is public and private.

All of the researchers that were interviewed for this present study had assessed and balanced various factors in order to assess what could be regarded as public, and what could be regarded as private within their respective research contexts. It was implied, as well as explicitly expressed by the informants that this had been a challenging balancing act. One researcher, the forum-researcher, mentioned that, in internet research, “there are no boundaries”, and another, the Instagram-researcher, that it was difficult to manage a research context where very little was certain.

NESH (2019) suggests that researchers may visualize a public/ private continuum to assess the publicness of online spaces, and that both sensitivity and accessibility in the public sphere plays a role in where something is placed on the continuum (NESH, 2019). Research ethical challenges may for example arise from sensitive information that is revealed on arenas that are not explicitly public (NESH, 2019). The Instagram researcher explicitly referred to visualizing a continuum of public and private as a tool for making ethical decisions. The other two informants expressed more implicitly that they had applied the concept of a continuum when assessing publicness and privateness. The guidelines (NESH, 2019) further emphasize the personal responsibility of researchers to assess reasonable expectations of privacy, and to include the criteria required for the specific context (NESH, 2019, p.9). All the informants interviewed for this present study had assumed personal responsibility, while at the same time expressing confusion related to not being adequately advised on how to make these assessments, and the forum-researcher had applied the overall strategy of *erring on the side of caution*, to make sure boundaries were not crossed.

5.1.2. User expectations of privacy

User expectations of privacy was a concern explicitly mentioned, or implicitly referred to, as an important consideration related to assessing publicness and privateness, and for assessing boundaries more generally. The guidelines by NESH refer to this as a concept named 'reasonable expectations of publicity' (NESH, 2019, p.10), a concept that is often referred to as 'user expectations of privacy' in contemporary research literature (Burles & Bally, 2018). This concept can be used to assess the degree to which users may expect that their information and communication can be used outside of the context where found (NESH, 2019). User expectations of privacy/publicity refers to the degree to which participants might be aware of, and understand, that their information is public, an even if personal information, sensitive or not is revealed in open spaces, it does not necessarily mean that users accept dissemination of this information in research (NESH, 2019). Moreover, it may not be reasonable to expect that social media have thought through the potential consequences of reaching unintended audiences, including internet researchers, albeit they are aware that their contents are public.

The informants interviewed for this present study acknowledged that user expectations of privacy may differ from those of the researcher and had reflected on the fact that technological settings are not always aligned with the actual expectations of users. The researchers took this into account when balancing different factors in the assessment of publicity and privateness. User expectations of privacy/publicity can be a tool for reducing harm and risk to social media users, by taking a second glance at communication contexts that may initially appear as clearly public. The researchers, by applying this concept, thus adhere to the principle of non-maleficence.

C*ontextual integrity* is referred to by NESH (2019, p.10) as a concept that point to the forementioned technology, and form of communication, as factors that may have relevance for ethical decision-making in internet research Many of the researchers' ethical assessments were related to the technology and settings of sites and platforms, in addition to social media user's choices, agency and expectations of privacy. The blog-researcher was the least unequivocal in the assessment of user expectations of privacy: for her it was clear that the blog writers understood that their blogs could be read by everyone, based on that specific advice was provided on the blog site , describing what writing publicly online may entail for bloggers, coupled with the autonomy and *control* the authors have of their blogs, as well as the desire many of the bloggers had to be cited and referred to. The Instagram-researcher reiterated the desire of informants to be cited and referred to, and also reiterates that users had choices related to where to write, and in adjusting their privacy settings. The researchers thus acknowledge the autonomy of the social media users, and further highlight that, if the owners of the Instagram account would have wanted to keep their information private, it was reasonable to think that they would have adjusted the privacy settings accordingly. The outlines of a potential conflict between the principles of autonomy and non-maleficence, between the desire of users to be referred to and cited, and the need to protect informants from harm. The principle of autonomy has been considered by informants in various contexts and seems to have been an important factor in their ethical reflection, along with, in particular, but not limited to, the principle of non-maleficence.

The literature also specifically discuss that users of social media sites have choices, and that they have agency, related to how to protect their own data: Kurtz et al. (2017) and Miller, Pole & Bateman (2011) (cited in Burles & Bally, 2018, p.4) supports these arguments, and notes that users have *choices* regarding protecting their privacy, e.g.: through choosing where to write, choosing to not disclose personal and intimate information, as well as choosing privacy settings on platforms and sites. Even if some factors were clearly indicative of “green light” for the material to be included in research, various assessments constituted a challenging balancing act for the researchers interviewed for this present study. Mirroring this, an informant in Warfield et al.’s (2019) study had reported that it had been challenging to balance user expectations of privacy and personal information with the aims of their own research. How to balance research aims and ethical principles in internet research may be particularly challenging in certain cases. This is not any less true in contexts where notions of sensitivity and vulnerability are involved, and where boundaries are unclear.

5.1.3. Potential risks related to reaching another audience than the originally intended

Ross (2020), in a reflection on ethical challenges in working with cancer blogs as material, writes that an unforeseen consequence of reaching an audience outside of the originally intended through research dissemination, may have unfortunate consequences for the authors and their genetic relatives: the author may not have intended that genetic relatives read their contents, and relatives may be burdened by the knowledge of potentially being genetically disposed to a serious illness.

Although this may or may not have been applicable for some of the informants of this present study, this risk, which also relates to the limits to the degree of confidentiality and anonymity internet researchers can ensure participants, was not something that was mentioned by any of the informants. This may be related to the role of the researcher, in the sense that the interviewees were not asked if they had considered additional risks besides the mentioned risk of deanonymization when including verbatim quotations in research dissemination. It could also be that this was something that the interviewees had not specifically reflected about, or that it was not considered as a risk in their particular context.

5.1.4. Potential harms versus the greater good

Additionally, the general research ethical consideration of weighing potential harms to participants that may occur from inclusion in research, against the greater good for the society (NESH 2016, p.19), is not something that the informants discussed explicitly. This may also point to the role of the researcher, as the informants were not directly questioned about this. Even though potential harms weighed against the greater good for society were not *explicitly* discussed or mentioned by any of the informants, the *benefits* of conducting qualitative internet research were nevertheless emphasized: all the researchers mentioned that the internet presented a valuable arena for obtaining data about their topic of interest. The research conducted by all informants involved illness related topics, which typically can be difficult for people to speak about in their offline lives. The alternative mode of observational social media research had provided a rich source for additional and different insights.

5.1.5. Balancing various ethical considerations in social media research: additional perspectives

Warfield et al. (2019), reports similar results in their study: the informants had acknowledged that user expectations of privacy were an important ethical consideration. All researchers had also attended to the concept of contextual integrity, either knowingly or unconsciously: balancing technological affordances and settings with user's motivations and possible interpretations of privacy (Warfield et al. 2019). Assessments of publicness and privateness were seen as more challenging on certain platforms, and easier on others (Warfield et al., 2019).

5.1.6. Informed consent and blurred boundaries between public and private

Elgesem et al. (2016) argue that the principles of information and consent hinges on assessments of publicness and privateness, and this is reiterated in the NESH guidelines (2019) that discuss the blurring of boundaries between public and private particularly in relation to the responsibility to inform and obtain informed consent.

In Internet research, both exceptions and the main rule: that researchers have responsibility to inform participants, and to obtain consent if sensitive information is included, must be specified. When the main rule applies, and when exemptions from this main rule apply can be challenging to assess, as this hinges on publicness and privateness, as well as sensitivity (NESH, 2019). NESH (2019) states that material that is openly accessible is not necessarily public, and that all information that in principle in public should not uncritically be used for research purposes, as some participants will require special protection, even from themselves (NESH, 2019). In other words, communication on social media can in principle be accessible for everyone, without password protection or other restrictions on access. At the same time, if the communication on the site may have been intended only for a selected audience, or when it is not necessarily expected that the communication is public, then the principle of informing is to be applied, and when sensitive topics are included, then consent should be obtained.

Moreover, when communication is conveyed on a site that is expectedly public, due care must be taken to protect persons in vulnerable life situations, such as patients, youth and children. NESH states that this is in alignment with “offline” research ethical considerations (NESH, 2019).

Different factors had been assessed by the researchers pertaining to the publicness and privateness of the data they wanted to include in research, and how accessible the information was, the vulnerability of the participants, as well as the sensitivity of the information. And, while the sites were regarded as clearly public, certain factors were pointing towards privateness. The fact that the participants in all the researchers’ studies were patients that revealed personal and potentially sensitive information had led to assessments pertaining to the need to obtain informed consent. The assessments of the researchers thus align with the advice on how to approach informed consent in the NESH (2019) document. Additionally, this assessment, made by all the informants, can be seen in light of Elgesem et al.’s (2016) argument that assessments of obtaining informed consent typically will be clearer if certain factors, such as sensitivity, characterize the material.

None of the interviewed researchers expressed that the decision to obtain consent was in itself a difficult decision: e.g., for the Instagram-researcher, sensitive and personal information revealed through the informants’ communication, made it clear early in the research process that informing and obtaining consent was the right thing to do. For the forum-researcher, informing and obtaining consent was also something that stood out as right to do based on the context and her personal morals: this researcher did not want to abuse the trust of the participants in the forum that she had studied, and herself was a member of.

Burles & Bally (2018) argue that adhering to the principles of informed consent and confidentiality is of particular importance when participants are sharing personal stories, as harm can potentially arise from participants disclosing personal identifiable information. The researchers that were interviewed for this thesis had conducted research on narratives and communication that was not deemed personal according to some contextual factors, and more private according to other factors: such as the users' revelation of personal and intimate information. Gao et al. (2022) advise that, when using illness communication as data, informed consent should be obtained *regardless* of the publicness or privateness of the material, as a precautionary measure. This argument was mirrored by the forum-researchers' overall ethical strategy of erring on the side of caution.

Contemporary literature also suggests that obtaining informed consent can be an opportunity to involve participants in research and setting boundaries for use of their data (Burles & Bally, 2018, p.7, Ross, 2020). The forum-researcher had taken this opportunity to involve participants in setting boundaries for the use of their data. Involving users in this manner can be a way of explicitly respecting the right of participants to decide over their own data. It can also enable participants to influence how they are represented in research (if consenting). Thus, this relational strategy can be a way of minimizing harm to participants[5]. Ongoing consent was a strategy all the informants in the study by Warfield et al. (2019) had applied as a strategy for negotiating ethical challenges in contexts characterized by uncertain and unclear boundaries, and where expectations and other contextual factors are suspect to ongoing, and sometimes rapid, change. Gerrard's article (2021) also emphasizes ongoing consent as a shortcut for considering ethics in a processual manner, and advice that consent is re-obtained throughout the course of a project.

Ongoing consent is not something that explicitly came up as a theme in this present study. Assumably, there are differences between researchers and research communities in how much awareness exists around ongoing consent as a strategy in internet research, and how to employ it in various contexts. Albeit the forum-researcher involving participants in setting boundaries

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[5] Consent alone will typically not mitigate harm alone (Markham & Buchanan, 2012), and may therefore beneficially be supplemented by other means, such as user involvement (Ross, 2020, Burles & Bally, 2018), especially coupled with the complex contexts of internet research, where it is not always clear what is public and private.

and checking in with them that they were fine with the way their data had been included, might not be ongoing consent per se, it includes elements of ongoing consent.

The researchers stated in the interviews that there had not been any major *practical obstacles* hindering them from obtaining consent from selected individuals. Contemporary literature points out obtaining informed consent as potentially challenging in internet research, e.g., when no contact information is provided, or when the number of participants is particularly large (Burles & Bally, 2018, p. 7).

5.1.7. Verbatim quotations and limitations to confidentiality and anonymity

There are limits to the degree of confidentiality and anonymity that internet researchers may be able to provide informants. This is something that can be seen as a novel challenge in internet research contexts: offline researchers do not have to consider this, as all data normally will be stored with restriction to access, while online, data can be publicly available (NESH, 2019), and it is suggested that researchers inform participants about this limitation in confidentiality and anonymity when informing and obtaining consent. Burles & Bally (2018, p.8) argue that evaluations regarding maintenance of confidentiality partially depend on disclosure of personal information and the level sensitivity and vulnerability of the topic and vulnerability. At the same time, complete maintenance of confidentiality may not be realistic in internet research scenarios, and that the same accessibility in the public sphere that was a criterion for data to be included in the informants of this presents study’s research, can make real anonymization difficult (NESH, 2019).

The researchers interviewed for this thesis, after obtaining informed consents from informants, included verbatim quotations in their research dissemination. The researchers left out identifiable information, but still the use of verbatim quotations in research dissemination included considerations of the risk of reidentification. Scholars, e.g., Gao et al. (2022), point to the risk of reidentification when using verbatim quotations and argue that researchers should be cautious.

Simultaneously, the inclusion of direct quotations was seen as important for the research dissemination. The researchers interviewed for this present study mentioned this as a challenge that they did not have to consider in offline research. For the informants interviewed for this thesis, the potential harms that could potentially stem from reidentification of informants were seen as low compared to the benefits of the research. In contemporary research, suggestions for minimizing risk of reidentification have been suggested. One suggested means to minimize this risk is to slightly alter quotations (Ross, 2015, cited in Burles & Bally, 2018), although no such strategies have been employed by the researchers interviewed for this present study.

NESH (2019) further points to the fact that, even if participants on social media use pseudonyms, that does not ensure the protection of participants' anonymity and confidentiality. Online searches can still reveal a participants' identity, through a compilation of information from various places where the user has used the same pseudonym (NESH, 2019, p.16).

Pseudonymous users can cause ethical doubts for researchers, related to the principles of anonymity and confidentiality, as noted by Gerrard (2021). Other scholars have pointed to the use of pseudonyms as a choice social media users can take regarding protecting their anonymity (Kurtz et al., 2017; Miller, Pole, & Bateman, 2011, cited in Burles & Bally, 2018, p.4). One informant had decided to not contact people who had written under a pseudonym, as it had been assessed that in this context, seeking out pseudonymous blog authors could potentially have been a cause of harm (Burles & Bally, 2018, p. 7). For another informant, pseudonyms were seen as an extra layer of protection from reidentification. However, this conflicts with, e.g., the NESH- guidelines which argue that pseudonyms do not ensure that participants are safe from reidentification via online searches (NESH, 2019, p.16). That one of the informants indicated that pseudonyms added a layer of protection from reidentification, may mirror the lack of resources on IRE that this informant expressed, or it may warrant more attention to addressing novel ethical challenges pseudonyms may present with, related to anonymity and confidentiality, as suggested by Gerrard (2021).

Something not discussed by the informants, while being described in the guidelines by NESH (2019), is the importance of internet researchers disclosing to informants in detail the limitations to the degree of which the researcher can ensure real confidentiality and anonymity, which goes beyond the statutory requirement of disclosing the limitations of professional secrecy and confidentiality, (NESH, 2019). The fact that the researchers did not discuss this is likely related to the fact that they were not explicitly asked about it in the interviews. Had the informants been asked about this directly, clarifying answers would most likely have been provided. It is assumed that the informants of this present study had met the statutory requirements related to secrecy and confidentiality, not least since the researchers had obtained ethical approval for their projects. However, the researchers may have reflected on this in detail, or acted on this, for example by describing limitations to real confidentiality and anonymity based on the online searchability, while it not being revealed in the interviews.

There may also have been other reasons for the researchers not speaking of this, such as it being regarded as a matter of course, or it could potentially also be related to resources. More specifically, it could have been a result of these limitations not being sufficiently discussed in guidelines, or by other resources, or it could have been related to a lack of resources experienced by the informants. Thoroughly informing informants is related to respecting the research ethical principle of autonomy, as sufficient information will aid in enabling informants to make an autonomous decision related to participating in research.

5.1.8. Approaching sensitivity and vulnerability in social media research

The results from this present study show that social media sites proved to be venues for novel/ different, rich and valuable information for communication about personal illness: one informant expressed that it was important not to back away from internet research that involves notions of sensitivity or vulnerability, just because it is complicated. Another informant said that internet research did not necessarily be a better arena for research about illness, but a different one. The third participant stated that it had had been a positive experience for her to conduct internet research about personal illness, even if it had been challenging. Ross (2020, p.46) confirms that the internet can be a rich source for information pertaining to illness.

As noted by two of the researchers, it did not seem that the patients included in their studies viewed themselves as being in a vulnerable situation. Neither did it seem that speaking openly about their experience with healthcare and being ill was regarded as a sensitive communicative act. The researchers also noted a positive attitude on behalf of the participants to being included in research. Some participants had expressed that they even wanted to be cited and referred to in the finished research: the social media users that may not have identified themselves as being vulnerable and would perhaps even find it inappropriate to be labelled as such. This presented as a situation where, besides the researchers’ duty to protect people in vulnerable situations and making sure that they are capable of giving informed consent, the principles of autonomy and non-maleficence needed to be weighed up against each other.

Tiidenberg (2020, p.572) argue that labelling certain groups as vulnerable may have unfortunate effects, as participants themselves may not agree to being vulnerable and may even find this to be patronizing (potential implications of this will not be further discussed here, as it falls outside of the scope of the study). At the same time, inherent qualities of the Internet may expose people to risk and harm. Thus, the need for protecting informants is not made any less important by online users not seeing themselves as being in a vulnerable situation or seeing the issues which they talk about as sensitive. Online behavior can in itself be a factor that puts people in a vulnerable situation, and not only be tied up to their offline situation (Tiidenberg, 2020, p.572). This means that participating in communication online, regardless of a person's offline situation, may expose people to risk. Coupled with the fact that social media may not always be able adequately protect their own interests (Tiidenberg, 2020, p.572-573), based on socio-technological factors that may be difficult to gain an oversight over. Also, the participants may fall under Hurst's (2008: 192) (cited in Solbakk, 2015) subcategory of vulnerability: those who are at risk for harm.

The social media user's vulnerable situation, in this case, can be said to be tied up to their offline situation. Nevertheless, their vulnerability may also have been exacerbated by what they revealed about themselves in their communication, and this places great demand on the researcher to adequately protect participants (Tiidenberg, 2020, p.573). Solbakk (2015) also refers to what layers of vulnerability that need to be taken into consideration. In the case of including users of social media sites in research, and their communication about personal illness, it is both the users offline and online life, the illness in itself, as well as the way the participants are behaving online (Tiidenberg, 2020, p.572) and whether or not this behavior, or socio-technological settings may add layers of vulnerability. This further emphasizes the need for attention to contextual factors and variables in negotiating vulnerability, as noted by Solbakk (2015).

The study by Warfield et al. (2019) did not explicitly discuss notions of vulnerability and sensitivity, or potential harms in related to this, this may be because the specific topics of communication that had been included in the interviewees research were not defined. The study by Warfield et al. (2019) also had a different perspective than this present study, as the exploration centered around the use of images and visual communication more broadly, and not textual communication.

5.2. Theme 2: Resources

In the next section, the results from the theme 'resources' will be discussed in relation to relevant theoretical perspectives and arguments.

5.2.1. Sensitivity, vulnerability, and guidelines for internet research ethics

Included in the second theme resulting from working with the data from the interviews, is an indication of a gap in guidelines specific for IRE, more specifically a gap in advice on how to handle the involvement of sensitive topics and people in vulnerable situations.

When it comes to the inclusion of people in vulnerable situations and sensitive topics in social media research, the guidelines by NESH (2019) do not outline detailed guidance on how researchers may approach specific ethical challenges, when using communication as data. Notions of sensitivity and vulnerability are nevertheless "sowed in" in the outlining of other internet research ethical considerations, including in the section on the requirement to inform and obtain consent, and in the section on considerations of confidentiality. The document by NESH (2019) provides advice on involvement of sensitivity and vulnerability that appear as clear on some points, such as: the need for protection of people in vulnerable situations and that researchers may have to obtain consent from third parties that become involved in research, e.g., in photos or comments.

The guidelines do not, however, go in depth to describe what further ethical considerations the involvement of people in vulnerable situations, or the involvement of sensitive topics, may entail, or give any in-depth descriptions of potential challenging situations. The results from the thesis at hand indicate that it may be beneficial if notions of sensitivity and vulnerability in social media research are more elaborately addressed, as a separate topic. One of the informants expressed that she had not really found any advice specifically related to the involvement of notions of sensitivity topics and vulnerability in any official guidelines, and implied that this had been an area where she would have benefitted from more specific advice.

This particular researcher had conducted research within a context where images were also a part of the data, although it was the textual data that was in focus in the interview, it is reasonable to assume that the inclusion of images may have additionally contributed to complexity in the ethical decisions that she had to make. It was not conveyed in the data if there was any specific challenge/s related to sensitivity or vulnerability this researcher had contemplated, and not found advice on in existing guidelines. What is known is that, to take the guidelines by NESH as an example, not much discussion or advice is provided on how to present material that is sensitive, including verbatim quotations, outside of the potential harm of reidentification. And, since internet research presents with novel challenges related to issues such as blurred boundaries between publicness and privateness, informed consent and confidentiality, it is reasonable to think that the entanglement with sensitivity and vulnerability may also present novel challenges not yet fully acknowledged or addressed.

Communication about health and illness is increasingly common on social media, and this coupled with the increased potential for *everyone* to be set in a vulnerable situation when participating on the Internet (Tiidenberg, 2020, p.573), warrants that related issued be adequately addressed in IRE resources. As indicated by the Instagram-researcher: a greater degree of specification in guidelines on how to manage already complex contexts further complicated by notions of vulnerability and sensitivity, may be of benefit for researchers.

5.2.2. A lack of resources

The researchers had all used a range of different resources. This mirrors the advice that researchers should consult as many resources as possible (Markham & Buchanan, 2012). The informants had used ethics guidelines: both general and more specific to IRE, peer literature and other text, discussions with colleagues, and drawing on previous experiences with IRE, all played a role in the researchers' ethical decisions. However, a general lack of ethics resources was reported, and weaknesses related to the available resources was pointed out by the researchers, such as a lack of relevant peer literature, a lack of resources at the place of work, as well as gaps and little clarity in guidelines for IRE. The informants found some support in contemporary peer-literature. Lomborg& Bechman (2014) (cited in Rensfeldt et al., 2019, p.198) notes that peer literature can be a good source to consult, as reflections learned through case based ethical reflection can be transferable to other cases. However, but also here a lack was reported: it had not been easy to find directly relevant literature, or enough literature, and one informant specifically highlights that there was no consensus to be found, as everyone had approached ethical matters differently. Combined with, a reported, overall lack of relevant resources, the lack of quantity of, and relevance in contemporary literature pertaining to IRE, can make finding adequate support in ethical decision-making challenging.

The forum-researcher had employed an overall strategy of erring on the side of caution, as besides being a way of lessening the risk of informants’ boundaries being overstepped, also was a response to the overall lack of advice and support in ethical decision-making related to the particularities of internet research that she had experienced.

The results also show that discussion with other people, such as colleagues, was an important resource. At the same time, it was noted a lack of people that were familiar with the specific context of internet research and related challenges. It was also found that it was little knowledge about internet research ethical challenges at the place of work, and in some governing bodies. Two of the interviewees explicitly reported that they had felt alone, with little to no directly relevant advice readily available for them. The Instagram-researcher argues that existing guidelines for IRE could be made more tangible, and that this would probably be appreciated by many researchers, such as herself. The blog-researcher took a similar stance: clearer, more standardized guidelines could be of benefit, and even a few rules could be added to the mix. Both of these researchers highlight the importance of guidelines remaining flexible and acknowledge that a universalized set of guidelines would probably not be feasible, nor desirable.

5.2.3. A call for a tighter ethics framework

Resources, the second central theme from the analysis, also includes that *clearer and more specific guidelines* would have been appreciated by the researchers.

The informants had utilized a wide range of resources, including the NESH guidelines (2019), and the AoIR document, both of which are based on a context specific and question-oriented approach to ethics. The AoIR (Markham & Buchanan, 2012) offers no guidelines for any specific field of inquiry, while the document by NESH (2019) is specifically aimed at researchers in the humanities and social sciences who study communication via the Internet. None of the documents presents any rules or strict set of guidelines. Both are meant to be *advisory*, and to act as tools for reflection and decision-making. Both the documents present an approach to IRE that is rooted in norm, values, and principles, and presents questions meant as aids in the process of assessing and solving ethical challenges specific to internet research. The bottom-up approach has become common in contemporary approaches to IRE, and Perez Vallejos et al. (2019) has argued that a question-based approach is a preferred approach to ethics in internet research involving sensitive topics.

The researchers interviewed for the thesis at hand expressed that they nevertheless would have appreciated clearer, more tangible guidelines, and this ca contest the bottom-up approach as the “only way to Rome”. Clearer guidelines, even the benefit of adding rules, were mentioned by the informants. One informant explicitly said that a tighter framework would probably have been appreciated by many researchers, as well as herself. The same researcher pointed to existing guidelines not being specific enough for her field of inquiry, language studies. All the researchers reported a lack of clear and relevant advice, including the two informants that had utilized IRE specific guidelines. Also, all of the researchers reported being on their own and feeling alone in the ins and outs of ethical decision-making in their research and had adopted various strategies in meeting with ethical challenges, such as staying on the cautious side.

The call for a tighter framework made by the informants, however, balanced with an emphasis on the importance that flexibility is retained, and highlighting of the context as an important factor when considering ethics. This reiterates arguments from contemporary literature: it is crucial to approach IRE challenges in a flexible manner, and approaches that do not have room for this flexibility would be undesirable. (Markham, 2006). Burles & Bally (2018) also supports this, as a wide range of methods and angles used in internet research, a top down, inflexible, approach can be problematic.

For one informant, the hurdles of feeling alone were lessened by the framework that had been built when seeking ethical approval. The researcher used the guidelines by NESH (2019) as a resource in this process, during the initial first year or so of the research process. However, after the initial first year, it was the framework that had been established in the process of gaining ethical approval that was consulted. One may reflect on the degree to which this informant had approached ethical matters in a situated, and processual, manner, as advocated in contemporary literature (Markham & Buchanan, 2012).

Predefined decisions are seen as less desirable in internet research (Markham & Buchanan, 2012), and Rensfeldt et al. (2019) (2019, p198) argues that situated ethical considerations involves viewing ethical considerations as intertwined with, among other things, the context of the research, including participants, as well as the aim and objectives of the research. Processual ethical decisions are part of the advocated bottom-up approach (Markham & Buchanan, 2012), and to account for all relevant aspects, it is argied that the researcher must take a processual approach to ethical decision-making and -reflection (Rensfeldt et al., 2019, p. 198). Here the author of this present study will argue that blog-researcher, to a degree, *had taken a processual and situated approach* to ethical decisions and reflection: the blog-authors had been taken into consideration, the context had been thoroughly assessed, and ethics was considered continuously throughout the project. Continuously considering ethics was however done with the support found in the framework that had been established in the process of seeking ethical approval, and not by consulting guidelines for internet research ethics, like the NESH (2019) guidelines.

Although making predefined ethical decisions were highlighted as challenging for the blog-researcher, who refers to challenges concerning addressing what one does not yet know. In the guidelines by the AoIR (Markham & Buchanan, 2012), it has been argued that a processual approach to ethical decision-making is useful, since different consideration appear as more salient in different stages of research, e.g., informed consent may be more salient in the start, and considerations pertaining to verbatim quotation later on in the project. The blog-researcher had to simultaneously address several ethical challenges at the start of the project. One may argue whether predefined ethical decision-making is more likely to produce desirable outcomes, or not. Albeit this would have to be a story for another day, since further exploration of this was not done in this present study. What *is* certain is that the researcher herself saw the benefits of having this framework to consult throughout the process of her research, thus the framework acted as an aid in processual ethical reflection, and lessened confusion and indecision. In contemporary research, the advantage of a processual approach is typically highlighted, while there are little mentions of the potential benefits of having a more specific framework to relate to.

The results from this thesis also reiterate the results from the study by Warfield et. al. (2019) where the interviewed researchers all had reported a lack of overall resources. At the same time, the interviewed researchers had been turning to a wide range of resources, such as advice from colleagues, compendiums, and discussions, in something the authors names ‘protocol assemblages’ (Warfield et al., 2019). The researchers interviewed for the study by Warfield et.al. had turned to a wide variety of resources in response to having little support in their ethical challenges, and this is mirrored by the informants of this thesis, that had also sought a wide range of formal and informal advice. Warfield et al. (2019) further stated that this way of consulting other scholars for advice is not new, but the wide variety, and quantity of resources that had been consulted, made it differ. In the study by Warfield et al. (2019), the lack of advice was reported as having affected the research and being a cause of confusion and uncertainty, and one of the informants had described the ethical process as out of control, it was “just running blind.” (Warfield et al.,2019, p.2074).

Warfield et al. (2019) discuss Research Ethics Boards in particular, when discussing ethics resources. The boards were perceived as both under protective and overprotective by the interviewees: they were either excessively cautious, or not cautious enough. Although Ethics Reviews Boards are not discussed in this thesis, the strategy that one of the researchers interviewed for this thesis had employed, staying on the cautious side, is a somewhat similar strategy of erring on the side of caution. It seems likely to assume that this strategy of staying cautious, if not excessively cautious, is partly a result of the lack of specific advice that had been available to her, and this lack was then mirrored in the researcher's actions.

Chapter 6 - Conclusion

In this chapter, this present study is briefly summarized, and the conclusions resulting from the discussion are described. Suggestions for future research is also provided in this section, and the study's limitations are outlined. Lastly, additional reflections are presented.

6.1. The study

The topic of this present study has been ethics, and more specifically applied ethics, in the form of internet research ethics resources and guidelines. It has further been an aim to explore researchers experience with, and perspectives on, various internet research specific ethical challenges, and through that, further explore qualitative researchers' perspectives on the usefulness of internet research ethics (IRE) resources, and more specifically guidelines for IRE.

In collaboration with expert Librarians at Inland University of Applied Sciences, searches in various databases revealed that there was a gap in literature pertaining to exploring researchers' experiences with ethical decision-making and ethics resources: previous research has identified gaps in current guidelines for IRE and has revealed that a sample of researchers experienced a lack of overall resources for ethical decision-making in internet research, when employing images obtained from social media sites as data. This present study builds upon, and extends the bounds of, these results, by exploring further areas of the ethical dimension of internet research. In order to explore issues related to this, qualitative in-depth interviews were undertaken, which subsequently were analyzed, using a standardized form of thematic analysis. Research ethics were considered throughout the study. Three interviews were conducted digitally, and the project was notified to SIKT, who decided that legal foundation for conducting the research was in place.

Through searches in databases, such as Academic Search Complete and Oria, the author of this thesis identified one study where qualitative interviews had been conducted in order to explore 16 social media researchers' experiences with ethical challenges and experiences on the use of ethics resources (Warfield et al, 2019). The results of the study by Warfield et al. (2019) showed that amongst the interviewees, shared similar challenges had been encountered. The study by Warfield et al. (2019) furthermore revealed that the interviewees had experienced a general lack of resources for negotiating IRE challenges.

An important rationale for undertaking this research, is the need to adequately protect the users of social media sites who are included in research against harm and risk, who prevalently share personal identifiable information about themselves and their lives, by contributing to the discussion on how best to support researchers in conducting ethically sound research. This seems especially important in internet research, in an arena that requires specific attention and is characterized by uncertainty and ambiguity, where algorithms and technology may pose threats to social media users. This ambition responds to the call for researchers to continue to develop IRE (Markham & Buchanan, 2012), and the argument regarding the importance of researchers sharing their reflections, so as to further build consistent and solid ethical practice (Samuel & Derrick, 2017, cited in Ross, 2020, p.46). Furthermore, the relevance of focusing on minimizing risk in relation to technology, can be exemplified by the AI Act- a coming EU legislation which aims to classify various AI tools from low risk to non-acceptable risk.

The exploration of researchers' perspectives on ethical challenges specific to internet research, and on IRE resources has been supported by the overarching research question and interim goals. The overarching research question has been:

> "How do researchers, who employ publicly accessible communication about personal illness as data experience, use, and evaluate resources for internet research ethics, in particular guidelines?"

The interim goals, supporting the overarching research question, has been:

A) Map how internet specific challenges related to internet research ethics are negotiated by the researchers, when employing textual communication about illness obtained from social media sites as data.

B) Map the researchers' experiences with, and perspectives on, guidelines for internet research ethics.

The quote by Storm King (1996, p.119), presented in the introduction of this thesis, has set the tone for the exploration in this present study:

> When a field of study is new, the fine points of ethical considerations involved are undefined. As the field matures and results are compiled, researchers often review earlier studies and become concerned because of the apparent disregard for the human subjects involved (cited in Buchanan & Zimmer, 2021).

6.2. The results

The results from this present study show that resources and guidelines for internet research ethics had been of help to some degree for the researchers interviewed for this present study, and the way that the researchers negotiated various IRE issues and challenges, in large part reflects current advice, found in literature and in guidelines for IRE. However, it was also indicated by the researchers evaluated current guidelines on IRE as not offering enough support. Furthermore, although flexibility was appreciated: current IRE guidelines were not experienced as descriptive, relevant and tangible enough to have been of adequate support within the various contexts and frames of research.

6.2.1. Negotiating encountered challenges and issues

The results of this present study show that main internet research ethical issues encountered by the researchers were related to assessments of publicness and privateness of material, informed consent, the use of verbatim quotations, as well as considerations related to sensitivity, people in vulnerable situations, and personal identifiable information.

When managing these issues, the concept *user expectation of privacy*, including considerations of social media users' *choices,* as well as *intended audience,* and contextual assessments, had been adhered to. The researchers had managed these challenges in great part as suggested by NESH (2019). The strategies of erring on the side of caution and involving social media users in decisions regarding their data were employed by informants. Assessment of these factors, and combining them with the aims of the research, had been a challenging balancing act. Nonetheless, the relevance and advantages of conducting research online were highlighted.

The researchers expressed that negotiating how to approach the social media sites, and to negotiate how to manage various IRE specific issues and challenges, were more complicated than in "offline research". When social media is the research context, it is not always clear how to assess what is public and what is private, and how to manage the material. This was confirmed by the researchers interviewed for this present study, which research contexts were further made complex by the involvement of sensitive topics and people in potentially vulnerable situations. Balancing different research ethical concerns with the aims of the research was implicated to be a challenging balancing act.

Defining boundaries between public and had been challenge in itself, for the informants interviewed for this present study. The results of this present study reveal that some IRE specific challenges were especially salient for the informants. These issues were largely tied up to the blurring of boundaries between what is public and what is private on the Internet. *, available data is not always as public as it may seem at first glance, something that was confirmed by all three interviewees: all had identified and negotiated challenges related to blurred boundaries between what is public and what is private online. Assessment of publicness and privateness on behalf of the researchers involved assessments and balancing of different parameters, such as user's expectations of privacy/publicity, technological settings (contextual integrity) and sensitive personal identifiable information, For all the researchers, user expectation of privacy was a central consideration in assessing whether material was public or private, and it was acknowledged that user expectations might differ from that of privacy settings of the social media site, and that of the researcher.

Another salient challenge was the use of direct quotations: a concern was that the use of quotations could potentially lead to participants being identified. All the informants had obtained informed consent from informants that they would directly quote, and none had directly included third parties in research, such as people commenting on threads or posts. Obtaining informed consent was seen as an important step in avoiding potential harm, such as a feeling of abuse of trust, or an uncomfortable feeling of unknowingly having been included in research. All the informants expressed that deciding on obtaining informed consent was not a difficult decision to make, and this was interesting to note, but also not surprising: informed consent is a standard ethical principle and is also widely discussed in literature on IRE. Additionally, none of the researchers had faced major practical challenges in obtaining consent.

For one researcher, working within the context of discussion forums, it was decided to use direct quotations from people using pseudonyms. However, it was interesting that the contexts of two researchers assessed the inclusion of pseudonymous participants differently: while one saw this as a factor that made using verbatim quotations safer, for another one it had been decided that pseudonymous users would not be contacted. This can point to both available resources; for the latter informant the guidelines by NESH (2019) had been readily available, and for the other, not much support and advice had been withing close reach. At the same time, the contexts in which they were carrying out research were also different. For the blog-researcher, to not contact pseudonymous participants may have been a decision that also hinged on the increased chance that individual writers could more easily be identified.

The same researcher also involved participants in setting boundaries for the use of their data. For another, working within a different socio- technological environment, namely blog sites, it was decided that people writing under pseudonyms would not be contacted. All participants had anonymized their informants.

The way these researchers had managed the various internet specific research ethical issues and challenges align with advice found in contemporary research publications and in e.g., the guidelines for internet research ethics by NESH (2019). Ethical decision-making within the various research contexts of the informants had been challenging, time consuming and at times confusing for the researchers.

6.2.2. A call for a tighter framework and more specified advice

Informants interviewed for this present study expressed that they, during their research, had not found sufficient support in ethical resources, and had experienced a lack of resources related to IRE in general. The results of this present study further show that the researchers had consulted a wide range of resources for reflection on ethical challenges and internet research ethical decision-making, as advocated by the Association of Internet Researchers (Markham & Buchanan, 2012). Even though a wide range of resources were consulted, this was not experienced as being sufficient, as many of the resources consulted did not provide enough consensus and/ or knowledge, to really be useful. For all the researchers, the lack of clear guidelines and available relevant resources seemed to be a source of frustration, uncertainty and confusion. The researchers had experienced a lack of relevance, knowledge and consensus regarding various ethics resources, and expressed a desire for guidelines on IRE that are more descriptive, concise and relevant.

One out of three informants had employed the strategy of erring on the side of caution, as a response to the lack of resources, and as a way of making sure no ethical boundaries were crossed. Informants expressed feelings of being alone in the ethical processes related to their research, and confusion and uncertainty were implicitly expressed. Furthermore, a gap in how inclusion of sensitive topics and people in vulnerable situations in internet research are addressed in existing guidelines, were indicated by one informant working with data obtained from Instagram. All informants expressed that a tighter framework for IRE might be of benefit for researchers such as themselves. One informant emphasized that having a framework to work within, as a result of the process of gaining ethical approval was of benefit for her in her research and was something that she consulted throughout the project. NESH guidelines for internet research was helpful in the process of gaining ethical approval but was not consulted after that.

One informant had employed the strategy of involving patients/ social media users regarding the use of their own data, something that aligns with the argument that decision-making in internet research should be *processual* (Markham & Buchanan, 2012), and furthermore points to an ideal in IRE, and may also be said to point towards future directions for IRE. The results further show that clearer, more specific guidelines, and a tighter framework, and perhaps even rules would have been appreciated by the researchers, based on their experiences with internet research.

While a tighter framework was expressed as desirable by researchers it was nonetheless emphasized that approaches to IRE need to retain room for flexibility. A gap in ethics guidelines pertaining to the inclusion of sensitive topics and people in vulnerable situations in internet research was directly expressed by one informant. Additionally, although expressed implicitly rather than explicitly: more detailed advice in guidelines pertaining to the protection of pseudonymous users in relation to the inclusion of verbatim quotations in research, as well as a more thorough description of what describing limitations to confidentiality and anonymity to informants, might entail in internet research, could possibly enhance current IRE-documents. These results can be seen as an important comment on the debate surrounding how to continue to develop a 'best ethical practice' in internet research and may also be a contribution to how we think about the design of IRE-guidelines, not least regarding how sensitivity and vulnerability is addressed, when researchers employ social media communication about personal illness as data.

Determining the publicness or privateness of social media, and the communication on these sites, is a complex task in and of itself, and when sensitive topics and people in vulnerable situations also are included, this adds additional layers of complexity to an already complex research context. Parameters indicating either publicness or privateness can be used as tools when making assessments of what can and should be included in research. Nonetheless, there is also the possibility of being perplexed by the complexity and certainty of the research context, and, according to the results of this present study, there may be a benefit in having clearer, more tangible guidelines to navigate by, in order to ensure appropriate and sufficient protection of users of internet sites that become subject to research, and their communication are being used in research dissemination. Not least, this seems particularly important when the topics that these people communicate about are sensitive, and the people are in what we may call a vulnerable situation.

6.2.3. Nuancing the advocated bottom-up approach to internet research ethics

The results from this present study indicate that the usefulness of the widely advocated bottom-up approach might be enhanced if balanced with more specificity and tangibility. Although an ideal of guidelines on IRE, overarching guidelines that in large work at the macro-level (Markham & Buchanan, 2012), might be the best way of capturing rapid technological developments and their accompanying evolving ethical landscapes.

On the foundation that internet research presents certain novel ethical challenges, the responsibility of the researchers and the research community to make sound ethical judgments is emphasized (NESH, 2016). However, it is important for researchers to have good tools that can aid in ethical decision-making, especially when the research involves human beings, and the contexts of research are not clear. The results from the interviews conducted for this present thesis contest the idea that an approach to IRE necessarily needs to be free of rules and specific guidelines, and proposes that a more standardized framework for IRE related to qualitative social media research could be of benefit for researchers, including master's students, doctoral students and seasoned scholars, as well as journal editors and ethics board members, and others who may be interested in internet research ethics.

At best, an adjustment of the tools for IRE may assist in better protection of users of social media sites. At the very least, it could relieve researchers from some of the added confusion and uncertainty related to internet research.

It is important to emphasize that two out of three researchers clearly expressed that guidelines on IRE were also evaluated as useful. Additionally, several of the main characteristics of the bottom-up approach, as described in the literature and by e.g., the Association of internet researchers (Markham & Buchanan, 2012), were adhered to by the researchers throughout their research process, such as processual decision making, involving participants related to the use of their own data, throughout the study, context specific decision making .Additionally, the IRE related challenges and issues were negotiated in ways that mirrors the advice found in e.g., the NESH-guidelines, and in contemporary research and -literature pertaining to IRE: this indicate that current advice and guidelines to internet research ethics to a large degree reflect, and can be applied to, researchers’ everyday practice. This can be seen as an indication of the relevance of current advice on IRE issues, and the critique being raised by this present study, are minor complaints in comparison to the important work done by bodies such as the AoIR (Markham & Buchanan, 2012), NESH (2019), and individual scholars, in developing advice pertaining to ethical matters in internet research.

6.3. Limitations

This present study has some limitations, including a relatively small number of informants, a non-representative sample. The theoretical background can be seen as both a strength and a limitation:

It is recognized by the author of this thesis that the geographic areas that were covered by the researchers interviewed for this present study encompassed only Western European countries. Thus, a selection of which guidelines would be used as theoretical perspective, had to be made. The selection included the documents by the Association of Internet Researchers, and more specifically the second document (Markham & Buchanan, 2012), as well as the guidelines on IRE issued by the Norwegian National Committee for Research Ethics in the Social Sciences and the Humanities (NESH, 2019). This selection allowed the author of this present thesis to focus on an in-depth discussion alongside two prominent ethical blueprints internet research, while at the same time, no perspectives from other, potentially relevant documents, could be made.

The cohort of researchers that were interviewed for this project was also relatively small (n= 3) and consisted only of female researchers, and only the ones that accepted the invitation to participate in research is included: all of these factors can provide biased selection.

This present study can be seen as complementary to study's employing more frequently used methods for studying decision-making in IRE, such as researchers' reflections on their experience with IRE and literature reviews. In-depth interviews have also allowed for in-depth perspectives into a specific research context, involving illness communication obtained from social media sites as data. Currently, internet sites such as Instagram, personal blogs and forums are prevalent in use for personal communication, and there are no signs that the usage of these sites for personal purposes will decrease any time soon. Thus, it is important to keep focusing on gaining insights into complex specifics of internet research ethics, while at the same time lifting the gaze to see internet research ethics from a macro perspective.

6.4. Suggestions for future research

Additional qualitative studies where researchers are interviewed could be conducted, to further build on the collection of knowledge stemming from everyday practices of researchers. Method triangulation could also help to further elicit relevant information missed by interviews alone. Health related communication has become prevalent in a variety of social media environments, and this data may be of interest for researchers from a variety of research fields, thus ensuring sound ethical practice seems relevant.

Studies that would include a broader selection of participants, and where all gender categories are represented, playing on a wider repertoire of experiences and reflections, may reveal other, supplementary results. Including a wider range of documents on IRE could also yield relevant information, perhaps best performed in conjunction with a larger cohort of informants, from corresponding geographical areas.

Lastly, exploring how researchers negotiate the principle of social media users' autonomy within various demographic research contexts, might additionally enrich the theory of the role of *ethical pluralism* in solving internet research ethical challenges, see Ess (2014), by further investigating the various expressions of autonomy in social media and social media research. This angle could perhaps also shed light on what one might call a "paternalism" of social media sites, where platforms in reality are governing a large part of the choices and actions of their users.

6.5. Final reflections

On a more personal note, it was interesting for me that it seemed as ethics pertaining to internet research had been something that the interviewed researchers had given much thought and time. It was also interesting to gain insight into their thoughts and perspective on internet research ethics, which both confirmed and deferred from initial assumptions. Moreover, it was interesting that it seemed that my conversations with the researchers seemed to be appreciated by the researchers as an opportunity to further reflect on internet research ethics, particularly guidelines.

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Appendix A: Documentation of assisted searches

Librarians at Inland University of Applied Sciences:

- Refseth, Per Steineide, Academic Librarian
- Hartveit, Kristin Marhaug, Academic Librarian

Dates of assisted searches:

- August 30, 2022
- October 13, 2022
- March 30, 2023
- February 21, 2023

Database*s:*

Academic Search Complete, CINAHL, Google Scholar, Medline, Oria, Psych Info.

Examples from searches

1) Examples of phrases and combination of phrases used in searches, illustrated in a search form:

Phrase 1	**Phrase 2**	**Combination**	**Phrase 3**
«Social media research»	«Research ethics»	«Social media research ethics»	«Illness representation»
«Social media»	«Ethical issues»	«Internet research ethics»	«Mental health»
«Virtual communities»			Other search words for illness
«Internet research»			

2) Examples of search words and phrases, from a search in the database Academic Search Complete (March 20., 2023):
   - (i) ("meta-research" OR "research on research" OR "social media research method*" OR "social media research*" OR researcher*) AND ("research ethics" OR "ethical challenges") AND ("digital culture" OR "digital humanit*"). 1 result.
   - (ii) ("research ethics" OR "ethical challenges") AND ("digital culture" OR "digital humanity*" OR "social media") AND ("meta-research" OR "research on research" OR "social media research method*" OR "social media research*" OR researcher*) AND ("RESEARCH personnel" OR researcher). 91 results.

By looking through references of identified and relevant articles, using a sort of “snowball” approach, additional research articles were found.

Appendix B: Interview guide in English

Interview guide

Introduction to the interview:

“Welcome- some information about the interview process, the project, a little information about the researcher”.

- Timeframe.
- Informants respond to what they know and want, and that the goal is first and foremost a good conversation about the topic of ethics and methods in Internet research.

Introduction questions

1) How much experience do you have with internet research/internet research?
2) What are your thoughts on making ethical choices in general in Internet research versus for in "offline" research?
3) How would you best characterize the method you have used, in your own words?

Online ethnography and ethical choices:

4) You chose a method that involved non-interactive observation of users online...Could you say a little more about why you chose this method?
    - **Probes:** Were other methods involved in the planning of the research?
5) Online observation as a method, could you tell me about how you would evaluate the research ethical factors of utilizing this method for obtaining data?

Follow-up question: How did the chosen method work considering that you were researching communication regarding a sensitive topic (illness).

Private/ Public, obtaining data, research context:

6) In your article, you have obtained data from personal blogs/ forum/ Instagram...Which assessments did you make regarding these data as being either private or public?

- **Probes**: did the way the social media users present themselves online matter, and to which degree? What about privacy settings on the platform?

7) What are your thoughts on how to assess whether data found on the Internet is private or public, in a research context?
8) What was it like to make ethical choices, with this in mind?

Dissemination of ethics, and resources for ethical reflection and choice:

9) What is particularly important to you in ethical decision-making? **Probes:** values? Having guidelines available? Considering the informants? The quality of research?
    - **Follow-up question:** Which resources have you used in your work on ethical choices?
    - **Probes :** people ? Guidelines (et cetera) ? Why did you use these particular resources?
10) Do you think something could, or should, be different regarding internet research ethics in your professional environment?
    - **Follow-up question:** What could potentially have been different?
    - **Probes:** is there anything you miss, or that you would have added?
11) The people you are researching find themselves in a vulnerable life situation due to illness
    - Can you say something about *how* the resources you had available assisted you in your work with ethical assessments related to this?
12) Was there anything that could have made conducting research that includes data obtained from internet sites, including sensitive topics easier for you as a researcher?
13) Is there anything else that you would like to say, or something you would like to add, that we have not spoken about?

Appendix C: Consent form in English

Invitation to taking part in the research project

“In the field of tension between the public and private spheres: the internet researcher's ethical assessments”

This is an invitation to participate in a research project (a master’s thesis).

The main purpose of the project is gain insight into how internet- researchers involved in a sensitive topic are making their ethical and methodological decisions, as well as gaining insight into their thoughts and perspectives on these processes. **The data will be gathered using semi- structured qualitative online video- interviews.**

The projects research question is:
“Which ethical reflections has internet- researchers using qualitative method(s), made in their research on people sharing their experience with illness on different social media?”

Which institution is responsible for the research project?

Inland University of Applied Sciences is responsible for the project (data controller).

Why are you being asked to participate?

In this study, the aim is to interview researchers that have experience with qualitative internet- research, that also involves sensitive topics
Your experience with ethical decision- making and methodological choices is valuable for this project.

What does participation involve for you?

The method that will be used in this project are semi- structured video- interviews, using Teams or Zoom (access provided by Inland University of Applied Sciences).

It is planned one interview per participant. The interview can take up to 90 minutes to complete, and includes questions about your experience with ethical and methodological decision- making in internet- research. **The focal point of the interview will be one article written by you.**

Audio will be recorded, using the “Diktafon”- application, which secures secure storage of the data: nettskjema.no. The audio will not be recorded in Zoom or Teams and will not be stored locally on any devices. Video will not be recorded.

It would be advisable that you have a location in which you are alone and where you are free from distractions. For privacy reasons it is also recommended that you blur your background, or use a virtual background.

Participation is voluntary

Participation in the project is completely voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made deleted.

There will be no negative consequences for you if you chose not to participate or later decide to withdraw. You can easily do this by e- mail or phone.

Your personal privacy – how we will store and use your personal data
We will only use your personal data for the purposes specified here and we will process your personal data in accordance with data protection legislation (the GDPR).

- Malin Bratvold Amsrud (master's student), will, in connection with Inland University of Applied Sciences, have access to the collected data.
- Audio will be recorded with the use of nettskjema.no and the "Diktafon"- application, that will securely store the recordings. Other data will be stored on OneDrive by Feide, through Inland University of Applied Sciences. Your name and contact details will be replaced by a code that will be stored away from the other data.
- To transcribe the interview, a software approved by Inland University of Applied Sciences will be utilized. The same goes for analysis- software, if used.

Your personal information and your identity will not be recognizable in the finished document.

What will happen to your personal data at the end of the research project?
The planned end date of the project is May 15th, 2023. Personal data, including digital recordings will be deleted at the end of the project by the end of the year 2023.

Your rights
So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?
We will process your personal data based on your consent, in line with Inland University of Applied Sciences' recommendations for approaching data- treatment.

Where can I find out more?
If you have questions about the project, or want to exercise your rights, contact:

- Inland University of Applied Sciences via Leonora Onarheim Bergsjø. Supervisor 1, on phone: 0047 69 60 84 01, or by e- mail: leonora.bergsjo@hiof.no
- Supervisor 2, Susan Lee Nacey, on phone: 0047 62 51 76 28, or by e- mail: susan.nacey@inn.no
- Data Protection Officer Usman Asghar, Inland University of Applied sciences,

, who can be reached using this number: 004761287483

Yours sincerely,

Leonora Onarheim Bergsjø	Susan Lee Nacey	Malin Bratvold Amsrud
Project Leader (Supervisor 1)	(Supervisor 2)	(Student)

Consent form

I have received and understood information about the project“"In the field of tension between the public and private spheres: the internet researcher's ethical assessments"” and have been given the opportunity to ask questions. I give consent:

☐ to participate in a digitally mediated video- interview/ online video- interview

I give consent for my personal data to be processed until the end of the project, and the final grade is given

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(Signed by participant, date)

Appendix D: Consent form in Norwegian

Invitasjon til å delta i forskningsprosjektet

«I spenningsfeltet mellom offentlig og privat: internett- forskeres etiske og metodologiske vurderinger»

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å få innsikt i hvordan internett- forskere tar sine etiske og metodiske valg. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Dette forskningsprosjektet er et masteroppgave-prosjekt, hvor formålet er å få innsikt i hvordan internett- forskere som forsker på sensitive tema tar, og reflekterer over, sine etiske og metodiske valg, med utgangspunkt i en forskningsartikkel denne har skrevet. Dataene vil bli samlet inn ved bruk av kvalitative, semistrukturerte video-intervjuer.

Prosjektets forskningsspørsmål er:
«Hvilke etiske refleksjoner har internettforskere som bruker kvalitative metoder gjort seg i sin forskning på mennesker som deler sin erfaring med sykdom på sosiale medier?»

Hvem er ansvarlig for forskningsprosjektet?

Høgskolen i Innlandet er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?

I denne studien er målet å intervjue forskere om deres erfaring med å jobbe med forskning på internett, som involverer sensitive tema. Denne erfaringen danner grunnlaget for vår samtale, og vil være av verdi for dette prosjektet.

Hva innebærer det for deg å delta?

Metoden som brukes for å samle inn data er semi- strukturerte video- intervjuer, via plattformern Zoom eller Teams.

Det er planlagt ett intervju per deltaker som vil kunne ta opptil 90 minutter å gjennomføre. Intervjuet inkluderer spørsmål om din erfaring med etiske og metodologiske valg i arbeid med internett-forskning. **Intervjuet tar utgangspunkt i en artikkel du har skrevet.**

Bare opptak av stemme vil bli gjort, ved bruk av «Diktafon»- appen, som overfører dataene til en sikker server på nettskjema.no. Opptakene vil ikke bli lagret på noen lokal enhet. Det vil ikke bli gjort opptak av video.

Det anbefales at du sitter et sted der du kan være alene og uforstyrret under intervjuet. I tillegg anbefales det å modifisere din bakgrunn i videointervju-plattformen, av personvernhensyn.

Du vil ikke bli gjenkjent i den ferdigstilte oppgaven.

Det er frivillig å delta
Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg. Du kan enkelt gjøre dette via e- post eller telefon.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil kun benytte opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt, og i samsvar med personvernregelverket.

- Malin Bratvold Amsrud (masterstudent), veileder 1- Leonora Onarheim Bergsjø og veileder 2- Susan Nacey vil, i samarbeid med Høgskolen i Innlandet, ha tilgang til de personlige dataene som er samlet inn.
- Stemmeopptak vil bli tatt opp ved bruk av nettskjema.no og diktafon- app, som sikrer trygg lagring med passordbeskyttelse på nettskjema.no. Øvrig datamateriale vil også oppbevares på en OneDrive server med Feide- innlogging, godkjent av prosjektansvarlig. Navnet og kontaktopplysningene dine vil jeg erstatte med en kode som lagres på egen navneliste adskilt fra øvrige data.

- Transkripsjon vil skje via programvare godkjent av programansvarlig, det samme gjelder eventuelt analyseverktøy.

Dine personlige opplysninger vil ikke publiseres, og du vil ikke kunne bli identifisert i den endelige oppgaven.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?
Prosjektet vil etter planen avsluttes når prosjektet er levert inn og karaktersatt. Planlagt sluttdato er 15.mai, 2023.

- Innlevering av prosjektet kan av uforutsett grunn skje i september, og dataene vil da slettes når endelig karakter er satt.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke, og i tråd med fremgangsmåten for databehandling anbefalt av Høgskolen i Innlandet.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke opplysninger vi behandler om deg, og rett til å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:

- Høgskolen i Innlandet ved Leonora Onarheim Bergsjø- telefon: 004769608401, eller e- post: leonora.bergsjo@hiof.no
- Vårt personvernombud, Usman Ashgar, som kan nås på e- post: usman.asghar@inn.no , eller telefon:
  +47 61 28 74 83

Med vennlig hilsen

Leonora Onarheim Bergsjø (Forsker/veileder)	Malin Bratvold Amsrud

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Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet **«I spenningsfeltet mellom offentlig og privat: internett- forskeres etiske og metodologiske vurderinger»**, og har fått anledning til å stille spørsmål. Jeg samtykker til:

☐ å delta i semi- strukturert video- intervju (via plattformen Zoom eller Teams, begge med sikker innlogging, tilgjengelig via prosjektansvarlig).

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, og endelig karakter er gitt

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(Signert av prosjektdeltaker, dato)

Appendix E: NSD report*

*(The NSD report is shown on the following page).

Sikt

Meldeskjema / «I spenningsfeltet mellom offentlig og privat sfære: internettforskerens… / Vurdering

Vurdering av behandling av personopplysninger

Referansenummer	**Vurderingstype**	**Dato**
233074	Standard	13.02.2023

Prosjekttittel
«I spenningsfeltet mellom offentlig og privat sfære: internettforskerens etiske vurderinger».

Behandlingsansvarlig institusjon
Høgskolen i Innlandet / Fakultet for lærerutdanning og pedagogikk / Institutt for pedagogikk og samfunnsfag - Hamar

Prosjektansvarlig
Leonora Onarheim Bergsjø

Student
Malin Bratvold Amsrud

Prosjektperiode
15.08.2022 - 15.05.2023

Kategorier personopplysninger
Alminnelige

Lovlig grunnlag
Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 15.05.2023.

Meldeskjema

Kommentar
OM VURDERINGEN
Sikt har en avtale med institusjonen du forsker eller studerer ved. Denne avtalen innebærer at vi skal gi deg råd slik at behandlingen av personopplysninger i prosjektet ditt er lovlig etter personvernregelverket.

FØLG DIN INSTITUSJONS RETNINGSLINJER
Vi har vurdert at du har lovlig grunnlag til å behandle personopplysningene, men husk at det er institusjonen du er ansatt/student ved som avgjør hvilke databehandlere du kan bruke og hvordan du må lagre og sikre data i ditt prosjekt. Husk å bruke leverandører som din institusjon har avtale med (f.eks. ved skylagring, nettspørreskjema, videosamtale el.)

Personverntjenester legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til oss ved å oppdatere meldeskjemaet. Se våre nettsider om hvilke endringer du må melde: https://sikt.no/melde-endringar-i-meldeskjema

OPPFØLGING AV PROSJEKTET
Vi vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!