Privacy on their terms: Exploring the rights, preferences, and experiences of child participants in research in digital environments.

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Abstract

Respecting participants' privacy rights is a vital component of research ethics, but conventional practices in this area may falter when research focuses on groups whose experiences and concerns diverge from those deemed normative, or when the experiences take place in novel environments where information flows and functions in unexpected ways. This article examines the specific example of research with young people in digital social spaces, discussing how online youth communities construct and maintain privacy and arguing that choices regarding research practices should be made in response to contextualized understandings of the perspectives, practices, and experiences at play in specific digital spaces.

Keywords: research ethics, digital research, methodology, youth research, childhood studies

Background

Ethical guidelines in research exist to protect the well-being of participants and the integrity of research observations and conclusions. Privacy figures on both sides of this equation: on one hand, breaches of participants' privacy may cause serious harm to individual participants; on the other, the perceived danger of such breaches can shape people's responses and willingness to participate in research at all, potentially creating blind spots in research and skewing results.

What is demanded by good research ethics often depends on how the subjects of research are fundamentally constructed and understood. Historically, children and young people have been viewed by academia (as by society) as vulnerable, incompetent, irrational, and unreliable. Framings of research ethics in the context of childhood have reflected such prejudices. It has paradoxically been common practice to 'protect' the well-being of child participants and the integrity of child-focused research by denying children some of the most basic rights of research subjects, including those relating to privacy (Christensen & James, 2008). Though significant progress has been made in recent years in many aspects of respecting children's right to be treated as equal and active participants in research, philosophical, practical, and legal considerations still stand in the way of assuring them the same level of privacy typically experienced by adults (Alderson & Morrow, 2011; Nairn & Clarke, 2012).

Research in digital contexts brings these issues into sharper focus by reshaping multiple aspects of the research process, from how participants are recruited to how data is collected and stored (Nosek, Banaji, & Greenwald, 2002). Perhaps the greatest novelty is in how information is shared, presented, and conceptualized by research subjects themselves. Social norms and expectations of what constitutes 'private' information in online spaces often conflict with legal and technical definitions, and it can be difficult to classify genres and contexts of speech and interaction based on conventional schemas. This paper is concerned with researchers' responsibility to protect the privacy of young people who participate in digital social research, and what we can learn from young people about how best to do so. It is not enough to simply safeguard the confidentiality of what might be conventionally thought of as 'private or 'personal' information collected in research instruments and observations through the typical methods of changing names

and obscuring demographic details. This approach has serious limitations even in more conventional research contexts. For instance, there is the potential for members of participants' communities to deduce their identities from contextual data (Kaiser, 2009), or for the seemingly innocuous disclosure of merely the fact that someone is participating in a study or meeting with a researcher to directly or indirectly bring about harm (Buchanan & Zimmer, 2016). Such dangers are particularly significant in the case of research with young people in abusive, neglectful, or dysfunctional family situations (Coyne, 2010). In digital contexts, these and other issues with a conventional approach are exacerbated by changes in how data, identities, and communities function.

I propose that we must work to protect the privacy of participants *on their terms* – to work within the cultural norms and technological possibilities of the contexts we enter as researchers, rather than bringing our own established assumptions and professional practices with us and presuming them universally appropriate. This paper explores the socially constructed conditions which surround the experience and exercise of privacy for young people in digital contexts; discusses some of the specific practices and concerns I have encountered among young people in online social contexts, and how I have responded to these in conducting and presenting my research. This paper proposes some general guidelines for protecting the privacy of young people in digital research; and presents questions for further study and discussion among researchers as we continue to navigate our ethical responsibilities to young participants in emerging media contexts. My analysis and proposals herein are derived primarily from my research and teaching in the broadly-constructed area of online youth culture over the past few years. The former provides a deep perspective on specific communities in which I have conducted long-term research, the latter a broader perspective on the ethical and methodological quandaries which emerge in research across various digital contexts.

From mid-2014 to early 2017, I conducted a long-term ethnographic study of teens and young adults who are part of the media fandom community on the multimedia blogging site Tumblr, a group united by a shared appreciation for books, films, television shows, and other texts. Many of these users exhibit very high levels of engagement in this space, often spending significant amounts of time on Tumblr on a daily basis, and characterize the fandom Tumblr community as highly meaningful in their lives. This

community also tends to remain mostly isolated from its users' offline social networks. These factors have led to the development of unique cultural practices and social norms, including many relating to privacy and disclosure. Speaking with these young people about their views on online privacy and observing the practices they used to control the flow of information about themselves, shaped my methodological choices and aspects of how I presented my research. Additionally, these conventions and observations became a significant component of my analysis.

During this time, I also taught an undergraduate course on youth culture and digital communities. These students and I explored the methodological and ethical issues inherent in online research with children and young people as vital topics in their own right. The students continued to grapple with these issues as they conducted their own research projects and were thus confronted with the widely varying privacy norms and practices at work in the diverse contexts of their research.

The State of Young People's Privacy

The right to privacy is not evenly distributed. The extent to which individuals are able to maintain control of information about themselves and their activities is a function of their position in society. Material resources play a significant role in this. For instance, a person who has the money to live alone generally has more reliable privacy than a person who is forced to share living space with family or roommates. Equally significant are moral discourses that establish some social categories as more deserving of privacy than others. Groups with greater social privilege have a perceived moral standing which leads others to interpret their actions to maintain privacy as the socially acceptable exercise of the right to be left alone; those with less social privilege, including children and young people, are morally stigmatized to the point that any attempt to conceal their activities is viewed as suspect and covering-up of potentially unsavoury behaviour (Warren & Laslett, 1977). It is therefore seen as not only acceptable but even, at times, morally obligatory for such people's privacy to be invaded by others, and indeed children's private spaces, possessions, and conversations are frequently constructed as private only to the extent that parents or other adult authority figures prefer them to be (Robson, 2015). This is perhaps nowhere as evident as in the digital realm, with constant

and detailed electronic surveillance of children and teenagers not only now generally perceived as socially acceptable, but fast becoming the default condition under which young people live and families operate (Wingfield, 2016).

Privacy is a fundamental condition of personal autonomy and development, trust, emotional stability, and honest, open communication with others; as such, it is not only an individual need but vital to the functioning of societies (Holvast, 2009; Westin, 1970). It therefore should be expected that those whose right to privacy is challenged and eroded by practical circumstance and social ideology rarely accept being denied it, or that communities of such people frequently develop practices for managing privacy and disclosure which reflect the unique pressures they face in the exercise of privacy, and thus diverge from broader social norms (Warren & Laslett, 1977). This has been the case among children and youth since long before the advent of contemporary digital technologies (Jenkins, 1999; Rasmussen, 2004), and the phenomenon now extends to the digital world as young people co-construct online social spaces and practices in response to their needs and priorities and the social pressures they face. Though varying significantly between individuals and communities, in general terms, online youth practices surrounding privacy and disclosure tend to diverge from practices common among adults in four key ways. First, they focus on managing impressions and on complex understandings of identity and relationships among socially relevant others, rather than on limiting broad third-party access to personal data points. Second, they recognize and take advantage of the sizable grey area between "public" and "private" spaces. Third, they rest on highly nuanced conceptualizations of what constitutes 'private' information and expression. Finally, they are enforced through complex social cues and shared expectations rather than strict control technologies built into systems and platforms. I have written a more detailed account of these practices themselves and discussed their socio-cultural significance in another recent publication (Burton, in press). Here, I am concerned with how each of these trends influences our ethical obligations as researchers.

Conceptualizing Privacy

One of the more significant distinctions between adults' and young people's views on privacy which has been seen in past research, and which my own observations have

also pointed to, is an orientation toward concern for *social privacy* among young people in contrast to adults' concern for *data privacy* (Lykens, 2015). As a determining factor in how and where information is shared, both highlight ideas about the potential consequences of disclosure. However, the two approaches diverge in the nature of the consequences that are the subject of greater concern.

Data privacy is concerned with the potential dissemination of personal data to unknown third parties or to institutions. It is also referred to as *informational privacy* (van der Velden & El Emam, 2013; Moscardelli & Divine, 2007). I would argue that the term 'data' makes clearer the specific kind of information at play in this paradigm which is comprised of large numbers of simple data points: phone numbers, addresses, work, and school histories, and so on. This is the kind of privacy which figures in anxieties about 'big data' and fears about digitally-enabled crimes. Thus, the consequences of unwanted disclosure within this frame are typically either impersonal – things like corporate profiling for marketing purposes – or deeply serious but very uncommon – identity theft or stalking and sexual exploitation, for example (Moscardelli & Divine, 2007).

Social privacy, on the other hand, is concerned with the potential for unintended disclosure to cause embarrassment, conflict, or other kinds of interpersonal challenges in relationships with known and significant others in a person's life. It is focused on controlling the kinds of information that are not easily reduceable to data useful to governments, corporations, or criminal enterprises, i.e., information about one's deeper thoughts, feelings, and opinions, or details about one's relationships and activities beyond daily minutiae (Boyd & Marwick, 2011). Where an orientation toward data privacy might prioritize controlling who knows one's 'relationship status' in the Facebook sense of single, married or divorced, the social privacy framework would focus on managing who knows what about deeper questions such as how happy one is in a relationship, what future one sees and wants with a current partner, and what kinds of hobbies a couple shares.

While some have interpreted young people's general orientation toward greater concern for social privacy as a product of naivety (eg, Stern, 2004), I contend that it is better understood as reflective of the fact that breaches of social privacy are both more

likely and more serious for young people than for adults. This is specifically because of the previously discussed normalization of surveillance of young people by parents and other adults, and because of the fact that the power adults hold over children means the disclosure of the wrong kind of information can easily bring consequences ranging from uncomfortable conversations too, for some young people, serious violence (Coyne, 2010; Mustanski, 2011). This is not to say that adults cannot face significant consequences to violations of their privacy; the privilege of controlling one's personal information is inequitably distributed along many lines of social categorization. Warren and Laslett (1977) specifically point to LGBTQIA identities, mental illness, and poverty, along with youth and advanced age, as statuses which reduce one's perceived right to control of information and confer a social stigma onto the exercise of privacy. The specific expression of this in the case of young people, however – like any specific group's experience of broader patterns of marginalization – is to some degree unique in its mechanisms and impacts. A lack of legal protections and the cultural normalization of parental surveillance, in combination with the practical implications of sharing living space with families and lacking financial and social resources to secure their communications, results in children generally experiencing privacy as a privilege granted or revoked at the whims of others, rather than as an inalienable right (Cherney, 2010). Children and youth thus face clear and immediately present privacy concerns which adults typically do not.

Regardless of the reasoning behind this orientation toward social privacy or the contextual factors at play, we must, as researchers, be aware and respectful of the fact that young people often experience and conceptualize the consequences of breaches of privacy in ways that stray from conventional understandings of internet safety, and thus think of privacy itself in different ways. Traditional notions of confidentiality in research certainly do not ignore the importance of social privacy, but understanding that it may hold a position of primacy in our participants' minds still can and should shape how we go about our work.

One of the most significant issues with protecting social privacy is the scale and complexity of the task of managing it. Social privacy is concerned with managing the aspects of oneself that are shared in specific spaces and with specific audiences, in a

manner which aligns well with contemporary ideas of identity itself as multiple and contextualized (Kennedy, 2014). Consider the case of Emily, a 17-year-old girl I interviewed as part of my recent research on Tumblr. On Tumblr, Emily is open about her identity as a bisexual woman and as an atheist and vocal about her progressive politics, which specifically include a strong belief in the self-ownership and self-determination rights of children and youth. Offline, she lives in a highly conservative community, with parents who are fundamentalist Christians with strongly authoritarian view of family norms. Given this situation, there is no single piece of data about her experiences that she must keep generally concealed in order to stay safe; she must rather be concerned with maintaining as complete as possible a separation between her online and offline lives and selves. Even letting slip to Emily's parents that she uses *tumblr* on a regular basis might put her in danger, as the surveillance tools available to parents would make determining her username and thus finding everything she has posted on the platform a simple matter. Emily is far from the only *tumblr* user in this kind of situation, and I was aware that the standard parental consent process itself, by giving parents details about the subject of my research, might bring about "context collapse" – the unintentional and unwanted merging of distinct social audiences (Marwick & Boyd, 2010). This possibility affected both the safety of individual participants and the integrity of my research, as potential participants' fears of this kind of context collapse might easily have discouraged them from agreeing to take part in my study. I, therefore, appealed to the Institutional Review Board at my institution to allow minor participants to consent on their own behalf – a request which was eventually granted, but, as described in a later section, not without issues which further illuminate the tension between conventional ideas of research ethics and the lived realities of young people.

Experiences of Public and Private Space

Emily's desire to maintain an isolated social world online may seem, at first glance, to conflict with her choice of Tumblr as her primary social media platform. Tumblr, after all, is a 'public' forum in the sense that, while users post under pseudonyms, their posts can be read by anyone, including people who do not even have Tumblr accounts, and where explicit privacy controls are virtually non-existent. Such apparent contradictions no doubt feed the ongoing belief among many researchers,

commentators, and parents that children and teens simply do not care about protecting their privacy, or do not understand how to do so (Henley, 2013). Marwick and boyd (2014) and Livingstone (2008) argue that this perception of a paradox - between young people declaring a concern for privacy while so much of their social lives revolve around interactions in networked publics - is the result of conflating public behaviour with public space: "They are trying to be in public without always being public," Marwick and boyd argue (p. 1); that is, to be visible and acknowledged as part of a wider social world, and able to engage with friends and peers outside the confines of strictly private spaces, without giving up the ability to set boundaries.

These concerns mirror how young people experience public and private spaces offline. Conventionally, the primary place in which absolute privacy is expected is the home, the "personal castle" in which one is separated from curious eyes and ears by distance, walls, and doors (Holvast, 2009). However, this does not mean that venturing into "public" spaces beyond this private sphere implies that all of one's actions and interactions are on display to the world. Public spaces can accommodate private expression, a simple example being the experience of holding a conversation with a friend while sitting in a coffee shop. Lacking power in the relationships through which family spaces are constituted, young people tend to experience the home as "adult space" in which they cannot count on boundaries being respected (Matthews, Limb, & Taylor, 2000). As a result, they may be more likely than adults to seek out moments of privacy in "public" spaces like workplaces, parks, and the street (boyd & Marwick, 2011; Rasmussen, 2004).

In speaking with young people about their online experiences, and in keeping with Marwick and boyd's (2014) observations, I have found that social media platforms are often seen in a similar way, as public spaces in which boundaries can still be drawn around private interaction. Many of the *tumblr* users I interviewed specifically described Tumblr as a place where they can enjoy more privacy than in their own homes and local communities, thanks to the camouflaging obscurity of being among thousands of people and away from any adult whose prying eyes might specifically be turned toward them.

How we conceptualize spaces as 'public' or 'private' has a direct and significant impact on our ethical obligations. In an undergraduate course I recently taught on

researching online communities, the question arose at one point as to whether posts and comments in blogging communities should be treated as documents or as social interaction. Are these writings, in other words, deliberate public statements, like a published memoir, or are they conversations that happen to occur in public space, like telling a friend a personal story while walking down the street? The former would carry an obligation to give due credit by accurately citing the author while the latter, an obligation to protect the privacy of subjects involved in participant observation by obscuring their identity. By the end of the discussion, the class had reached a near consensus (with which I wholeheartedly agree) that the decision should be made based on which option would have the least potential to do harm. This, in turn, I submit, must be determined through a thorough understanding of the norms and expectations present in the community being studied, as well as the social context around that community in both the online and offline worlds.

This is, of course, a complex and demanding standard, requiring much more time and thought than basing ethical protocol decisions on, for instance, whether or not an online piece of writing is 'publicly accessible' in technical terms. However, it is also much more responsive and respectful of the feelings and experiences of research participants. This is particularly true in research involving children and youth, whose experiences of spaces as public and private, as noted above, often diverge from conventional understandings and rely more on grey areas of social context than on hard-and-fast individual control. Indeed, Ben, another young Tumblr user I spoke to, explicitly described the platform as "the internet equivalent of sitting on a bench on a crowded street," explaining that statements, conversations, and interactions here are private, not in the sense of being unwitnessed, but in the sense that they easily fade into the noise. Conversely, platforms such as Facebook, which afford much stricter explicit privacy controls, were seen by many of the young people I interviewed as less private, primarily because of social expectations that push them to friend family members and classmates with whom they might not actually be comfortable sharing certain information.

It was as a result of statements like this from my participants that I decided, in my analysis to take every measure possible to make sure my research did not diminish the privacy participants enjoyed through online obscurity by inadvertently shining an

unwanted light on their online presences. Since Tumblr blogs are thoroughly indexed by search engines like Google, this included the unusual step of making minor changes to word choice and phrasing in direct quotes, in order to make it more difficult to track quotes back to their sources. Markham (2012) defines actions like this as "ethical fabrication," and argues that the realities of how information now functions necessitate a rethinking of how we define accuracy and honesty in research on human experience. In response to the view that "making up" data always constitutes misrepresentation, Markam proposes that equating the *fabrication* of observations with deliberate *falsification* of results and conclusions "fall[s] apart when researchers are working within non-positivist paradigms" (p. 341). Since ethnographic and interpretive data gathering always involves the active construction of meaning by the researcher, the deliberate reconstruction of observations in a way that preserves meaning while improving privacy for participants is an ethical choice and does not mean the resulting observations are inauthentic. Of course, in order to reconstitute interpretive data in this way while remaining faithful to the personal and cultural meaning of the statements and interactions being documented, the researcher must work within a thorough contextual understanding of what elements and styles of interaction are meaningful to participants; there are, for instance, elements of writing style and of non-standard orthography and grammar that have particular significance attached to them within the Tumblr community.

Defining Private Information

Conventional discourses of internet privacy tend to focus on the security of data about one's identity and daily activities. This includes information such as addresses, phone numbers, school or employment details, and personal photos (Madden, et al., 2013). This kind of data is the logical currency of data privacy, and of a conceptualization of privacy in which private spaces are defined by control and public spaces by exposure. Given young people's tendency toward prioritizing social privacy and seeing privacy as more contingent upon social context, however, it is little surprise that they often hold a different and more complex view of what constitutes privileged information.

Young people who have active social lives online tend to shy away from the conventional binary model which sees information as either open or secret, safe to share or unsafe (Livingstone, 2008). They prefer, instead, to manage disclosure by sharing deliberately selected pieces of information based on audience and context. For many of the young people I have spoken to in the course of my research, the disclosure of identifying data or information about the minutiae of their daily lives is something that is managed consciously and deliberately, with an attitude that the potential dangers of such disclosure should be acknowledged but not afforded undue weight in making decisions. Within this frame, young people primarily choose to share details of their identities which are socially relevant, such as first name, age, gender, and general location (i.e., to the country or region level). What constitutes socially-relevant data can and does shift from one community to another; participation in specific creative pursuits such as painting, or writing are shared widely within online artists' groups, for instance, while participating in online mental illness support groups engenders the sharing of diagnoses and the broad strokes of personal medical histories.

This framework of managed disclosure also applies to the kind of information that is more obviously the province of social privacy: information about one's deeper thoughts, feelings, values, interests, and opinions, or details about one's relationships and activities beyond daily minutiae. Platforms like *tumblr* and Twitter are often used for an erratic combination of different kinds of interaction, including statements which speak to deeply personal experiences and concerns. These interactions are often conceptualized very differently from other content by users, even if it is treated in the same way by the platforms themselves. Broadly referred to simply as 'personal' content and described by one of my research participants as a case of using social platforms as 'a public diary', expression in this category might include everything from complaints about conflicts with family or roommates to anecdotes about friends and romantic partners to reflections on life events like birthdays and graduations.

Despite young people's tendency to be concerned with maintaining social privacy, this kind of information is clearly not always kept closely guarded; in fact, its disclosure in the right context is desirable and beneficial to the establishment of friendship and community (Bauminger, Finzi-Dottan, Chason, & Har-Even, 2008). While the disclosure

of these rich details about their lives and experiences is not something young people broadly aim to avoid, it is something they take very seriously, and it is their wish to manage the disclosure of this kind of information which most often fuels their concern for the separation of audiences and social contexts. The same information that might be treated as secret in one's offline life might be shared with an audience of hundreds online merely for the sake of catharsis or an amusing anecdote. Perhaps more strikingly, many young people have indicated to me that different expectations exist within individual online communities for this kind of content, with posts and comments that fall into the category of 'personal' less likely to be shared or commented on by others. Such posts thus speak to a smaller, more tightly-connected audience than a less personal expression which theoretically takes place in the same space and with the same technical restrictions.

The important point to consider here from a research ethics perspective is that rather than presuming a normative view of what information should be considered confidential with respect to an imagined singular 'public' audience, we should pay close attention to the kinds of information that research participants themselves wish to exert significant and specific control over. Certain information about participants' lives that do not fit conventional ideas of protected personal data might, in their eyes, be more important to protect, particularly in the context of their interactions with specific communities or acquaintances. Furthermore, it might often be the case that information has been revealed in what looks, from an outside perspective, like an open forum, but might not be conceptualized as public information by participants. In presenting my work on Tumblr, I have responded to these realities by avoiding any discussion of specific posts which were marked as personal, either explicitly, through use of Tumblr's content tagging system, or implicitly, by the topics discussed or subsequent comments from other Tumblr users. Personal posts, that would conventionally be thought of as public expression, have in fact, been treated in my work as even more privileged than one-on-one interview responses. The somewhat paradoxical understanding behind this is that the latter, while given under condition of anonymity, were offered under the expectation of their being broadly shared, while the former, despite being made in a much more open space, were intended to attract only limited attention.

Enforcing Boundaries

The conceptualizations of privacy, experiences of public and private space, and ideas of what constitutes privileged personal information I have outlined here have one clear element in common: they are highly complex and nuanced, with little room for binaries. Unfortunately, most systems of 'privacy controls' available to social media users are extremely binary, categorizing others simply as 'friends' or 'not friends,' and information as openly available or restricted. This situation sometimes frustrates young people's ability to disclose what they desire to disclose (and no more) to their desired audiences (and no one else) in their desired contexts (and nowhere else) (Livingstone, 2008). What I have observed in my research indicates that this gap in the affordances of social media technologies is often filled by users' development of cultural norms, expectations, and practices employed to control how information is framed, perceived, and shared.

As noted earlier, *tumblr* users manage and maintain social privacy in large part through the separation of their online and offline lives. This is, in turn, accomplished not simply through individual choices but through the establishment of a community norm of maintaining distance from offline social networks. Nearly every user I interviewed indicated that sharing a Tumblr URL with an offline friend was a rare and significant act of trust, offered perhaps once for every hundred connections made exclusively online through Tumblr itself. This norm is something people report 'just understanding' from their earliest days using the platform, perhaps in part due to popular posts which have circulated for years humorously describing the dangers of these discrete social contexts coming into contact, mocking the very existence of an option to link one's Tumblr account to Facebook, and even proposing secret code phrases for recognizing other Tumblr users in offline contexts.

The norm of the 'bench on a crowded street,' a public space in which private matters may be discussed with the expectation of some level of privacy, is similarly socially constructed and enforced, as are definitions of what constitutes controlled or privileged information. Users often use Tumblr's content tagging system to mark posts as "#personal," or employ individual personal tags of their own devising such as "#Ben's ramblings." Posts which touch on subjects like family, health, or relationships might be

perceived as personal without necessarily being tagged, though this is far from universally the case, especially if the post is written in a humorous style. There is a broad recognition in the community that posts established or perceived as personal are not to be reblogged (i.e., shared to the tumblr blog of a user other than the originator of the post). When greater certainty is desired, users often employ *tumblr's* content tagging system to explicitly indicate that a post is not for broader consumption by tagging it with phrases like "#don't reblog". Users sometimes even write entire posts in tags or use hidden text which must be revealed by clicking a "read more" link, to make their personal posts less visible and more difficult to share. Conversely, when a post that touches on personal topics is actually intended to be a more public statement, it may be tagged "#okay to reblog".

The shared presumption is that others will, by and large, respect the norms of the community and the wishes of their fellow users by respecting the special status of content considered "personal," not sharing posts that are marked as private or privileged in any way, and not acting in ways that would contribute to the 'context collapse' of Tumblr and other social contexts. Like any system based on social cues, this system is not perfect or infallible, but it seems to answer this community's needs better than strict platform-mandated privacy controls. The users I interviewed routinely spoke of preferences and respect as more important than strict control, indicating a preference for social management of disclosure over technological. The obligation for the researcher here is clear: maintaining confidentiality on participants' terms requires that sharing of observations and dissemination of findings be undertaken within the framework of a thorough understanding of the norms which govern information and identities in the communities in which research is taking place. Based on this understanding, they should make every attempt to follow social cues that indicate how information should be treated in the specific case of each piece of data or observation. In the case of my own research, this has led to choices such as treating 'popular' posts – those which have been reblogged thousands or tens of thousands of times – as a distinct category from which it was more appropriate to quote directly or discuss in detail, because such posts are often seen by users as shared cultural artifacts quite divorced from their original contexts or the users who originally created them.

General Guidelines

The specific choices I have offered as examples above are far from universally useful or applicable, and my intent has not been to suggest that they constitute a single correct approach even in the specific context of my own research. Rather, they are illustrative of the general need for researchers to consider how participants experience online social settings, and to take care that we rethink things that may at first appear obvious and avoid falling back on our own external norms of space and context as default. Not only does this responsive approach help protect the well-being of research participants, but it also protects the integrity of our research by helping to frame observations and conclusions within a more genuine understanding of how participants experience privacy and disclosure. With this in mind, I offer some more general guidelines for conducting social research with young people in online settings:

1. While this may not be fully possible in more quantitative research such as large-scale survey studies, researchers should make attempts to develop an emic understanding of privacy as it is conceptualized, experienced, and practiced within communities of interest.
2. The consequences of potential disclosure of information for participants' well-being should be considered and analysed from multiple perspectives. Researchers should be aware of what kinds of potential consequences – and thus, what kinds of breaches of privacy – are of greatest concern to participants, and prioritize these when considering protective measures.
3. Researchers should avoid schemas which presume a strict dichotomy between private and public. In particular, information should not be treated as open and public simply because it is stated in a forum which is freely accessible. Rather, we should adopt and work within the framework of managed disclosure, understanding that things may be revealed in 'public,' which are intended for specific audiences.
4. Researchers must consider how the technological affordances of online social spaces may undermine standard confidentiality practices. Elements of online life such as searchable profiles, search engine indexing of online statements, social recommendation algorithms, and marketing databases based on deep

data mining may make conventional precautions, such as the creation of pseudonyms insufficient.

5. Researchers must endeavour to gain a working understanding of how people in particular online communities express their wishes regarding information they disclose and should respect these wishes as they are expressed with regard to how, and in what context, information is to be protected or shared.
6. The broader social context of young people's privacy should be taken into account. Specifically, it must be understood that children and youth as a class must contend with different conditions and pressures in maintaining control of information about themselves, and must fear different consequences of unwanted disclosure. Ethical choices in research must, therefore, be made with the understanding that both normative adult frameworks of privacy and conventional perspectives on the 'protection' of young people may be inappropriate guidelines.

It is worth discussing the practical limitations that researchers face in considering divergent and responsive privacy frameworks while working under more rigid and conventional rules and regulations set down by government bodies and research institutions. Rules defining minors as 'vulnerable subjects' carry requirements, which may conflict with the goal of protecting young participants' privacy on their terms. For instance, parents are generally required to be fully informed about the nature of any research in which their children are participating, potentially creating significant problems as they are also often the audience to which young people are most concerned about some types of personal information being divulged. The Institutional Review Board at my university initially rejected my appeal, described earlier, to waive parental consent and notification requirements. In fact, their response went so far as to suggest that the very rationale I had given for requesting the waiver – the fact that participants might use social media as a place to discuss sensitive topics outside the reach of parental surveillance – was the reason parental consent should not be waived, arguing that not informing parents of young people expressing themselves in ways they might not condone constituted the real risk.

This is merely one example of how the conventional framing of young people as lacking agency and capacity can conflict with a desire to respond to their experiences, perspectives, and preferences in regard to the protection of their own well-being. Such approaches are part of a larger and persistent social paradigm which denies children and young people self-ownership and self-determination based on the assumption that adults are better equipped to make decisions for them and will reliably act in their best interest, whether this is supported by evidence or not (Qvortrup, 1994). Certainly, my experience suggests a belief on the part of the IRB at my institution that researchers should act against young people's wishes with regard to their own privacy if such wishes conflict with conventional ideologies of adult control.

This view is hardly universal, however, and progress is certainly being made. The majority of IRB chairpersons at universities and hospitals across the United States believe it is at least sometimes appropriate to waive parental consent requirements, particularly when sensitive information is involved, and over nine in ten feel that regulations should be permanently changed to give minors the right to consent for themselves in non-invasive, anonymous research (Mammel & Kaplan, 1995). With regard to this last point, I was eventually able to secure the waiver I requested only under the condition that I make the interview process fully anonymous and avoid collecting any 'identifying data' about participants. Some review boards are moving to accept the notion that young people be given more agency in online research specifically because of the reality that their online experiences are generally characterized by less direct oversight and more independent decision-making than their offline lives (Flicker, Haans, & Skinner, 2004). Researchers, professional organizations, parents, and children themselves are broadly aligned in their view that young people have the capacity to responsibly manage their participation in studies that present minimal risk, and ethical oversight bodies are beginning to take note (Coyne, 2010; Mustanski, 2011). Still, there is work to be done on this front, and researchers wishing to explore novel approaches to research ethics with young participants must be prepared for challenges that would not arise were they to work under a more conventional framework.

Limitations and On-going Questions

While I believe the guidelines I have proposed here are of value in moving the ethics of online research with young people in a more holistic and responsive direction, they are limited in their scope and applicability. Perhaps the most significant limitation of my argument is that my work, being ethnographic in nature, naturally lends itself to an emic perspective and to methodological decisions made in response to community-specific norms and practices. It might not be so easy for quantitative work, studies of larger and more diverse populations, or studies that cut across many online communities with different cultural expectations to take the kind of responsive approach I have proposed. It is also worth noting, as a potential limitation of my underlying observations, that my analysis is primarily based on experiences in the context of research undertaken as sociocultural analysis of young people's experiences of online communities; observations on research ethics happened as a by-product of this work rather than as a central goal. While I have spoken with a number of young people over the past few years about their perspectives on privacy and disclosure in online settings, these discussions were geared more toward understanding their everyday experiences of privacy – managing disclosure with friends, parents, and learning institutions – rather than explicitly eliciting their thoughts on participation in research. On a connected note, the guidelines I propose here, because of their reflexive and context-specific nature, are inherently difficult to codify or monitor; they are thus not particularly well-suited to incorporation into governmental research regulations or institutional review and approval processes, which by their nature operate better with clearer and more universal guidelines. As I have experienced in my own research and described here, there thus remains a significant question of how researchers can engage with participants and communities in the flexible and responsive nature I advocate while satisfying the expectations of the various bodies which regulate research ethics – or how those regulatory bodies can integrate that flexibility into their role of applying standards of practice.

Though I intend for the broad recommendations in this piece to stand on their own, they can also be seen as a jumping-off point for future research, which may address these limitations. I intend, in the near future, to embark on a long-term, multiple-context

study with the primary objective of exploring young people's perspectives on online privacy, with an eye from the beginning toward understanding their expectations and standards with regard to confidentiality in digital research. I hope, as well, to continue to see other researchers asking these questions and helping us work toward the broad principle of protecting the privacy of young research participants on their terms.

References

- Alderson, P., & Morrow, V. (2011). *The Ethics of Research with Children and Young People*. Los Angeles: SAGE.
- Burton, J. (in press). Screaming into the void: Reconceptualizing privacy, the personal, and the public through the perspectives of young Tumblr users. In A. McCracken, L. Stein, & A. Cho (Eds.), *A Tumblr Book*.
- Bauminger, N., Finzi-Dottan, R., Chason, S., & Har-Even, D. (2008). Intimacy in adolescent friendship: The roles of attachment, coherence, and self-disclosure. *Journal of Social and Personal Relationships*, 25(3), 409-428.
DOI: 10.1177/0265407508090866
- boyd, D. & Marwick, A. (2011). Social privacy in networked publics: Teens' attitudes, practices, and strategies. Privacy Law Scholars Conference. Berkeley, CA.
- Buchanan, E., & Zimmer, M. (2016). Internet research ethics. In E. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy*. Retrieved from <https://plato.stanford.edu/archives/win2016/entries/ethics-internet-research>
- Cherney, I. (2010). Mothers', fathers', and their children's perceptions and reasoning about nurturance and self-determination rights. *International Journal of Children's Rights*, 18(1), 79-100.
- Christensen, P., & James, A. (2008). Introduction: Researching children and childhood cultures of communication. In P. Christensen, & A. James, *Research with Children: Perspectives and Practices*. New York: Routledge.
- Coyne, I. (2010). Research with children and young people: The issue of parental (proxy) consent. *Children & Society*, 24, 227-237.

- Flicker, S., Haans, D., & Skinner, H. (2004). Ethical dilemmas in research on internet communities. *Qualitative Health Research*, 14(1), 124-134.
- Henley, J. (2013, October 21). Are teenagers really careless about online privacy? The Guardian. Retrieved from <https://www.theguardian.com/technology/2013/oct/21/teenagers-careless-about-online-privacy>
- Holvast, J. (2009). History of privacy. In V. Matyáš, S. Fischer-Hübner, D. Cvrček, & P. Švenda (Eds.), *The Future of Identity in the Information Society* (pp. 13-42). Berlin: Springer.
- Jenkins, H. (1999, May 4). Congressional testimony on media violence. Washington, DC. Retrieved from http://web.mit.edu/comm-forum/papers/jenkins_ct.html
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, 19(11), 1632-1641. doi: [10.1177/1049732309350879]
- Kennedy, H. (2014). Beyond anonymity, or future directions for internet identity research. In A. Poletti, & J. Rak (Eds.), *Identity Technologies: Constructing the Self Online*. Madison, Wisconsin: University of Wisconsin Press.
- Livingstone, S. (2008). Taking risky opportunities in youthful content creation: Teenagers' use of social networking sites for intimacy, privacy, and self-expression. *New Media & Society*, 10(3), 393-411. Retrieved from <http://eprints.lse.ac.uk/27072>
- Lykens, J. (2015, August 5). *What you need to know about teens and online privacy*. Retrieved October 12, 2016, from Yth.org: <http://yth.org/what-you-need-to-know-about-teens-and-online-privacy/>
- Madden, M., Lenhart, A., Cortesi, S., Gassir, U., Duggan, M., Smith, A., & Beaton, M. (2013). *Teens, Social Media, and Privacy*. Washington, DC: Pew Research Center.
- Mammel, K., & Kaplan, D. (1995). Research consent by adolescent minors and institutional review boards. *Journal of Adolescent Health*, 17, 323-330.
- Markham, A. (2011). Fabrication as ethical practice: Qualitative inquiry in ambiguous Internet contexts. *Information, Communication & Society*, 15(3), 334-353.

- Marwick, A., & boyd, D. (2014). Networked privacy: How teenagers negotiate context in social media. *New Media & Society*, 16(7), 1051-1067.
- Marwick, A., & boyd, D. (2010). I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. *New Media & Society*, 13(1), 114-133.
- Matthews, H., Limb, M., & Taylor, M. (2000). The 'street as thirdspace'. In S. Holloway, & G. Valentine (Eds.), *Children's Geographies: Playing, Living, Learning*. New York: Routledge.
- Moscardelli, D., & Divine, R. (2007). Adolescents' concern for privacy when using the internet: An empirical analysis of predictors and relationships with privacy-protecting behaviors. *Family and Consumer Sciences Research Journal*, 35(3), 232-252.
- Mustanski, B. (2011). Ethical and regulatory issues with conducting sexuality research with LGBT adolescents: A call to action for a scientifically informed approach. *Archives of Sexual Behavior*, 40, 673-686.
- Nairn, A., & Clarke, B. (2012). Researching children: are we getting it right? A discussion of ethics. *International Journal of Market Research*, 54(2), 177-198.
- Nosek, B. A., Banaji, M. R., & Greenwald, A. G. (2002). eResearch: Ethics, security, design, and control in psychological research on the internet. *Journal of Social Issues*. 58(1), 161-176. <http://dx.doi.org/10.1111/1540-4560.00254>
- Qvortrup, J. (1994). Childhood matters: An introduction. In J. Qvortrup, M. Bardy, G. Sgritta, & H. Wintersberger, *Childhood Matters: Social Theory, Practice and Politics*. Aldershot, UK: Avebury.
- Rasmussen, K. (2004). Places for children - children's places. *Childhood*, 11(2), 155-173.
- Robson, J. (2015). *Parents' perceptions of children's rights in the family setting*. Auckland University of Technology, Auckland. Retrieved from <http://aut.researchgateway.ac.nz/bitstream/handle/10292/9834/RobsonJ.pdf?sequence=3>

- Stern, S. (2004). Studying adolescents online: A consideration of ethical issues. In E. Buchanan (Ed.), *Readings in Virtual Research Ethics: Issues and Controversies*. Hershey, PA: IGI Global.
- van der Velden, M., El Emam, K. (2013). "Not all my friends need to know": A qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association*, 20(1), 16-24.
- Warren, C., & Laslett, B. (1977). Privacy and secrecy: A conceptual comparison. *Journal of Social Issues*, 33(3), 43-51.
- Westin, A. (1970). *Privacy and Freedom*. New York: Atheneum.
- Wingfield, N. (2016, November 9). Should you spy on your kids? New York Times, Retrieved from <https://www.nytimes.com/2016/11/10/style/family-digital-surveillance-tracking-smartphones.html>