Ethical dilemmas in researching sensitive issues online: lessons from the study of British disability dissent networks

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This paper presents an unconventional approach to the resolution of the key ethical dilemmas raised by the study of politically charged personal content posted on social media. In particular, this study suggests that Internet research ethics should remain informed by the disciplinary perspectives of those who study online communities. Hence, Internet scholars must build on established ethical practices from their respective disciplines in such a way as to address these 'human-centred' ethical issues. A 'medium-cloaked' strategy towards data anonymization was adopted for this study of the comments posted on the Facebook pages of UK disability rights groups. Key themes were typically conveyed without the disclosure of personally identifiable information and direct quotes were only used if they could not be located using a search engine. The rationale for such an approach is elucidated in order to identify the limitations in the ways in which such ethical issues are dealt with in existing guidelines in this area. The paper suggests that the automatic categorization of disabled people and others experiencing disadvantage as 'vulnerable groups' in many of these protocols might further disempower these stakeholders through the omission of their personal stories from relevant scholarship. A more nuanced approach towards the protection of user privacy is advocated; one that allows for the use of direct quotes when it is unlikely to prove harmful to the user but also sets out to provide the maximum level of anonymity possible for those who divulge sensitive information in these semi-public spaces.

Keywords: ethics; research methods; social media; sensitive issues; online politics; disability

Interest in online research ethics has grown exponentially over the past decade, generating a burgeoning sub-discipline of Internet studies. The 'universal' ethical guidelines provided by organizations such as the Association of Internet Researchers (AoIR) in the early noughties have rapidly become outdated, as both new media technologies and user behaviours have evolved. In particular, the blurring of boundaries between personal and political content on social media creates an ethical dilemma for researchers in relation to which measures, if any, should be taken to protect the privacy of participants. Disciplinary perspectives might determine whether such content is treated as a published text or the property

of a human participant (the 'human subject' approach). Researchers with a background in arts and humanities are more likely to favour the former position, which does not require steps to protect participants from any potential harm that might arise from the use of their content (White, 2002). Conversely, social scientists will typically adopt the latter perspective and attempt to safeguard the privacy of users through the use of strategies such as informed consent and data anonymization. Yet, the lack of discipline- specific frameworks has arguably restricted the scope for reflexivity in online research ethics, leaving researchers of digital politics in particular with no solid reference points for the resolution of salient ethical dilemmas raised by the study of personal content posted online. Hence, scholars such as Whiteman (2012) have suggested that such issues can only be addressed through the development of localized ethical perspectives that incorporate not only the ethics of the academy but also the 'institution, researcher and the researched' (p. 140).

This paper uses evidence from a study of the role of social media in contemporary British disability activism to explore three specific dilemmas that emerge from the analysis of politically charged personal content posted on social media:

(1) Should online discussion sites, and social media platforms in particular, be treated as 'public' spaces by researchers?

(2) Are researchers obliged to filter out sensitive content posted on these sites by 'vulnerable groups' if it has been obtained without their consent?

(3) To what extent can established ethical practices inform online research, especially in relation to data visualization and presentation strategies?

In collecting data for the project that inspired this paper, it became immediately apparent that users had posted vast amounts of personal information on Facebook pages set up to discuss disability policy issues. This raised two questions for which established institutional codes of practice provided no straightforward answers. First, should these personal stories be excluded from the study due to the perceived 'vulnerability' of their authors? Key stakeholders might have considered it patronizing if disabled people were categorized as 'vulnerable'. If these personal stories were not analysed then this would have meant that the un-mediated online 'voices' of disabled users would not be heard. Such an approach would have been incongruent with the participatory ethos of disability studies and likely to further disempower these users. The decision to exclude these data might also have hindered efforts to draw out key themes from the political debate on these online spaces, which is invariably interwoven with every day and seemingly 'mundane' talk (Graham, 2012). This was particularly relevant in the context of disability scholarship, where feminist writers have long highlighted the 'political' nature of disabled people's seemingly 'personal' experiences (Fawcett, 2000; Morris, 1992).

Second, should this content be treated as a published artefact? Clearly, it might have been problematic to adopt this approach given that the political relevance of some comments would be open to interpretation. There were also concerns about the ways in which the use of this content might compromise the privacy of these unaware participants.

Although the examples discussed in this paper focus specifically on the analysis of Facebook content, a platform-centred approach would be of ephemeral value to the researcher. Hence, this paper suggests that although the Internet has many distinctive characteristics, it should not be treated as a discipline in and of itself. Rather, the analysis and presentation of user-generated content should be shaped by the strategies adopted in research examining comparable offline spaces and be consonant with the overarching aims of the fields to which a given piece of research is seeking to contribute, in this case political communication and disability studies. An ethical stance is proposed that allows for the use of direct quotes when it is unlikely to prove harmful to the user but also sets out to provide the maximum level of anonymity for those who divulge sensitive information in these online spaces. Consequently, a critical appraisal of techniques, such as the use of word visualizations to convey key themes from social media data sets without the disclosure of personally identifiable information (PII), is undertaken in order to identify how best to achieve the appropriate level of protection for unaware participants.

Moving forward: the benefits of discipline-grounded ethical reflexivity

The formulation of ethical codes of practice has been identified as a key priority for Internet scholars since the first wave of online research in the mid-1990s (Mann & Stewart, 2000). Much of this early work had an interdisciplinary focus and sought to develop universal protocols that could be applied to all forms of online media. This 'catch-all' approach towards online research ethics was, by necessity, open to interpretation and no consensus was reached among scholars from different disciplines in relation to the frequency with which these 'manuals' should be updated. Hence, researchers were encouraged to protect online participants from any potential harm that might arise from their data being used in academic publications but it was acknowledged that there was 'more than one ethical decision-making framework' through which this could be achieved (Ess & AoIR Ethics Working Committee, 2002, p. 3).

The advent of Web 2.0, the section of the World Wide Web that revolves around user-generated content, has cast further doubt upon both the viability and operationalization of these universal guidelines. Indeed, methodologists detected the specific challenges involved in analysing 'everyday' online conversation (Sharf, 1999) and personal narratives (Ridderstrøm, 2003) long before the social

media boom of the late noughties. Nevertheless, the exponential growth of user-generated content and the blurring of boundaries between private and public in the online sphere (Baym & boyd, 2012; Marwick, 2011) have raised ethical concerns on an unprecedented scale. Hence, organizations such as the AoIR have revised their framework for ethical online research as recently as 2012. This document recognizes the 'grey areas' that continue to exist in ethical decision-making and provides researchers with a series of questions to consider, as opposed to strict guidelines on how to resolve specific issues, inviting scholars to 'remain flexible, be responsive to diverse contexts, and be adaptable to continually changing technology' (Markham, Buchanan, & AoIR Ethics Working Committee, 2012, p. 5).

The challenges associated with the use of social media data are particularly salient in online politics research. This is because new theoretical trends have recently emerged, which focus on the discussion and deliberation among ordinary users on interactive online media (Chadwick, 2012; Wright, 2012). Moving from the assumption that 'everyday talk' encourages civic learning and provides the fundamental building blocks of political discussion (Mansbridge, 1999), this tendency has already fuelled some ground-breaking empirical work on the ubiquity of politically relevant user-generated content in non-political online spaces (see e.g. Graham, 2012). Furthermore, both established and emerging political organizations such as parties and advocacy groups, as well as social movements are seeking to harness the potential of social media to attract, organize and mobilize supporters (Bimber, Flanagin, & Stohl, 2012; Gerbaudo, 2012; Lilleker & Jackson, 2011). Thus, just as political content is inadvertently 'hosted' on non-political online spaces, it is also reasonable to expect personal content to increasingly feature on the social media platforms maintained by political groups. Recent studies in the United States, the UK and Australia have suggested that advocacy and protest groups have been able to draw in more online supporters by allowing ordinary members to personalize campaign messages (Bennett & Segerberg, 2013) and organizing individual narratives into coherent campaign messages when necessary (Vromen & Coleman, 2013).

Overall, this leaves scholars of political communication in a particularly difficult position, enthused over the prospect of analysing the use of personal experiences as tools of political persuasion yet often inadequately equipped to address the ethical challenges that arise from the use of these data. Clearly it may be helpful to ask whether practices such as quoting directly from user- generated content, while rhetorically effective, ultimately contribute to the advancement of Internet politics scholarship. Arguably, key themes that emerge from the analysis of this content might be represented in academic research without the need to compromise user privacy. To discuss this approach in detail, the rest of this paper focuses on examples drawn from the study of social media's role in contemporary British

disability activism.

Keep calm and tweet on: disability dissent goes digital

Previous research indicated that until recently UK disability rights groups, irrespective of their founding ethos and structure, were reluctant to embrace interactive online media for campaigning purposes (Trevisan, 2012). However, the economic crisis experienced by industrialized countries from 2008, as well as the associated policy responses, created an 'emergency' climate that may have prompted disability organizations to adopt innovative approaches to online communications. Thus, a project was set up in the wake of the radical disability welfare reforms announced by the UK's Conservative-led coalition government in 2010,[1] in order to establish whether such an acute policy 'crisis' could fundamentally alter the perspective of British disability advocates on new media. Results exceeded expectations that social media would support more interactive campaigning styles among existing organizations, revealing that online platforms had in fact enabled the creation of both new groups and new repertoires of disability activism (Trevisan, 2013). At least three different types of collective actors made extensive use of social media – especially Facebook and Twitter, but also Flickr and YouTube – as part of their efforts to oppose disability welfare changes between 2010 and 2012. These included formal disability organizations (i.e. pre-existing organizations that used the Internet to boost their campaign efforts; a prime example was The Hardest Hit alliance – www.thehardesthit.org.uk); digitized activists (i.e. experienced self-advocates who set up a Web presence after meeting at protest rallies; one of the most prominent of these groups was Disabled People Against Cuts (DPAC) – www.dpac.uk.net); finally, digital action networks (i.e. online-only campaigns created by disabled bloggers-turned-activists, the most visible of which was The Broken of Britain – www.thebrokenofbritain.org).

The social media pages of these groups rapidly attracted thousands of supporters. While disability scholars have linked the ideological nature of government proposals to this surge of support for the disability movement (Oliver & Barnes, 2012; Roulstone, 2011), the projected impact of these changes on the daily lives of disabled Britons also resonated with the principle that disruptive events and what are perceived as outrageous violations of established 'rights' can push otherwise disengaged citizens towards direct participation (Woliver, 1993). Assuming that such 'everyday' concerns constituted the main driver behind this growth in online participation, it was therefore unsurprising to find that the Facebook pages of these high-profile campaigns hosted a considerable number of personal stories (Table 1). This echoed the conclusions of previous studies of deliberation that have demonstrated the existence of a tendency for discussants to rely on personal stories in order to overcome certain barriers to participation and become engaged in

public debates (Black, Brukhalter, Gastil, & Stromer-Galley, 2011; Ryfe, 2006).

Although investigating the reasons behind the different frequency of personal stories on each Facebook page under scrutiny would go beyond the scope of this paper, retrieving this kind of content on social media spaces maintained by disability groups was in and of itself a remarkable finding. Traditionally, self-advocacy disability groups have been suspicious of including personal

Table 1. Percentage of Facebook posts including personal stories of disability (February–May 2011).

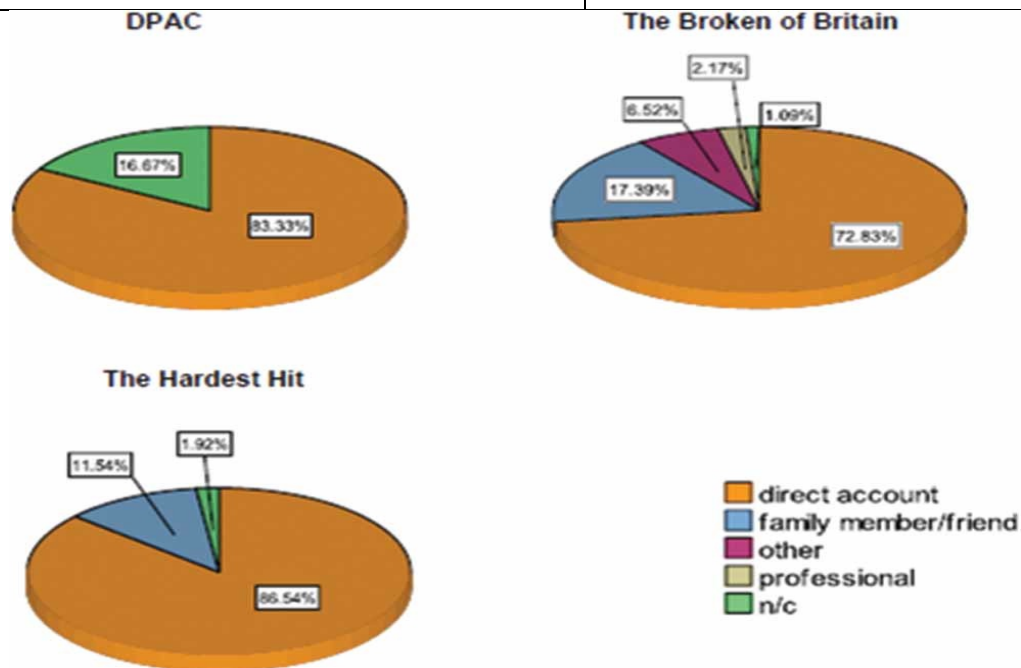| Campaign/group	Posts including personal stories (%)
DPAC	7.8
The Broken of Britain	9.6
The Hardest Hit	26.2

Figure 1. Personal stories authorship (direct disabled person's account; friend/family member's account; carer/doctor's account; other author; n/c, not classifiable).

stories in campaign messages because of the perceived risk that they could be framed in ways that reinforce negative disability stereotypes and fuel victimization (Barnett & Hammond, 1999). In addition, the relevance of these results was further enhanced by the fact that the vast majority of personal accounts had been posted directly by disabled Internet users (Figure 1). This was a testimony to the fact that welfare policy, while a seemingly dry and 'technical' topic, had clearly resonated with many in the disability community.

These narratives featured most often in comments that drew specifically on policy issues, and in particular those that addressed disability welfare reform and problems with the benefits system. This tendency was particularly strong on the pages sponsored by two of the groups listed above: The Broken of Britain and The Hardest Hit (Table 2). This suggested that personal experiences provided disabled users with a lens to interpret the effects of policy measures and participate in relevant online conversations.

These findings resonate with that part of the disability studies literature that values experience- sharing as a fundamental step in the creation of group identity and collective agency. As Watson (1998) argued, 'it is through the sharing of stories that communities grow and a political sense of citizenship evolves. This citizenship can help people challenge the prevailing orthodoxies surrounding disabled people and [...] begin to define their own identity' (p. 162).

UK disability rights Facebook pages: navigating the private–public blur

Probably the most pressing ethical concern revolved around the issue of whether an in-depth qualitative analysis of these pages was at all appropriate. Clearly, such an analysis would

Table 2. Topic of Facebook posts containing personal stories (February–May 2011).

Topic of posts containing personal stories of disability	The Broken of Britain (%)	The Hardest Hit (%)
Welfare reform	20.7	17.65
Other issue with benefits system	19.54	62.75
Other barriers and discrimination	15.21	-
Media representations of disability	10.86	1.96

Politicians attitudes to disability/inequality	5.34	1.96
Other government policy	4.49	-
Sponsor organization's own initiative	4.4	11.76
Other organization's initiative	3.26	-
Institutionalized politics	1.08	-
Other	8.6	-
Not classifiable	6.43	3.92

provide an unprecedented opportunity to explore the mechanisms that had drawn disabled Internet users to the sites of activist groups. Yet, the nature of this content also posed some significant ethical challenges, especially in relation to whether the findings should be presented in such a way as to preserve the privacy and anonymity of these users. Many personal narratives included extremely intimate or potentially harmful details, from episodes of discrimination and abuse to expletives directed at specific individuals who were unaware that they had been referred to in these posts. All of these issues were linked to a first key dilemma that can be easily overlooked by researchers eager to analyse user-generated content: to what extent can Facebook pages and social media platforms more generally be treated as 'public' spaces? While answering this question once and for all might indeed be impossible in the face of constant technological evolution and changing user habits, the most useful strategy ought to be a case-by-case approach that accounts simultaneously for the features of individual online platforms, relevant experiences in comparable offline spaces, as well as the overarching aims of the fields to which one is trying to contribute.

Although the Facebook pages under scrutiny in this project had been set up in such a way as to allow any Facebook user to freely view their content, it was problematic to categorize them as open-access public spaces. Existing guidelines for research in 'non-virtual' public spaces allow for the retrieval of information about participants without their informed consent (British Sociological Association, 2002; Social Research Association, 2003). The adoption of this perspective towards the Internet might lead researchers to classify some forms of user-generated content as 'public data' due to the ease with which they could be accessed by other users more broadly (King, 1996). Yet, this approach did not

seem appropriate for the study of a site such as Facebook, which not only hosts both public and private groups but also requires users to register to access its services (Svenningsson-Elm, 2009). Moreover, previous work on Internet research ethics has proposed that researchers should assess the perceived level of privacy within online communities before deciding what steps, if any, are necessary to protect the privacy of unaware participants (Eysenbach & Till, 2001; Nissenbaum, 2010; Walther, 2002). Participants may not be comfortable with their content featuring in academic publications even if it has been previously available on social media sites that others would categorize as public spaces (Zimmer, 2010).

Doubts also persisted about the validity of treating this content as a text. This problem has been previously highlighted in other work investigating online disability communities. Most notably, in their pioneering discussion of methodological approaches towards online research involving disabled participants, Bowker and Tuffin (2004) categorically ruled out using naturalistic discourse analysis on online material due to the high number of variables and the level of risk involved. Clearly this would have constituted the safest of all possible approaches. Yet, it also appeared to be at odds with the fundamental ethos of disability studies, which, since its inception as a discipline, has advocated for the perspective of disabled people to be included in scientific research about disability and impairment (Mercer, 2002). The methodological debate on the nature of disability research has flourished in recent years. 'Second-wave' theorists such as Watson (2012) and Thomas (2010) have exposed the epistemological flaws of a rigid 'emancipatory' approach and called for a critical-realist turn in research, recognizing the complexity of disability and the need for a multi-layered approach to its scholarship. This follows on the feminist arguments about the centrality of personal experience in disability politics mentioned above, calling for research capable of capturing the diversity that is intrinsic to the disability community.

In light of these arguments, there appears to be a consensus among disability researchers in favour of drawing upon the perspectives of disabled people to develop an adequate understanding of key issues in this field. Given the controversial nature of the proposed welfare reforms launched by the UK Conservative–Liberal Democrat coalition government in 2010, the view prevailed that the omission of the naturally occurring discussion on these 'semi-public' Facebook pages from the study would have in fact equated to the 'silencing' of disabled people's voices. In other words, a decision taken in good faith, and with the wellbeing of participants in mind, would have paradoxically resulted in more harm than good, mirroring some of the patronizing practices that have traditionally hindered the emergence of the perspectives of disabled people in both policy-making processes and political organizations (Drake, 2002; Morris, 2005). Rather, the potential for this type of analysis to contribute to a fairer representation of disabled people's involvement in online politics surpassed the risks associated

with the use of this content. In this framework, examining the direct contributions that disabled Internet users had made to online disability rights forums constituted a form of 'action research' as it helped remedying 'situations where people are believed to have been silenced or excluded from decisions which would directly affect them and which do not acknowledge their knowledge or expertise' (Townsend, 2013, p. 36). Having resolved to approach Facebook as a 'semi-public' space, consequential issues that needed to be considered included whether to alert users that research was being conducted and, if not, what measures should be taken in order to protect their privacy and anonymity.

Challenging established conventions: 'vulnerable groups' vs. 'sensitive topics'

Ethical guidelines have suggested that online participants should be protected from any additional harm that might arise from the use of their data in academic research through two processes, namely obtaining informed consent from the participant prior to the use of the data and the anonymization of data sets (British Psychological Society, 2007; Ess & AoIR Ethics Working Committee, 2002). Clearly, the former would be neither feasible nor appropriate for the study of 'semi-public' sites such as Facebook (Whiteman, 2012). That is not to say that all such research should be covert in nature. Rather, in this study the Facebook page administrators were not only informed about the study but were interviewed in order to provide some context for the data collected 'on screen'. Nonetheless, the adoption of practices associated with research into 'offline' public spaces, such as the posting of 'Research in Progress' messages to inform participants they were being observed, was ruled out on the basis that they might deter some commenters or alter the naturally occurring conversations on these pages (Farrimond, 2013, pp. 116–117). Thus, as a pragmatic approach to covert observation (Lee, 1993, p. 144), a decision was taken to proceed by devising a strategy to minimize risk for participants who were unaware that their contributions to these pages would be used in the study. This was based on an assessment of the content rather than the individuals responsible for its creation. In this way, it was congruent with recent approaches towards institutional archiving in the United States, which have restricted access to sensitive data that might have led to the identification of users in a bid to assuage public fears over such practices (Marshall & Shipman, 2011).

The consolidated concept of 'vulnerable social groups' was re-considered in this context. While disabled adults continue to be referred to as vulnerable subjects in many institutional ethical frameworks, placing additional obligations on researchers wishing to investigate experiences of disability, this practice was found to be unhelpful on this occasion. This was mainly for two reasons. First, it is difficult, if not impossible, to verify the identity of individual members of online communities. This means that, except for filters set up by administrators who are themselves often self-appointed, virtually anyone can join a discussion on social

media, making the composition of 'vulnerable groups' uncertain. This would appear to defeat the very purpose for which this concept has been devised, which is to ensure additional protection for people who may be especially fragile due to their personal circumstances, calling instead for a more flexible approach capable of dealing with sensitive material irrespective of the identity of those involved. Second, the default categorization of disabled Internet users as 'feeble' and 'vulnerable' remains a contested practice, which disability scholars have criticized as effectively 'disabling' since the early days of disability studies (Finkelstein, 1980). Therefore, being too cautious in the handling of this content would have meant turning back to a disempowering 'experts know best' approach that does not represent the lived experiences of disabled people (Shakespeare, 2006; Watson, 2012). In other words, characterizing digital disability rights groups as 'vulnerable' by default would not only have constituted an inadequate response to the challenges posed by the uncertainty surrounding online identities but also jeopardized the very nature of the study.

This is not to suggest that there was no consideration of the potential harm to participants that might arise from the use of user-generated content. Rather, concentrating on what was said instead of trying to establish who said it meant that some potentially patronizing assumptions were avoided during the data analysis, focusing the attention on those conversations that were most likely to present specific ethical dilemmas regardless of the identity of their authors. For example, in the case of the study of online disability activism, the list of 'sensitive topics' to be handled with additional care included:

- personal daily routines;

- individual details about impairment and/or medical records;

- emotional accounts of pain and chronic illness;

- financial information about income and/or welfare payments;

- discrimination and abuse episodes;

- criticism/praise of individual providers of healthcare and support services;

- suicidal thoughts.

User-generated content covering any of these topics was granted additional attention, thus affording every user the same level of protection. Furthermore, the topics list was kept open to new additions throughout the analysis, acknowledging the fact that when studying social media it is impossible to anticipate the exact content of user contributions. This type of approach was possible due to the

relatively small sample examined in this study (2126 Facebook posts), which enabled the inductive identification of conversation themes through discourse analysis. Indeed, this would make for an impractical strategy to analyse substantially larger social media data sets, even when the subjectivity involved in this process is accounted for and tolerated. However, the continuing development of new software packages for the automated collection and analysis of online content suggests that this process may be much easier in the future (for an overview, see Hopkins & King, 2010).

Presenting the data: projecting participants' voices while protecting them from harm

Having traced the contours of particularly sensitive content, the next step was to devise presentation strategies that would respect the principle of 'nonmaleficence' in social scientific research while at the same time ensuring the involvement of participants as autonomous and competent agents in the research process (Farrimond, 2013, pp. 26–29; Kitchener & Kitchener, 2009, pp. 12–15). In particular, it was essential to provide appropriate levels of protection for these unaware participants based upon the sensitivity of the information disclosed. Traditionally, direct quotes have been the primary method for the illustration of key themes that emerge from qualitative data analysis. However, the 'long tail' of online data raises the issue of whether this can at all be regarded as a 'safe' system. The incorporation of perceived levels of privacy within online communities inevitably leads to a debate over whether researchers should present results in such a way as to 'please' participants (Bruckman, 2002; Kozinets, 2010). Thus, data anonymization may be the preferred option for researchers interested in using content from social media sites. However, implementing this strategy while at the same time ensuring a fair representation of participants' voices presents some significant challenges.

Recent research has suggested that the redaction or removal of the name used by an online participant may not protect their anonymity after the data has been published. The verbatim reproduction of text from the author might enable the original post to be located via the use of a search engine (Markham, 2012). PII may also be inadvertently revealed by the researcher through the use of content that refers to the economic, social, or cultural identity of the contributor (Zimmer, 2010). With specific reference to Facebook, it could indeed be argued that, at the moment, it does not allow for its content to be freely searched.[2] Yet, in recent years Facebook has changed its data management policies several times, generally without prior consultation with its users. Therefore, it cannot be assumed that search engines will forever continue to be banned from browsing individual comments. For these reasons, it may be appropriate for researchers to seek alternative and more creative ways of analysing and presenting user-generated

content.

This issue was particularly salient in the study of online disability activism, which focused on relatively small groups. Although thousands of users had joined the Facebook pages of the groups listed above, discussion on these platforms occurred primarily among restricted circles of about 30–35 'super' users. The working solution for this project was to avoid the use of direct quotes if the user could be re-identified through the use of search engines to locate their original post. In this way, the study conformed to the 'agile' version of online research ethics that has been advocated as an antidote to excessively generic guidelines (Markham, 2012; Neuhaus & Webmoor, 2012). It was also anticipated that the granularity provided by the use of verbatim text in the study was not necessary in order to illustrate the collective response of disability rights activists towards the proposed changes to the welfare system that would affect disabled people.

Having said that, it should be noted that this approach did not constitute a 'mantra' against the use of direct quotes per se. Rather, these remained useful when the identification of the author was not possible or would not cause specific ethical problems. For example, certain 'memes' were repeated and modified as they were passed on from one user to the other, thus making user identification from verbatim quotes less likely. Furthermore, a distinction could also be made between the content contributed by 'ordinary' users and that posted by core campaigners. While the former may not realize the full implications of posting personal information on publicly available online forums, the latter could be regarded as public figures. They were more likely to be aware of the ethical issues relating to the posting of sensitive content on Facebook due to their responsibility for enforcing community standards and moderating content posted on their group's page. As such, they were unlikely to publish content that was contrary to their own rules. Thus, provided that informed consent could be obtained, it was possible to lift some precautions when dealing with material posted by administrators. Overall, this strategy fell in the category of 'medium-cloaked' approaches as described by Kozinets (2010, pp. 154–155), for which verbatim quotes are admissible under carefully controlled circumstances. However, this did not address the issue of how to contextualize and exemplify the growing overlap between personal and political in social media analysis.

Fabrication

One innovative practice that draws upon user-generated content without the need for verbatim quotes is the 'fabrication' strategy recently proposed by Markham (2012). This requires the researcher to create composite accounts that convey key themes from a data set without reproducing the text as provided by participants. This unconventional approach builds on the idea that qualitative research is

ultimately interested in exposing and discussing patterns that may be represented just as successfully through fictional narratives as they would be by direct quotes. However, its applicability may depend on the specific context of the discipline(s) to which a given research project seeks to contribute. While it is clear that specificity may not be necessary to illustrate key themes, 'fabrication' presents a particular problem to those researching in the field of disability studies. Although in recent years this discipline has moved on from the restrictive 'emancipatory' approach that characterized its origins, the perspectives of disabled people remain an essential component of disability research and the ways in which they are 'mediated' are subject to careful scrutiny. As such, 'fabrication' represented a high-risk practice that may ultimately have distorted disabled people's online 'voices' as it works on the assumption that the researcher should elaborate 'proxy' accounts to prove rhetorical points. Similarly, it could also be argued that 'fabrication' mirrors too closely the disempowering practice among British disability non-profits of selecting, editing and mediating the personal disability stories included in their campaign literature.

For these reasons, 'fabrication' was not used in the study and solutions were sought that would protect user anonymity without requiring excessive manipulation or misrepresentation of data. While this decision originated from considerations specific to disability studies, the principle behind it is in no way exclusive to this particular discipline. Rather, it extends to other areas in which both online and offline participant accounts are acquired with a view to enriching scholarship through the inclusion of the perspective of social groups that are typically marginalized or experience a condition of oppression and dependence, such as migrants and children.

Word visualizations

One strategy that proved particularly effective in conveying key themes from disability stories without the need to use direct quotes was that of visualizing the concepts that most frequently featured in personal accounts through the use of word clouds. Online word cloud generators have long been considered useful teaching devices and information-retrieval tools on popular websites (Sinclair & Carew-Hall, 2008). However, their use in social science research remains limited and the methodological debate on their potential benefits and drawbacks, as part of a broader debate about the 'Big Data' phenomenon, remains in its infancy (boyd & Crawford, 2012). In particular, word visualizations would appear to illustrate key themes without breaching the privacy and anonymity of individual users who contribute to public Facebook pages. While they are built on a fairly straightforward principle (i.e. word frequency), word clouds provide very rich visualizations with which it is possible to integrate the discussion of both quantitative and qualitative content analysis results, thus constituting an ethically

sound channel for researchers to draw directly upon user-generated material. Hence, they could serve a double purpose by simultaneously protecting users and catalyzing the discussion onto fundamental patterns of language and meaning.

However, that is not to say that there are no ethical issues that emerge from the use of these tools. For example, 'Reading the Riots', an innovative study conducted by the Guardian newspaper in collaboration with several UK universities, used visualization tools to provide the names of those Twitter users who had been responsible for spreading rumours and misinformation during the riots in London, Birmingham, and Manchester in August 2011 (Procter, Vis, & Voss, 2013). An emerging critique of the methods used in this project has suggested that the 'openness' of this data set may in fact have caused reputational harm to these users, from whom consent had not been obtained by the research team (Krotoski, 2012). What is clear is that the researcher may have to 'clean' the data before visualization in order to ensure that PII or any other details that may lead to the identification of an individual user are not present in the text entered in a given visualization tool.

To ensure the removal of all PII, the best option remains to carry out this operation manually, although this may restrict the amount of data that can be analysed at any one time. Equally, key themes might also be clearer in the word cloud through the removal of 'function' or 'stop' words that are unlikely to contain meaning. Certain word cloud generators carry out this task automatically.[3] However, as this feature generally relies on rigid lexicons that are inaccessible to researchers, some have argued that it ultimately creates more problems than it solves because context cannot be taken into account when choosing what words should be excluded from the analysis (Monroe, Colaresi, & Quinn, 2008, p. 378). For this project, the following visualization of the content of personal stories posted on the Facebook walls of UK disability rights groups was created using Tagul (www.tagul.com), a flexible Web-based word cloud generator that enables the researcher to create customized exclusion lists that can be expanded and amended in an iterative fashion (Figure 2):

Figure 2. Words used to narrate personal stories on Facebook pages of British disability groups (February– May 2011).

Besides demonstrating the centrality of Disability Living Allowance (DLA)[4] to the testimonies of disabled users, this visualization also facilitated the representation of key themes emerging from content analysis of personal stories posted on the Facebook pages of disability dissent networks without identifying individual members. In particular, content analysis revealed that disabled users relied on five main 'lexicons' for articulating and framing their stories (impairment, illness and pain; needs; family; money and work; and fear of the future), all of which are exemplified by several of the most prominent entries in the word cloud above. While this paper is not concerned with the results of the study per se, the prominence of words associated with impairment, illness, and pain was significant due to its resonance with the arguments of those scholars who have called for a reassessment of the relationship between the body and the process of disablement (Thomas, 2010). Furthermore, the position occupied by words associated with 'need' and 'help' also offered an insight into how disabled users perceived the welfare system. This is especially relevant given that the idea of 'rights' is absent from the word cloud. Although this is not the place for it, a wider analysis could involve mapping the evolution of these lexicons over time or comparing them to the language used in policy documents, political debates, and mass media coverage of the disability welfare reform.

Although this approach to data analysis and visualization preserves the privacy and anonymity of Internet users, it nevertheless has some important limitations. As McNaught and Lam (2010) noted, the main drawback associated with the use of word cloud generators in qualitative research is that they focus on word frequency, disregarding both the context and semantics that characterize the text under scrutiny. While context-retaining applications are being developed (Cui et al.,

2010), it would be potentially misleading to adopt currently available cloud generators as stand-alone research tools. Rather, their most valuable contribution to the study of online politics is likely to be as visual aids to complement and enrich the presentation of in-depth content analysis and discourse results or, at most, as applications to generate preliminary observations and inform a more detailed qualitative investigation.

Conclusion

Using examples drawn from a study of social media use in contemporary disability protest networks, this paper has discussed the key ethical dilemmas that are likely to emerge in studies concerned with user-generated content on potentially sensitive issues. In addition to evaluating a parallel between social media inquiry and research in physical public spaces, this paper has questioned some of the fundamental assumptions that lie at the root of ethical practices in the burgeoning field of online research. In particular, this paper has argued that, although the Internet has many distinctive characteristics, it does not constitute a new entity to which established norms of qualitative research do not apply. Instead, Internet research ethics should remain informed by the disciplinary perspectives of those who study online communities. Hence, Internet scholars must build on established ethical practices from their respective disciplines in such a way as to address these 'human-centred' ethical issues. As digital media open up new avenues of social science research, the ethical challenges involved in this process represent an opportunity to challenge the suitability of established protocols not only in light of the specificities of the online context, but also vis-à-vis the overarching aims of the discipline(s) to which one is seeking to contribute.

In this paper, established protocols on dealing with 'vulnerable groups' provided insufficient protection for the unaware participants who had posted personal stories on the Facebook pages of UK disability rights groups. This created an opportunity to devise an alternative solution that was not only compatible with social media inquiry, but also supported the participatory ethos of disability studies scholarship. Thus, a decision was taken to concentrate ethical reflexivity on what was said rather than who said it. Similarly, direct quotes were allowed when they did not generate risks for participants, but at the same time novel visualization techniques were also preferred when political communication scholarship required to place an emphasis on general themes over individual opinions. Overall, this type of approach to online ethical issues can support the adaptation of traditional methods to the challenges set by new media and help avoiding that in-depth qualitative enquiry is entirely overshadowed by the growing popularity of 'Big Data' approaches and associated quantitative strategies. Qualitative research is fundamental to achieving a full understanding of online media's impact on society. However, creative solutions are also necessary to

ensure that this is 'upgraded' to meet the challenges of the digital era.

Notes

1. Plans for a comprehensive reform of government welfare provision were introduced to the UK Parliament in February 2011. These included proposals for replacing DLA with a new Personal Independence Payment for all claimants aged between 16 and 64 years. A legislation introducing these changes was approved in March 2012 and gradually implemented from April 2013. Both disability campaigners and scholars were extremely critical of these changes, arguing that they amounted to 'rolling back the state to a level of intervention below that of the United States – something which is unprecedented' (Taylor- Gooby & Stoker, 2011, p. 14).

2. At the time of writing (November 2013), Facebook had made a beta version of their 'Graph' semantic search engine available to all English language users in the United States. They have confirmed their intention to extend this service to all users in the future. See https://en-gb.facebook.com/about/ graphsearch.

3. For example WordSift: www.wordsift.com.

4. DLA is a non-means-tested benefit paid in the UK to all disabled people who request it to support their personal needs.

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