

CHAPTER I

*Introduction to Digital Platforms and Digital
Research Approaches, Encryption, Cybersecurity
and Bandwidth**Considerations for Qualitative Researchers*

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The introduction of digital approaches is perhaps the most significant change to the way that healthcare research is conducted that has been seen since computers first came into use. This introductory chapter will set the tone for the rest of the book. The book is divided into two parts: 1. digital platforms, and 2. approaches to healthcare research that are either uniquely digital or are adaptations of existing approaches to the online context. Within each of these parts, a collection of chapters by distinguished and rising authors present digital platforms and techniques and consider these as applied to a wide range of healthcare studies. This introduction will consider the broad area that the book addresses and will similarly be divided into the same two sections. The unique aspects of digital research approaches will be highlighted and emphasised, and the reader will be prepared for the chapters that follow.

Chapter 2: ‘Doing Digital Qualitative Research: Key Ethical Considerations’, by Rebecca Wise, Jeff Gavin and Karen Rodham, focuses on ethical challenges for researchers who are engaged in qualitative digital research. The authors argue that while the digital world has opened up significant opportunities for researchers, it has also presented complicated and multifaceted ethical challenges. The authors offer examples of these ethical issues by drawing from a range of research from diverse disciplines.

Chapter 3: ‘Using Video Diaries for Remote Observational Research’, by Steve Hagelman and Melinda Rea-Holloway, considers the essential benefits of using video diaries in corporate ethnography as a tool to collect observational data in health care and consumer research. Drawing on the authors’ experiences, the chapter explores the strengths and limitations of

video diaries, and serves as a guide for how to engage video diaries in ethnographic and qualitative research.

Chapter 4: '(In)Equitable Shifts: Mapping a Pivot to Digital Diary and Remote Research Methods with Queer Youth in the Times of Covid-19', by Rodney Stehr, Danya Fast, and Rod Knight, presents the authors' experiences of evolving research regarding sexual and gender-identity minority young people (ages 15–29) towards an online protocol using digital methods. The authors discuss their use of and experience with using digital diaries to conduct virtual longitudinal qualitative research, and present both the strengths and weaknesses of this method.

Chapter 5: "'To Be or Not to Be?' Qualitative Research upon and during a Pandemic Outbreak', by Gillie Gabay, aims to disentangle the problems qualitative researchers may experience when planning and implementing rigorous research upon and during a crisis. The chapter address practical and necessary concerns for the qualitative researcher and works as a guide for how best to conduct research during challenging times.

Chapter 6: 'Adopting Digital Methods: Conducting Qualitative Interviews and Focus Groups in the Midst of a Pandemic', by Ruth Strudwick and Hollie Hadwen, explores the foundational theory of qualitative research methods, specifically semi-structured interviews and focus groups, and the issues that arise when adopting a digital approach. The authors explore the practical considerations, challenges and benefits of utilising digital methods.

Chapter 7: 'Lessons Learned Conducting Online Qualitative Interviews during Covid-19', by Sally Lindsay, Hiba Ahmed, Vanessa Tomas, and Abirami Vijaykaumar, discusses the barriers to, advantages of and crucial lessons learned by the authors while conducting online interviews during the pandemic. The chapter engages a qualitative study focusing on the employment experiences of youth with and without disabilities throughout Covid-19.

Chapter 8: 'Virtual Interviewing in the Age of Covid-19: Considerations for Qualitative Research', by Charles Edmund Degeneffe, focuses on the use of virtual approaches to data collection in qualitative research during the Covid-19 pandemic. The chapter provides background information on virtual interviewing, investigating researcher and participant perspectives, and offers best-practice considerations qualitative researchers should be aware of when managing the technical aspects, participant engagement, and ethical issues of virtual interviewing.

Chapter 9: 'Minimizing the Impact Technology Has on Interviewer–Interviewee Rapport: An Existential-Phenomenological Analysis', by

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Patrick M. Whitehead and Gary Senecal, discusses post-phenomenology as a form of conducting qualitative research. The chapter examines whether something of importance is concealed when qualitative researchers depend on the use of technology. A three-year international qualitative study on PTSD with active-duty military, which relied heavily on technology, is used to examine the strengths and weaknesses of combining technology with phenomenological healthcare research.

Chapter 10: ‘Participatory and Invasive Online Worlds: Exploring the Research Method of Qualitative Digital Ethnography’, by Adele Philips and Shane Blackman, argues that there is great value in utilising online ethnographic approaches. Whilst the chapter notes the caveats to these approaches, the authors position the strengths as outweighing the potential negatives.

Chapter 11: ‘Using Online Survey Tools to Improve Access to International Experts: The ‘E-Delphi’’, by Georgina Clutterbuck, presents the E-Delphi method as a modern, flexible research approach with the potential to produce quality data in a time- and cost-effective manner. The chapter discusses the challenges and advantages of the method and suggests best practices for employment.

Chapter 12: ‘Refining Interview Protocols for Online Interviews on the Employment of Persons with Down Syndrome: Insights from a Pilot Test’, by Md Mizanur Rahman, Abg Safuan, Sharifa Ezat, Razitasham Safi, Chen Yoke Yong, Rosalia Saimon, and Ting Chuong Hock, notes the increased necessity for adopting online interviews in qualitative research during the Covid-19 pandemic. The chapter discusses the challenges related to ensuring the validity of the interview protocol, especially when involving people with intellectual disabilities. The authors conducted a pilot test in an attempt to validate the interview protocol and to solidify the trustworthiness of the data. The authors discuss the experience and their findings.

Chapter 13: ‘Technology-Aided Programs to Support Leisure, Communication, and Daily Activities in People with Intellectual and Multiple Disabilities’, by Giulio E. Lancioni, Nirbhay N. Singh, Mark F. O’Reilly, Jeff Sigafoos, and Gloria Alberti, provides an overview of studies assessing technology-aided programs to promote independent leisure and communication or combinations of independent leisure, communication and daily activities in people with mild to moderate intellectual disability often associated with sensory and/or motor impairments. The chapter presents the studies’ programs and their outcomes and discusses three key challenges found within the studies.

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Chapter 14: ‘Virtual Qualitative Data Collection: A South African Autoethnographic Perspective’, by Shantel Lewis, Charlene Downing, and Christopher M. Hayre, presents an account of virtual qualitative data collection using autoethnographic approaches. The chapter illustrates a PhD candidate’s experience whilst conducting individual and focus group interviews virtually in a developing nation. The authors discuss the narrative and offer recommendations for conducting virtual qualitative data collection.

Chapter 15: ‘Afterword’, by Paul M. W. Hackett, Christopher M. Hayre, Ava Gordley-Smith, Marcia Scherer and Dave J. Muller, briefly discusses the authors’ projections for the future of digital research tools in healthcare research. The authors share qualitative survey results to support their claims and present a forward-looking perspective to conclude the exchange of diverse views within this book.

CHAPTER 2

Doing Digital Qualitative Research
*Key Ethical Considerations**Rebecca Wise, Jeff Gavin, and Karen Rodham***Introduction**

As we write this chapter in June 2021, researchers are conducting and designing studies whilst navigating the ever-changing Covid-related restrictions. The Covid-19 pandemic has forced some researchers to rethink their approach to recruitment and data collection, and many have turned to the digital world to continue their research (see Nind, Meckin and Coverdale, 2020 for an overview). Indeed, as Howlett (2021, p. 1) has noted:

The methods many of us came to employ, or will be employing, were not part of our original research plans, nor ones with which we have had much training or experience, or even gave much thought to, prior to the pandemic.

With this in mind, it is important to consider the ethical challenges for researchers who are, or who will be, employing qualitative digital research. However, it is important first to explain what we mean by ‘digital research’. Put very simply, we define digital research as that which is conducted on or by the Internet or on or by digital social media. Similarly, the British Psychological Society (2021, p. 6) uses the term ‘Internet-mediated research’ (IMR), and broadly defines it as ‘any research involving the remote acquisition of data from or about human participants using the Internet and its associated technologies’.

Digital research offers the qualitative researcher new opportunities to conduct their research. Perhaps they will conduct their interviews via video technology or through online messaging. Maybe they will choose to run online focus groups, which then allows people from all over the world to join in. Alternatively, perhaps they will collect pre-existing online qualitative data: for example, Instagram posts, Tweets, Snapchats and so forth. Or they could collect such data prospectively. Indeed, digital research presents

researchers with myriad opportunities to collect data in ways that are often cheaper than traditional methods (e.g., no travel costs, no postage costs). It also provides access to a diverse participant pool (see, e.g., Gavin and Rodham, 2020; Lobe, Morgan and Hoffman, 2021; Rahman et al. 2021; Roberts, 2015). The digital environment also allows researchers to observe behaviour and communication. For example, Keim-Malpass et al. (2013) analysed online blogs written by young women living with cancer to better understand their experiences, whilst Talbot et al. (2017) wanted to understand whether and how photographs might be used in social media to encourage and inspire emulation of those depicted. Neither of these studies prompted the production of the data (blogs and photographs); the researchers simply analysed data which was freely available in the digital world. They were therefore able to observe their participants without influencing the communication or behaviour of interest.

Having defined what we mean by ‘digital research’ and highlighting some of the opportunities it presents researchers, it is important to remember that the digital world is fast paced and ever changing. For example, when Kosinski et al. (2015) were writing their article on the opportunities, challenges, ethical considerations and practical guidelines for using Facebook as a research tool, they noted that the American Psychological Association’s website only listed three documents containing guidelines relating to research on the Internet, all of which had been written before Facebook came into being.

A couple of years later, the British Sociological Association (2017) stated that it was not possible to create guidelines that could address all current and future forms of digital research. This inability to keep up with the fast-changing online world and the impossibility of creating a set of all-encompassing rules that account for all eventualities means that the onus is on all of us to take collective responsibility. Similarly, the British Psychological Society’s (2021) comprehensive internet-mediated research guidelines bring to researchers’ attention issues with which they should familiarise themselves. At the same time, the guidelines raise awareness that as technology advances, changes and grows, it both extends opportunities for research and introduces extra complexities and challenges to interpreting and applying ethical principles in ways that might not at first be obvious.

In short, it is not possible to have a set of ethical rules that can deal with all situations. Indeed, if we consider our own personal lives for a moment, we can neither control nor plan for all eventualities. Yet we (mostly) find that we can apply our existing skills, experience and ‘rules-of-thumb’ to

cope with (to steal a phrase from Donald Rumsfeld; see Seely, 2003) the ‘unknown unknowns’ that occasionally crop up unexpectedly in our lives. It is the same for researchers venturing into the ever-changing digital world. Here we need to think about how the multilayered digital world impacts on our approach to doing, managing and disseminating digital research – in other words, the basic ethical principles underpinning research remain universal (see The Belmont Report, written by the Department of Health, Education and Welfare (1979), for more detail):

Respect for persons: ensuring that individuals are treated as autonomous agents, and that anyone with diminished autonomy is protected.

Beneficence: maximising possible benefits whilst minimising possible harms.

Justice: ensuring participants are recruited and treated, and research outcomes are disseminated: fairly, equitably, and appropriately.

However, what is different now is how these principles might be applied in a fast-changing, multilayered context which brings a high risk of unintended consequences. Therefore, how the principles are applied *and* how unexpected happenings are dealt with will rely on researchers’ and ethics committees’ ability to act carefully, with due diligence, with the information they have at that time. Indeed, we have argued elsewhere (Gavin and Rodham, 2017) that researchers would do well to accept that ethics for our digital age requires the development of a different mindset: one that maintains the central ethical mantra of ‘do no harm’ but no longer relies on traditional, clear-cut ‘If–Then’ rules and regulations. Instead, the application of ethical principles has become more a process of solving puzzles.

In this chapter we focus on the key ethical challenges (puzzles) facing researchers engaged in qualitative digital studies and highlight questions we believe researchers should be asking themselves. We conclude with some important messages for supervisors, researchers and members of ethics committees.

Recruitment of Participants

In terms of the principle of justice outlined in the introduction to this chapter, researchers should consider who is likely to participate in the proposed research. Researchers should consider accessibility when designing their studies, whether they be analogue or digital. Work requiring face-to-face, in-person participation can be difficult for those with, for example,

mobility or speech problems. Transport to and from the research location, or difficulty with communication, may exclude people from taking part. The digital world could allow members of previously excluded groups to participate by removing the need to travel or to communicate verbally. However, conducting interviews and focus groups online may also inadvertently exclude groups of people whose voices ought to be included. For example, this type of research could exclude those who cannot access the Internet, as well as those who do not have a private space where their participation in our research will not be disturbed or their contributions will not be overheard (if spoken) or seen (if written). For example, Howlett (2021, p. 9) noted that some of her participants were not alone during the data collection:

One participant, for instance, introduced me to his two young daughters when they entered the room he was sitting in, and near the end of the conversation, he presented his cat to the camera. Similarly, the participant who sat in his family's backyard during the focus group introduced his mother to everyone on the call.

Confidentiality of participants' contributions cannot therefore be protected by researchers. As researchers we may not know whether anyone else is sharing the space with our participants and we have no power to ensure that participants' contributions are not overheard or seen. These issues have come to the fore in recent years as many of us moved our lives online to cope with the restrictions imposed upon us by the various Covid-related lockdowns. Many people have had to share computers, Internet connections and rooms, whilst others lacked the connection, equipment or finances to purchase data to enable them to access the Internet.

Similarly, observational research drawing on social media, such as X (formerly Twitter), Facebook or Instagram, may also inadvertently silence particular voices. This is particularly problematic in research that claims to be exploring 'public discourse' (e.g., Lachmar et al., 2017; McHugh, Superstein and Gold, 2019), public opinion (or 'collective sentiment' as it is often referred to when expressed on X; e.g., Cody et al., 2015) or public understandings of health and/or risk (e.g., Hou et al., 2021). Often, much of the public is excluded from such research. For example, software enabling the collection of social media data can only access publicly available posts; that is, it cannot collect posts from accounts that are set to private. On social media platforms such as Facebook or Instagram, this excludes almost half (45 per cent) of users (Tankovzka, 2021).

One way around this is to include ‘participants’ in data collection – for example, researchers can ask users for access to their pages; however, the compromise with this is that such an approach undermines the benefits of naturally occurring data. In other words, we know that if a participant knows they are being observed, they may alter the way they behave (see Cambridge, Witton and Elbourne, 2014 for an explanation of how the Hawthorne Effect has come to be interpreted). Furthermore, accessing someone’s private Facebook, X or Instagram involves requesting and being accepted as a ‘friend’ or ‘follower’ of that person. This raises ethical questions with respect to boundaries between the researcher and the researched and the notion of a ‘friend’.

Researchers will need to show that they have a clear rationale for their choice of desired participants/sample and would be well advised to explore the inclusion of strategies to help overcome some of the barriers in order to widen participation. For example, in a recent funding application (unpublished and awaiting outcome), one of the authors of this chapter (Rodham) was part of a team that built in the purchase of mobile phones and tablets to loan to those without access to equipment so that they could participate in their proposed study.

Consent

Consent is a cornerstone of conducting research ethically. Whilst some researchers have reportedly moved their research online as a means of circumventing the ethical approval process (see the example detailed by Roberts, 2015), the key issue is that the level of ‘publicness’ of social media data is not always clear cut (e.g., Gavin and Rodham, 2020; Lange, 2008; Roberts, 2015):

In an IMR context, the distinction between public and private space becomes increasingly blurred. For one thing, much Internet communication can take place in both a private (e.g., the home) and public (e.g., open discussion forum) locations simultaneously. (BPS, 2021b, p. 8)

A post can be public in the sense that it reveals identifying information, but private in the sense that it is only accessible to approved ‘friends’ or ‘followers’ of the poster’s private account (i.e., it is ‘publicly private’). On the other hand, posts can contain no identifying information but be accessible to anyone with Internet access (i.e., ‘privately public’). Such distinctions make basic ethical guidelines from our professional bodies difficult to interpret and put into practice in the context of the ways that

social media use is understood by users. The UK Economic and Social Research Council (ESRC), for example, states that:

Information provided in forums, social media or spaces on the internet that are intentionally public would be considered ‘in the public domain’, but the public nature of any communication or information on the internet or through social media should always be critically examined. (ESRC, 2021)

But this intentionality is at the core of this ethical dilemma with regards to collecting social media data. As we ask in a previous study on ethics (Gavin and Rodham, 2020, pp. 3–4), ‘How can we be sure that someone posting information online knows or expects it to be public? Does it matter if information is posted (and collected for research) on discussion forums, Twitter, YouTube or Facebook?’ The BPS recommendation is that on occasions where there is ambiguity about whether IMR data is in the public realm, as researchers we ought to consider the potential harm our research could cause:

When there is a level of ambiguity concerning whether data are ‘in the public domain’ or not, researchers should particularly consider likely user perceptions and attitudes, and the extent to which undisclosed observation may have potentially damaging effects for participants, before making decisions on whether to use such data and whether gaining valid consent is necessary. (BPS, 2021a: p. 9)

Furthermore:

Valid consent should be obtained where it cannot be reasonably argued that online data can be considered ‘in the public domain’, or that undisclosed usage is justified on scientific value grounds. (BPS, 2021a: p. 10)

Choice of Digital Platform

During the pandemic, familiarity with digital platforms increased hugely, and engagement with such platforms has thus become more normal amongst the Western general population. For example, in April 2020, Kate Murphy, writing for *The New York Times*, said: ‘Last month, global downloads of the apps Zoom, Houseparty and Skype increased more than 100 percent as video conferencing and chats replaced the face-to-face encounters we are all so sorely missing.’

In the same way that the general population have been familiarising themselves with this technology, so too have researchers, and the choice of