



This is a repository copy of *Researching experiences of cancer risk through online blogs: a reflexive account of working toward ethical practice*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/167174/>

Version: Accepted Version

Article:

Ross, E. orcid.org/0000-0002-5165-7649 (2020) Researching experiences of cancer risk through online blogs: a reflexive account of working toward ethical practice. *Journal of Empirical Research on Human Research Ethics*, 15 (1-2). pp. 46-54. ISSN 1556-2646

<https://doi.org/10.1177/1556264619867840>

Ross E. Researching Experiences of Cancer Risk Through Online Blogs: A Reflexive Account of Working Toward Ethical Practice. *Journal of Empirical Research on Human Research Ethics*. 2020;15(1-2):46-54. Copyright © 2019 The Author(s). DOI: 10.1177/1556264619867840

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Abstract

By providing space to document personal narratives and hold virtual discussions, the Internet represents a fruitful resource for sociologists of health and illness. However, the use of social media content for research entails complex ethical considerations. Due to the fluidity of online material, existing ethical guidelines advise a deliberative approach. However, this has led to disparity in the use of social media resources within the social sciences.

I share an account of 'doing ethics' for qualitative research with blogs focused on hereditary cancer risk. Blogging emerged as cathartic for authors, but also a means of accessing support. Blogs may thus be construed as constitutive and not only representative of cancer (risk) experience. Ethical questions surround anonymity, and the appropriation of authors' accounts beyond the context in which they are composed. By sharing reflections on working with hereditary cancer risk blogs, I contribute to the continued reflexivity of social media researchers.

Article: 5371 words

Introduction

Online research methods present social scientists with novel opportunities to access personal accounts of illness experience. Social media platforms provide access to a variety of forms of illness narrative, crafted by patients and family members in dynamic and creative ways through personal blogs and social networking sites. However, the use of this diverse content in social scientific research brings with it complex ethical considerations. Engaging with social media for qualitative research entails an appreciation of its many forms, which vary in terms of user interaction (one-time or ongoing), types of content produced (e.g. text, images, audio), and the kinds of accounts that can be relayed through these varying mediums, which can include in-depth compositions or be limited to a small number of characters. Social media descriptions of illness experience also serve a variety of functions, including support-seeking, information sharing, and awareness raising (Ziebland et al., 2004).

Due to the fluidity of uses and content within online settings, existing guidelines advise a 'deliberative' approach to research ethics (Markham and Buchanan, 2012). However, this has facilitated disparity in approaches to ethical practice within social media research, with the potential for ethically problematic research to proceed unchecked (Samuel and Derrick, 2017). Reflexivity is thus required by researchers working with this material to develop approaches to the analysis and reproduction of online accounts that are sensitive to their authors' situations and protect them from potential harm. It is key that researchers share their reflections on ethical practice in social media research, to contribute to an 'ethics ecosystem' (Samuel and Derrick, 2017), and move towards a robust, and as far as possible, consistent approach to ethical practice.

In this article, I contribute to this aim by sharing experiences of 'doing ethics' for qualitative research with online blogs. I outline literatures engaging with online environments for health research, and particular ethical considerations within this context. I describe the blogs drawn on for piece of research conducted with colleagues on experiences of living with cancer risk (see Ross et al, 2018) and the unique attributes of these as a form of research material; with these depicted as not only reflective but constitutive of illness experience. From this position, I describe the ethical approach taken to the use of social media content for this research, and the implications of this for social scientific reflection on online environments more widely.

Social media and health research

Social media, by providing spaces for individuals to document personal narratives in online web logs (blogs), and hold virtual discussions in online forums centred on shared experiences, may be viewed as a rich resource for qualitative researchers. This is particularly true for those working in the field of

health and illness, as Internet use becomes increasingly entwined with wider health-related practices (Nettleton and Burrows, 2003). In areas of the world with ready access to the Internet, face-to-face clinician-patient interactions are today commonly supplemented by the use of online resources (Ziebland and Wyke, 2012). This may take the form of obtaining medical information (Hardey, 1999; McMullan, 2006), seeking immediate health-related advice (Doyle, 2013), or interacting on a longer-term basis with those sharing a health condition (Broom et al., 2009; Seale et al., 2006). Social media platforms may thus be seen as a 'social science laboratory' (Eynon et al., 2008) for scholars of health and illness.

Unlike qualitative data produced in the presence of a researcher, or structured by survey methods, narratives produced through social media platforms are spontaneous (Snee, 2013b), created independently of interaction with an interviewer or facilitator. Analysis of online communication thus allows for reflection on research questions in new and sometimes unexpected ways. Existing studies using social media to explore sociological questions have demonstrated the ways in which these platforms can facilitate the composition and communication of in-depth illness narratives through online blogs (Kotliar, 2016) and the exchange of disease experience within online forums (Armstrong et al., 2012). Micro-blogging has also emerged as a site for sociological investigation, with sites such as Twitter facilitating short accounts of experience and appeals, around which collective user action and debate can be mobilised (Vicari, 2017). This is also true of the networking site Facebook, which allows access to sources of specialised support through pages aligned with particular health conditions (Gage-Bouchard et al., 2017). More recently, mixed media sites such as Snapchat and Instagram allow users to express illness experience in wider creative ways, through images, sound and video (Stage, 2019). Conceptually, researchers have shown how sociological attention to the material produced within online spaces such as these can shed light on the explanatory devices used by individuals to make sense of illness experience (Pender, 2012; Coll-Planas and Visa, 2016). With respect to the illness narratives, personal blogs provide a particularly rich source of material for sociologists seeking to understand the ways in which personal accounts of disease are shaped by wider sociocultural factors. In what follows, I reflect on working with blogs for the purposes of social science research on hereditary cancer risk.

[Ethical issues associated with the use of blogs in social research](#)

In terms of research seeking in-depth reflection on emotions and experiences, blogs may be preferable to resources such as online forums and microblogging sites, with the latter comprised of shorter posts and/or discussion, sometimes from multiple users. Blogs are generally created by one author making regular posts of varying lengths. Posts may reflect on experiences, recount events or share information, and can comprise of images, videos and links to other webpages. Blogs may be

viewed as akin to diaries (Barlow, 2008: 15), providing a space for individuals to share intimate thoughts and emotions. Like the maintenance of a diary, blog posting is an ongoing project. This allows researchers to explore processes of change in emotions and experience over time (Hookway, 2008). However, blogs generally exist in a public space, rendering them accessible to a large audience. Though this audience can never be fully known, blogs may be written with a specific viewer in mind – serving as a means of keeping in touch with loved ones (Snee, 2013a), or of accessing support through isolating periods of illness (Kim and Gillham, 2013).

The use of blog content as sociological research data is subject to the wider ethical guidelines associated with the discipline, with the responsibility to safeguard the interests of those involved in or affected by their work remaining paramount (British Sociological Association, 2004). This commitment entails respecting participants' anonymity and privacy, and ensuring that personal details remain confidential (*ibid*). However, the use of online material for social research demands new ethical considerations and guidance, with issues of informed consent, anonymity and confidentiality not adequately addressed by ethical guidelines applied to more familiar social research methods. This is partly attributable to the malleability of material accessed via the internet, which straddles the boundaries between 'public' and 'private' data. Added to this is the fact that the mediums through which individuals publish material online, and the search facilities available to users, are constantly evolving. Due to these factors, ethical guidance with regards the use of online data is dynamic, and no official guidance regarding internet research has been adopted at national or international level (Markham and Buchanan, 2012).

As such, guidelines produced by the Association of Internet Researchers (AoIR) (Markham and Buchanan, 2012), generally cited in research using online methods, advocate a 'bottom-up' approach which allows for differing disciplines and research contexts, as opposed to providing a 'top-down', universal set of principles and regulations. Researchers are advised to engage in a deliberative process when making ethical decisions about online research, taking into account the vulnerability of online data, and balance the rights of authors (who might be considered 'communities', 'authors' or 'participants') against the potential benefit of the research (Markham and Buchanan, 2012). This contextual approach is also taken by the British Sociological Association, who advise familiarity with emergent guidelines and debates, and 'erring on the side of caution' when making judgements as to the wellbeing of online research participants (British Sociological Association, 2004).

Existing studies demonstrate the range of strategies adopted by researchers when engaging with online material. Turner's (2013) work, exploring patient and professional accounts of oophorectomy,

treats text taken from publically available blogs as published work, citing blog authors by name alongside peer reviewed social scientific research. As such the research has not been considered to involve 'participants', and ethical considerations concerning the inclusion of blogs are not outlined. Kotliar (2016: 1207) followed the same approach in research concerning women with depression, viewing blogs as "creative works that should be properly credited". Kotliar explicitly notes that ethical approval from a review board was not sought. Snee (2013b), exploring young people's narratives when embarking on gap years from the UK, frames the personal travel blogs she draws on as 'representations of experience', viewing these as her object of study as opposed to their authors as research subjects. Snee argues that there is strong case for viewing blogs as situated in the public domain, and depicts the use of these blogs as not being subject to informed consent. She did, however, remove the personal details of authors, blog URLs, and identifiable information when publishing verbatim quotes. In more recent research, von Benzon (2019) reflects that seeking consent for the use of publically available online data, and researcher efforts to preserve anonymity, may be viewed as paternalistic. Positioning blog authors as vulnerable, she argues, denies their status as cogent actors, with this raising its own ethical concerns surrounding the author's right to representation in the public domain (see also Bassett and O'Riordan, 2002). The use of blogs in social research, argues von Benzon, demonstrates respect for the blogger as 'author', and in taking this perspective blogs might be cited in the same way as online articles, including names and online locations, without seeking consent. This however, would be subject to researcher "discretion and judgement"; indeed, having not sought consent von Benzon changed blog and author names in her own research, and did not use verbatim quotes (2019: 185).

The variability of approaches within existing publications reflects the flexibility granted to researchers through guidelines around online methods in the social sciences. However, there is increasing recognition that this flexibility may be detrimental to researchers, as well as social media users. As Samuel and Derrick (2017) make plain, where researchers are left to make their own judgements about the use and publication of social media material, this can risk important ethical decisions being left unresolved, or of more concern, that ethically problematic research 'falls through the cracks'. Further, related to variations in researcher practice and the submission of social media research proposals to research ethics committees (RECs), REC members may advance conflicting views when reviewing social media research, or feel inexperienced for this task (Hibbin et al., 2018). In what follows, I outline the approach taken to a piece of research conducted with a social media platform (online blogging), as part of a sociological investigation into living with inherited cancer risk. I focus in particular on two key ethical issues which, as described above, have proved contentious within existing literature; the seeking of consent from authors to use their blog

content in social scientific research, and the preservation of authors' anonymity. By sharing personal experiences of research in this area, I highlight some of the complexities involved in studying online blogs, and contribute to ongoing discussions around what ethical social media research in the field of health and illness might look like.

Research context: Narrating cancer (risk) online

Due to their composition as ongoing and in-depth accounts of experience, sociologists of health and illness have engaged with blogs as a means to access illness narratives (Kleinman, 1988). Illness narratives allow individuals to articulate trauma, pain and recovery, providing researchers with insight into how individuals make sense of disease (Frank, 1995). Illness narratives are frequently engaged with in social scientific research on experiences of living with and beyond cancer. As a health condition, cancer is associated with mortality and suffering (Bell, 2009), and known through visceral imagery and metaphor (Sontag, 1978). Existing research with online blogs documenting experiences of cancer has demonstrated how authors may use blogging as a tool for emotion management in the face of traumatic physical and psychosocial impacts of cancer and its treatment (McCosker and Darcy, 2013), but also as a way to advocate for awareness raising and healthcare improvement (Stage, 2017) and work with and/or challenge medical information in empowering ways (Pitts, 2004; Coll-Planas and Visa, 2016). Such work has enriched social scientific understanding of the disease, providing insight into the everyday labour required to live with cancer. Less often considered through social media research are experiences of living with inherited cancer *risk*.

Those living with hereditary cancer syndrome (HCS) have a genetic mutation associated with a heightened risk of the disease, and HCS accounts for 5-10% of all cancers (Garber and Offit, 2005). Social scientific research has increasingly focused on experiences of living with inherited cancer risk as the availability of genetic testing for these conditions widens (Wright et al., 2018), and as high profile cases of living with a BRCA 1/2 mutation (predisposing individuals to breast and ovarian cancer) have appeared in the media (Dean, 2016). The stories of these individuals are important to capture within the sociology of health and illness. Narratives of cancer risk further understandings of how the extension of illness experiences beyond diagnosis might shape patient engagement with medical care and prevention, and how being rendered a 'patient in waiting' (Timmermans and Buchbinder, 2013), impacts on relationships and identity. For example, knowing about genetic risk may position individuals in a liminal state between health and illness (Scott et al., 2005), whilst others may see themselves as already living with cancer, conflating risk with the disease itself (Prior, 2007; Pender, 2012). Genetic information also has implications for family members, some of whom may not wish to know of their own risk status (Etchegary et al., 2009).

Though hereditary breast and ovarian cancer is most often discussed in sociological literature (Kenen et al., 2003; Hallowell et al., 2004), there are over 50 forms of hereditary cancer syndromes, including conditions predisposing individuals to colorectal cancer, such as Lynch Syndrome and Familial Adenomatous Polyposis (FAP). Those living with a predisposition to colorectal cancer face significantly different physical and emotional issues to those living with other forms of cancer risk. Preventative surgeries often require removal of all or part of the bowel (colectomy), entailing lifelong physical consequences including the use of a colostomy bag and/or chronic conditions such as short bowel syndrome (Tudyka and Clark, 2012). Blogs written by those with an inherited predisposition to cancer have great potential to enrich our understanding of this lesser researched condition. The longitudinal element of blogging provides insight into how significant events play-out for authors over weeks and months, including major preventative surgeries and associated decision-making, and screening events. Such perspectives have the potential to contribute to existing sociological literature considering the impacts of living with disease risk on daily life (Etchegary, 2010), and reflections on (invasive) treatment for the purposes of disease prevention (Fosket, 2010).

As such, the research reported below set out to analyse blog accounts composed by those living with an HCS predisposing them to colorectal cancer. Initially, twelve blogs were identified using an online search engine (see Ross et al, 2018 for further detail about the sample and methodology). These were wide and varied in their scope and duration, with some being composed over months and others several years. Initially the posts featured in all twelve blogs were considered with reference to sociological literature on living with risk, along with any images used and written exchanges with readers. At this stage, the ethical approach to this research was still evolving. Indeed, the act of *reading* blog posts alone was not considered to pose specific ethical concerns, due to this being publically available material. This raises questions with regards when research ‘begins’ when working with social media material, and at what point these published accounts of experience become data. As acknowledged within existing guidelines, an appropriate and responsive ethical approach to this material emerged as the research progressed, with the research context, blog content and potential academic outputs all taken into consideration.

Exploring narratives of cancer risk through online blogs: Ethical considerations and approach

When working with HCS blogs, the negotiation of ethical practice was as much instinctive and affective as it was procedural; drawing on ‘personal ethics’ (Samuel and Derrick, 2017), and deeply tied to the unique content of the blog posts. **Importantly, a consideration of blog posts as constitutive of illness experience was key to the shaping of the approach outlined below. From this**

position, the blog posts analysed for this research were not viewed as simply representative of (pre-)illness experience; i.e. as a textual description of this experience that may be considered to exist as separate from and subsequent to diagnostic, treatment and embodied health events. In the approach taken below, blog posts and the act of blogging are instead perceived as *integral to and inextricable from* the illness experience of blog authors considered for this research. This is due to their facilitation of the creation and expression of personal illness narratives to make sense of ill health (Frank, 1995), and the role of blogging in treatment decision making, support seeking and wider illness trajectories for these authors (see also Ziebland et al, 2004). As such, it was felt that research with cancer risk blogs defies categorisation as involving either 'text' or 'human subjects', with this discussed further below.

This shaped the way in which extracts from blogs were handled within this research. To develop an appropriate procedure, colleagues in the field were consulted when deciding how to approach the use of blogs in this research, but also prior experiences of data collection with those experiencing cancer, and literature around cancer (risk) and illness narratives. In what follows, I outline the approach taken with regards anonymity and informed consent in research with HCS blogs, two key issues that have been the focus of debate within existing literature.

Maintaining anonymity

Reflection on the point at which blog content came to be considered as 'research data' was an important factor contributing to decision-making around an appropriate ethical stance. The use of pre-existing online blogs authored by those with hereditary cancer syndrome did not pose as obvious an ethical dilemma as might be expected with, for example, use of online material discussing criminal actions, or covert research involving the researcher masquerading as a patient (Brotsky and Giles, 2007). Instead, the online blogs located through internet searches detailed mundane activity including personal accounts of surgeries and decision-making, but also wider reflections on friendships, support and community. Each blog was publically available, often with minimal effort made to ensure anonymity on the author's part. In many cases personal names were frequently used along with photos of people and places, and authors often encouraged their audience to share the blog with others; indeed, three of the bloggers were also strong advocates for raising awareness of their condition, and had made TV and/or radio appearances as a result of their blog. As such, the argument for using blogs in social science research without restriction, due to these being publically available, seems appropriate here.

However, the specific context for this research entailed considerations of the consequences of publishing names and verbatim quotes for those other than the author themselves. For example,

some blog posts candidly described discussions with family members around the topics of hereditary risk and reproductive decision-making. There were also vivid descriptions of unpleasant encounters with potentially identifiable medical professionals, often in cases where there was a lack of awareness of hereditary cancer syndrome on the part of the health professional. Further, and of additional concern, were the intimate details of surgery posted by some authors, alongside photographs of these operations and recovery, intended to provide information to others experiencing similar interventions. Photographs also often captured friends, family and other bloggers, who may not have been aware of their presence on the blog.

Of equal significance was the potential for any academic publication, an output that blog authors would likely not have anticipated, to be read by genetic relatives of the authors. Qualitative research has demonstrated the impacts that knowledge of genetic risk can have for individuals, with these ranging from a burden of responsibility to decide whether to undergo monitoring or risk-reducing surgeries (Hesse-Biber, 2014), but also guilt and blame for potentially passing mutations on to children (Hallowell et al., 2006). It is incumbent upon researchers to consider the wider implications of our research, particularly in the case of genetic information which cannot be 'unknown'. As described above, other researchers have argued that blog authors may be recognised and accredited akin to other forms of published material. However, with regards the specific (pre-)illness contexts of these bloggers, it was felt the implications of waiving anonymity outweighed any justification for the explicit use of author names in academic work.

As such, when drawing on blog posts in publication, which entailed the reproduction of verbatim quotes, anonymity was assigned to all authors as far as possible. Pseudonyms were used, and identifying information excluded. This was also with bloggers' significant others in mind, due to the presence of sensitive material including reflections on mortality and having children. This approach was outlined to blog authors themselves, discussed further below.

Informed consent

I have alluded to the emotional and physical burdens that living with hereditary predisposition to colorectal cancer can present to individuals. As we have observed, existing work has shown how living with cancer risk can entail difficult decisions with regards life-impacting surgeries and the long-term consequences of these. Further, a diagnosis of hereditary cancer syndrome can place individuals in a liminal position between health and illness as they become aware of their heightened cancer risk, entailing a heavy emotional burden.

On reading the selected blogs it became clear that authorship of posts could be interpreted as a means of managing the difficulties of living with hereditary cancer syndrome. For example, many of the blogs considered in this research pointed to the therapeutic or “cathartic” effect of maintaining a personal blog; a place where one blogger described he could do the “heavy lifting” that would otherwise intrude on his subconscious (see Ross et al, 2018). Some authors used their blog to “rant” when feeling particularly worried, angry or frustrated, or as a way of “offloading” emotions they found difficult to harbour by themselves. This could be at the time of yearly screening appointments to monitor for signs of colorectal cancer, or anniversaries of family bereavements, when fears and anxieties were often brought to the fore. Importantly, the act of blogging served an important means of connecting with others. The audiences addressed by blog authors considered in this research were generally their family, supporters, and the wider ‘chronic illness’ community; indeed, bloggers often thanked their readers for direct communication they had received, which included offers of support and advice. Authors reached out to others experiencing hereditary cancer syndrome within their posts, but also those with non-hereditary colorectal conditions entailing similar surgical procedures. Through blogging, authors described learning from others’ experiences of surgeries and treatment decision-making, as a means of feeling more prepared to undergo their own procedures (*ibid*).

From this perspective, the act of blogging and its product does something beyond the representation of experience, and may be viewed as simultaneously *constitutive* of illness experience, for authors and their readers. As Kotliar (2016) argues in his work with blogs written by women with depression, blog authorship allows those experiencing illness to collaboratively reconstruct personal illness narratives as a means to cope with ‘etiological suffering’. The act of blogging, argues Kotliar, thus has therapeutic potential (2016: 1212). In the context of cancer, (McCosker, 2008) also points to the role of online spaces as a forum for configuring illness experience as meaningful, and recover a sense of agency amidst trauma. Drawing on Frank (1995), McCosker and Darcy (2013: 1269) thus assert that in writing one’s story online, “the truth of illness is not only what was experienced, but equally what becomes experienced in the telling and its reception”.

In this way, blog posts can be seen as productive, and not solely representative of illness experience. Such an understanding challenges depictions of blog posts as merely textual representations, to which the application of the human subjects model of research ethics, necessitating informed consent, is deemed inappropriate (White, 2002). A view of blog authorship as playing a constitutive role in experiences of health and illness blurs the boundaries between viewing online material as either a ‘representation’ or ‘human subject’ (White, 2002; Basset and O’Riordan, 2002). Indeed,

Lupton notes that online spaces may be viewed as active and dynamic “affective atmospheres”, which she argues contribute to emotional wellbeing and good health through the alleviation of isolation (2017: 7). From this perspective, online material may be seen to entail a ‘liveliness’ and sociality (cf. de la Bellacasa, 2011). I argue that such a position causes us to consider ethical issues around the appropriation of posts for academic research in new ways. In the context of blogs recounting experiences of hereditary cancer syndrome, where blog posts and the act of blogging served to contribute to authors’ efforts to physically and emotionally manage cancer risks, there were questions around the acceptability of viewing these as text to be engaged with in the same way as academic or news publications (von Benzon, 2018; Turner; White, 2002). Appropriating these carefully crafted therapeutic tools beyond the purpose and audience for which they were imagined, to the arena of academic research, emerged as a key concern going beyond issues more often emphasised in existing guidelines for research in these settings, such as confidentiality. With each author considered beyond their textual representation, and their blog viewed as both an extension, and constitutive of the individual and their illness experience (Reed, 2005), ethical issues were raised by the reproduction of this material for an academic audience without the permission of authors.

For example, there may be potential for harm should blog authors unexpectedly find themselves re-reading their personal accounts of illness journeys, including fears and reflections on mortality, which may assume new forms and meaning should they travel beyond their original source to academic outputs. Also considered was the labour invested by authors to create blogs, a resource constituting their own experiences of illness (risk) but also those of others living with HCS, and engaged with by wider publics and academic researchers. This comprised affective labour, with bloggers discussing emotional reflections on their condition and the illness experiences or loss of family members, and the act of expressing this entailing further implications for their own wellbeing. Social media users themselves have voiced discontent at attempts to exploit the often unacknowledged labour required to create and maintain illness blogs, particularly when simultaneously undergoing gruelling treatment regimes (McCosker and Darcy, 2013: 1275).

Due to these considerations, prior to publication bloggers were approached by email using contact details given in online blogs, or via their associated Twitter account if one existed, to seek consent to reproduce content from their blog in published research. The majority responded positively, and those who did not respond, blog content was not reproduced verbatim but paraphrased.

Institutional approval from the University of Edinburgh Research Ethics Committee (REC) was also obtained to reproduce verbatim quotes taken from blog posts in academic outputs, and to approach blog authors for permission to do this.

Contacting each author individually was a positive experience, and resulted in gains beyond acquiring permission (in most cases) to reproduce blog posts in academic research. Those who responded were positive about their blog being used, welcoming this as an opportunity to raise awareness of their condition. Three authors offered further assistance, for example links to other resources about the condition produced by themselves or others. This additional communication gave further insight into the reasons for blogging, providing further depth to analysis of posts. Most importantly, contact with individual blog authors served to re-centre the person (cf. White, 2002) and their experiences. As forms of social media shift and expand, and social scientists engage with these in new ways, it is important that author experiences, along with their social contexts and histories, remain at the forefront of our practice.

Reflections

Ongoing personal blogs authored by those living with hereditary colorectal cancer syndrome provide unique opportunities to explore the meanings of cancer risk and its management by individuals. Blog authors featured in this research candidly documented their experiences with surgery, family cancer histories and the impacts of this on their illness experience and identity. Engaging with the unique content of hereditary cancer blogs demonstrated that the act of blogging was not merely representative, but also constituted the illness (-risk) experiences and narratives of authors (Kotliar, 2016; McCosker and Darcy, 2013). This has afforded wider reflection on the use of social media data in social research.

The experience of conducting this study raised questions around the commencement of social media research, and when online resources become defined as research data. As these blog posts were publically available, the act of solely *reading* personal blogs did not 'feel' unethical, despite the fact that this was for the purposes of research, conducted as part of a funded programme of work. Issues surrounding the preservation of anonymity were also unclear. Blog posts were publically available, and not generated through qualitative research methods. However, upon in-depth engagement with the blogs, it became clear that these were intimately connected to illness experience and recovery, and their reproduction for an academic audience caused ethical concern. Attention to existing literature on the subject of genetic risk also highlighted the wider-reaching implications of this material for individuals beyond the author. As such, for this research it was decided that it would be ethically correct to omit personal details, and contact blog authors individually for permission in order to translate extracts from blogs to published academic research.

This approach may not be possible for all research studies drawing on social media data, particularly for mediums where there are high volumes of users such as Facebook and Twitter. As previous

authors have noted, because online research is more dynamic and varied than traditional qualitative methods, blanket guidelines for social media ethics are inappropriate, and a 'personal ethics' approach (Samuel and Derrick, 2017) is more widespread amongst researchers engaging with social media. This is recognised in existing guidelines, which advocate flexibility, and delegate ultimate responsibility to the researcher and relevant ethics committees (Townsend and Wallace, 2016; Markham and Buchanan, 2012). The experience of research with hereditary cancer risk blogs has drawn attention to the individual author behind the published text, but also the importance of their blog posts to their illness experience and recovery. It has also demonstrated that a sensitivity to the research context, gained through engagement with existing research and literature, is key to navigating the complexities of ethical decision-making online. Further, consultation with users and/or user representatives can add insight into the potential far-reaching implications of using social media material in social science research, for authors but also their wider networks. As such, this article echoes calls for a more collaborative approach to social media ethics for individual research projects, not only involving Research Ethics Committees and researchers (Samuel and Derrick, 2017), but also the voices of users themselves.

- Armstrong, N., Koteyko, N. & Powell, J. (2012) 'Oh dear, should I really be saying that on here?': Issues of identity and authority in an online diabetes community, *Health* 16, 4, 347-365.
- Barlow, A. (2008) *Blogging America: The New Public Sphere*. Westport, Connecticut; London: Praeger.
- Bassett, E. H. & O'Riordan, K. (2002) Ethics of Internet research: Contesting the human subjects research model, *Ethics and Information Technology* 4, 3, 233-247.
- Bell, K. (2009) 'If it almost kills you that means it's working!' Cultural models of chemotherapy expressed in a cancer support group, *Social Science & Medicine* 68, 1, 169-176.
- British Sociological Association. (2004) *Statement of Ethical Practice for the British Sociological Association* [Online]. Available: <https://www.york.ac.uk/media/abouttheuniversity/governanceandmanagement/governance/ethicscommittee/hssec/documents/BSA%20statement%20of%20ethical%20practice.pdf> [Accessed 12 September 2017].
- Broom, A., Hand, K. & Tovey, P. (2009) The role of gender, environment and individual biography in shaping qualitative interview data, *International Journal of Social Research Methodology* 12, 1, 51-65.
- Brotsky, S. & Giles, D. (2007) Inside the "Pro-ana" Community: A Covert Online Participant Observation *Eating Disorders* 15, 2, 93-109.
- Coll-Planas, G. & Visa, M. (2016) The wounded blogger: analysis of narratives by women with breast cancer, *Sociology of Health & Illness* 38, 6, 884-898.
- de la Bellacasa, M. P. (2011) Matters of care in technoscience: Assembling neglected things, *Social Studies of Science* 41, 1, 85-106.
- Dean, M. (2016) Celebrity Health Announcements and Online Health Information Seeking: An Analysis of Angelina Jolie's Preventative Health Decision, *Health Communication* 31, 6, 752-761.

- Doyle, E. (2013) Seeking advice about children's health in an online parenting forum, *Medical Sociology Online* 7, 3, 17-28.
- Etchegary, H. (2010) 'I put it on the back burner most days': Living with chronic risk, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 15, 6, 633-649.
- Etchegary, H., Miller, F., deLaat, S., Wilson, B., Carroll, J. & Cappelli, M. (2009) Decision-Making About Inherited Cancer Risk: Exploring Dimensions of Genetic Responsibility, *Journal of Genetic Counseling* 18, 3, 252-264.
- Eynon, R., Fry, J. & Schroeder, R. (2008) The Ethics of Internet Research, in Fielding, N., Lee, R. M. & Blank, G. (eds.) *The SAGE Handbook of Online Research Methods*. London: SAGE, 22-41.
- Fosket, J. R. (2010) Breast Cancer Risk as Disease: Biomedicalising Risk, in Clarke, A. E., Mamo, L., Fosket, J. R., Fishman, J. R. & Shim, J. (eds.) *Biomedicalisation: Technoscience, Health and Illness in the U.S.* London: Duke University Press, 331-352.
- Frank, A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Gage-Bouchard, E., LaValley, S., Mollica, M. & Beaupin, L. K. (2017) Communication and Exchange of Specialized Health-Related Support Among People With Experiential Similarity on Facebook AU - Gage-Bouchard, Elizabeth A, *Health Communication* 32, 10, 1233-1240.
- Garber, J. E. & Offit, K. (2005) Hereditary Cancer Predisposition Syndromes, *Journal of Clinical Oncology* 23, 2, 276-292.
- Hallowell, N., Arden-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C. & Watson, M. (2006) Guilt, blame and responsibility: men's understanding of their role in the transmission of BRCA1/2 mutations within their family, *Sociology of Health & Illness* 28, 7, 969-988.
- Hallowell, N., Foster, C., Eeles, R., Arden-Jones, A. & Watson, M. (2004) Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer, *Social Science & Medicine* 59, 3, 553 - 565.
- Hardey, M. (1999) Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise, *Sociology of Health & Illness* 21, 6, 820-835.
- Hesse-Biber, S. N. (2014) *Waiting for Cancer to Come: Women's Experiences with Genetic Testing and Medical Decision Making for Breast and Ovarian Cancer*. Ann Arbor: University of Michigan Press.
- Hibbin, R. A., Samuel, G. & Derrick, G. E. (2018) From "a Fair Game" to "a Form of Covert Research": Research Ethics Committee Members' Differing Notions of Consent and Potential Risk to Participants Within Social Media Research, *Journal of Empirical Research on Human Research Ethics* 13, 2, 149-159.
- Hookway, N. (2008) 'Entering the blogosphere': some strategies for using blogs in social research, *Qualitative Research* 8, 1, 91-113.
- Kenen, R., Arden-Jones, A. & Eeles, R. (2003) Family stories and the use of heuristics: women from suspected hereditary breast and ovarian cancer (HBOC) families, *Sociology of Health & Illness* 25, 7, 838-865.
- Kim, B. & Gillham, D. M. (2013) The Experience of Young Adult Cancer Patients Described Through Online Narratives, *Cancer Nursing* 35, 5, 377-384.
- Kleinman, A. (1988) *The illness narratives: suffering, healing and the human condition*. New York: Basic Books.
- Kotliar, D. M. (2016) Depression Narratives in Blogs: A Collaborative Quest for Coherence, *Qualitative Health Research* 26, 9, 1203-1215.
- Markham, A. & Buchanan, E. (2012) *Ethical decision-making and internet research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)* [Online]. Chicago: Association of Internet Researchers, Research Ethics Working Committee. Available: <http://aoir.org/ethics/> [Accessed 13 December 2017].
- McCosker, A. 2008. Blogging Illness: Recovering in Public. *M/C Journal* [Online], 11. Available: <http://journal.media-culture.org.au/index.php/mcjournal/article/view/104>.

- McCosker, A. & Darcy, R. (2013) Living with cancer: Affective labour, self-expression and the utility of blogs, *Information, Communication & Society* 16, 8, 1266-1285.
- McMullan, M. (2006) Patients using the Internet to obtain health information: How this affects the patient–health professional relationship, *Patient Education and Counseling* 63, 1–2, 24-28.
- Nettleton, S. & Burrows, R. (2003) E-Scaped Medicine? Information, Reflexivity and Health, *Critical Social Policy* 23, 2, 165-185.
- Pender, K. (2012) Genetic Subjectivity in Situ: A Rhetorical Reading of Genetic Determinism and Genetic Opportunity in the Biosocial Community of FORCE, *Rhetoric and Public Affairs* 15, 2, 319-349.
- Pitts, V. (2004) Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace, *Health* 8, 1, 33-59.
- Prior, L. (2007) Talking About the Gene for Cancer: A Study of Lay and Professional Knowledge of Cancer Genetics, *Sociology* 41, 6, 985-1001.
- Reed, A. (2005) 'My blog is me': Texts and persons in UK online journal culture (and anthropology) *Ethnos* 70, 2, 220-242.
- Samuel, G. & Derrick, G. (2017) Social media research, "personal ethics," and the Ethics Ecosystem [New Social Science Blog]. *New Social Media* [Online]. Available from: <http://nsmnss.blogspot.co.uk/2017/10/social-media-research-personal-ethics.html> [Accessed 13 September 2018].
- Scott, S., Prior, L., Wood, F. & Gray, J. (2005) Repositioning the patient: the implications of being 'at risk', *Social Science & Medicine* 60, 8, 1869 - 1879.
- Seale, C., Ziebland, S. & Charteris-Black, J. (2006) Gender, cancer experience and internet use: A comparative keyword analysis of interviews and online cancer support groups, *Social Science & Medicine* 62, 10, 2577-2590.
- Snee, H. (2013a) Framing the Other: cosmopolitanism and the representation of difference in overseas gap year narratives, *The British Journal of Sociology* 64, 1, 142-162.
- Snee, H. (2013b) Making Ethical Decisions in an Online Context: Reflections on Using Blogs to Explore Narratives of Experience, *Methodological Innovations Online* 8, 2, 52-67.
- Sontag, S. (1978) *Illness as Metaphor*. New York: Farrar, Straus and Giroux.
- Stage, C. (2017) *Networked Cancer: Affect, Narrative and Measurement*. Cham: Springer International Publishing.
- Stage, C. (2019) Affective measures: self-measurement and gridding in female cancer patients' storytelling practices on Instagram, *Distinktion: Journal of Social Theory* 20, 1, 77-100.
- Timmermans, S. & Buchbinder, M. (2013) *Saving Babies? The consequences of newborn genetic screening*. London: University of Chicago Press.
- Townsend, L. & Wallace, C. (2016) *Social Media Research: A Guide to Ethics* [Online]. Available: <http://www.dotrural.ac.uk/socialmediaresearchethics.pdf> [Accessed 9 December 2016].
- Tudyka, V. N. & Clark, S. K. (2012) Surgical treatment in familial adenomatous polyposis, *Ann Gastroenterol* 25, 3, 201-6.
- Turner, S. (2013) The blogosphere and its enemies: the case of oophorectomy, *The Sociological Review* 61, 160-179.
- Vicari, S. (2017) Twitter and Non-Elites: Interpreting Power Dynamics in the Life Story of the (#)BRCA Twitter Stream, *Social Media + Society* 3, 3, 2056305117733224.
- von Benzon, N. (2019) Informed consent and secondary data: Reflections on the use of mothers' blogs in social media research, *Area* 51, 1, 182-189.
- Wright, S., Porteous, M., Stirling, D., Lawton, J., Young, O., Gourley, C. & Hallowell, N. (2018) Patients' Views of Treatment-Focused Genetic Testing (TFGT): Some Lessons for the Mainstreaming of BRCA1 and BRCA2 Testing, *Journal of Genetic Counseling* 27, 6, 1459-1472.
- Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S. & Rozmovits, L. (2004) How the internet affects patients' experience of cancer: a qualitative study, *BMJ* 328, 7439, 564.

Ziebland, S. & Wyke, S. (2012) Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health?, *The Milbank Quarterly* 90, 2, 219-249.