

2015

## Young people's views regarding participation in mental health and wellbeing research through social media

Helen E. Monks  
*Edith Cowan University*

Patricia Cardoso  
*Edith Cowan University*

Alana Papageorgiou  
*Edith Cowan University*

Catherine Carolan  
*Edith Cowan University*

Leesa N. Costello  
*Edith Cowan University*

*See next page for additional authors*

Follow this and additional works at: <https://ro.ecu.edu.au/ecuworkspost2013>



Part of the [Medicine and Health Sciences Commons](#)

---

Monks, H., Cardoso, P., Papageorgiou, A., Carolan, C., Costello, L., & Thomas, L. (2015). Young people's views regarding participation in mental health and wellbeing research through social media. *International Journal of Emotional Education*, 7(1), 4 - 19. Available [here](#)  
This Journal Article is posted at Research Online.  
<https://ro.ecu.edu.au/ecuworkspost2013/3074>

---

**Authors**

Helen E. Monks, Patricia Cardoso, Alana Papageorgiou, Catherine Carolan, Leesa N. Costello, and Laura Thomas

## **Young people's views regarding participation in mental health and wellbeing research through social media**

**Helen Monks<sup>a 1</sup>, Patricia Cardoso<sup>a</sup>, Alana Papageorgiou<sup>a</sup>, Catherine Carolan<sup>a</sup>, Leesa Costello<sup>a</sup> and Laura Thomas<sup>a</sup>**

*<sup>a</sup> School of Exercise and Health Science, Edith Cowan University, Western Australia*

Social media is a central component in the lives of many young people, and provides innovative potential to conduct research among this population. Ethical issues around online research have been subject to much debate, yet young people have seldom been consulted to provide a youth perspective and voice. Eight (8) focus groups involving 48 Grade 9 Western Australian secondary school students aged 13-14 years were held in 2012, to investigate how young people perceive the feasibility and acceptability of social media when used as a research tool to investigate various issues relevant to their mental health and wellbeing. Whilst young people recognise many benefits of researchers using social media in this way, such as its relevance, innovation and accessibility, there were salient issues of privacy, consent, and practicality that require careful negotiation. There is a need for continued exploration and scientific debate of the moral and ethical implications of using social media for research, to help ensure this is employed in an appropriate and effective way that is respectful of and sensitive to the needs and views of young people.

**Keywords:** social media, online research, adolescents, young people, internet-based research

First submission 27<sup>th</sup> November 2014; Accepted for publication 24<sup>th</sup> March 2015.

### **Introduction**

The permeation of Information and Communications Technology (ICT) in 21st century society has provided seemingly infinite opportunities for conducting research in relation to human social practices than ever before (Markham & Baym, 2009). Whilst providing innovative and unprecedented potential for research,

<sup>1</sup> Corresponding author. Email address: [h.monks@ecu.edu.au](mailto:h.monks@ecu.edu.au)

the advent of internet-based research methods also presents important challenges for researchers to negotiate. One aspect of modern ICT that has been utilized as a platform for research is social media, and this medium may have particular relevance for conducting research with young people, who are major contributors to this space.

Over 80% of adolescents use some form of social media on a regular basis (Madden et al., 2013; Mitchell, Patrick, Heywood, Blackman, & Pitts, 2014). Various forms of social media include social networking sites, blogs, microblogs, image sharing sites, video sharing sites, social games and discussion forums. Such online spaces are a source of rich description, allowing a powerful opportunity to enter cultural lifeworlds and conduct unobtrusive naturalistic observation of social phenomenon (Kozinets, 2010; Kraut et al., 2004). These communication channels also offer considerable potential to engage with young people for research purposes as this is an environment frequented by the large majority of this population in the Western world, and a setting in which young people are likely to be at ease with employing ICTs to interact with others (Brockman, Christakis, & Moreno, 2014; Hinton, 2013).

Researchers have previously utilised social media as a setting for research examining the mental health and wellbeing of young people, including: social aggression and cyberbullying behaviour on mobile devices (Underwood & Card, 2013), personal information disclosure on social networking sites (Hinduja & Patchin, 2008), 'friending' practices, privacy settings and profanity (Thelwall, 2008a, 2008b), 'sexting' behaviour (Ringrose, Gill, Livingstone, & Harvey, 2012), as well as the use of social networking in relation to alcohol use among young women (Lunnay, Borlagdan, McNaughton, & Ward, 2015).

Despite its considerable use hitherto, many challenges surround the use of online environments, such as social media, for research purposes. Despite the public nature of their communications online, young people may believe they are communicating in a private setting and accordingly there is considerable ambiguity surrounding whether consent is needed to collect this data from users, or whether it should be treated as publicly accessible information (Henderson, Johnson, & Auld, 2013; Lunnay et al., 2015). The public accessibility of data does not necessarily indicate the data were envisioned by young people as public or intended for a public audience (Henderson et al., 2013). However, if young people are informed of research being conducted in social media settings they frequent, this may bias the research through young people changing their online behaviour in response to the knowledge they are being observed (King, 1996). It is believed the ethical obligation for the researchers to disclose themselves accurately is paramount (Kozinets, 2010), although there may be some resentment to being studied on the part of users of social media (Hudson & Bruckman, 2004), particularly when they disclose intimate details and personal information.

A review of the ethical issues of qualitative research in online communities recommended considering issues of privacy and consent around this form of research in consultation with members of the online groups researchers wish to study (Eysenbach & Till, 2001). Certainly, salient issues of privacy, appropriateness and acceptability among the target group of online research methods need to be investigated prior to the widespread adoption of social media as a research tool, particularly among vulnerable populations such as young people. Perceptions of privacy among young people may differ considerably to that of adults,

with young people seeming to be more willing to disclose private information to public audiences online, not necessarily considering the long-term consequences of this (Henderson et al., 2013; Hinton, 2013).

Utilising social media when conducting research may provide opportunity for different understandings, in an increasingly networked society, of how youth is constructed, embodied, communicated and experienced in this environment (Hinton, 2013). Typically young people are positioned as dependent and passive by current ethical frameworks for conducting research, however they have the capacity to play an active role in shaping research processes, agendas and findings (Claverling & McLaughlin, 2010; Hinton, 2013; Lunnay et al., 2015; Park & Calamaro, 2013). This appeal for young people's active participation in the research that affects them is in accordance with the United Nations' decree of "respect for the views of the child" (United Nations, 1989). It is imperative that young people are also consulted and engaged with in relation to online research methods, particularly given their advanced ability to appropriate new media which is not always matched by earlier generations (Henderson et al., 2013). Partnerships with young people should be formed that enable them to act as co-researchers in this area, such that they can be 'change partners' and their youth voice can be heard and contribute to social change (Spears et al., 2011; Wong, Zimmerman, & Parker, 2010). Engaging young people as co-researchers allows for disruption of the usual power relationship between participant and researcher, enabling young people to have an equal relationship with researchers and for their opinions, experiences and insights to be shared (Spears et al., 2011). Continuous engagement and knowledge generation with young people as co-researchers will allow their youth voice to be heard, providing a greater understanding of the acceptability of online research methods among this group (Spears & Kofoed, 2013).

### **Aims and objectives**

This study aimed to determine how social media research methods can be used to promote health and wellbeing among young people, and specifically how young people perceive the feasibility and acceptability of social media as a platform for conducting research with and/or about them in relation to various mental health and wellbeing issues. The main research questions guiding this study were:

- How do young people perceive the appropriateness of different methods of online research compared to offline research?
- What factors would influence young people's participation in research via different forms of social media?, and;
- What are young people's perceptions of the issues of consent and privacy around the use of their social media data for research purposes?

The main outcome of the study was to formulate a list of fundamental issues to guide researchers in their decisions about the use of social media as a research tool among this population when there are no clear ethical boundaries present.

## **Method**

As a qualitative study, epistemological and ontological assumptions informed the research methodology. Ontologically, this study embraces the idea of multiple realities (essentially of a social world of meaning) and represents these realities through the actual perspectives and experiences of its participants (Creswell, 2012). Focus groups facilitated an investigation of young peoples' opinions, feelings and experiences of researchers using social media to conduct research about mental health and wellbeing issues relevant to young people. A post-positivism paradigm underpinned the philosophical assumptions of this study, which embraces multiple realities from participants, but uses a reductionism oriented approach to inquiry (Creswell, 2012). A post-positivist framework also recognises possible effects of biases and pursues objectivity to ensure the emic views and experiences of participants shape the direction of the research.

## **Participants**

Focus groups were held with 48 Grade 9 (13-14 year old) students from 12 secondary Perth metropolitan schools of the Catholic Education Office (CEO) of Western Australia or Association of Independent Schools Western Australia (AISWA) sectors. This sample of convenience was drawn from students participating in a leadership workshop as part of a larger three-year study, the Cyber Friendly Schools Project (Cross et al., 2014). The nominated students required their parents' active consent for participation in this project. Participants were informed their participation would include a focus group discussion about the implications of researchers using social media in their investigation of adolescent mental health and wellbeing issues. Based on qualitative research, focus groups with 48 participants represent a sufficient number to reach data saturation when information becomes repetitive and no new patterns emerge (Krueger & Casey, 2000). Ethics approval for the CFSP project and this sub-project was obtained from the Edith Cowan University Human Research Ethics Committee and the Catholic Education Office in Western Australia and parental active consent was obtained for all student participants. Formal approval from AISWA was not required.

## *Protocol*

The focus group protocol comprised semi-structured open-ended questions aimed at understanding how young people perceive the use of social media for researching issues of adolescent mental health and wellbeing. Consultations with stakeholders at the outset of the project assisted in determining key issues for investigation through the focus group protocol.

An introduction to the focus group questions asked students about their use of electronic devices, commonly used spaces/sites for communicating online, and their perceptions of various social media sites as public or private spaces. Four different scenarios (vignettes) were proposed detailing situations where social media was used in research with young people and participants were asked questions in relation to these vignettes (Table I).

**Table I. Focus group vignettes about researchers use of social media to investigate various mental health and wellbeing issues among young people**

<p><b>Vignette (a) Research in public profiles without consent (passive research in private spaces) to investigate social media use among young people</b></p> <p>A group of university researchers wanted to know how young people used Social Networking Sites in positive ways with their friends. The researchers looked at some young people's Facebook profiles that were set to public. After reading the Facebook pages, the researchers categorised young people's comments and counted the number of comments where young people were supporting a friend. As the Facebook profiles were public, they did not ask the participants for permission. The information helped the researchers to find out how young people are using technology in positive ways, and to what extent they needed to be encouraged to use Social Networking Sites to interact with their friends in positive ways. The researchers wrote an article about the positive ways young people use Social Networking Sites, which was available in online libraries worldwide.</p>
<p><b>Vignette (b) - Research in public profiles with consent and participants active in the research (active research in private spaces) to investigate binge drinking behaviour among young people</b></p> <p>Researchers wanted to know how to help young people reduce their binge drinking behaviour. The researchers created an ad on Facebook asking young people to visit their page and share their ideas about how harmful binge drinking is, and how programs and messages can help prevent and reduce their binge drinking behaviour. As soon as they commented, young people are consenting to participate in the research. The researchers used this information and quoted young people's comments (not using their names) to develop a program, website and radio advertisement about binge drinking for young people.</p>
<p><b>Vignette (c) - Research in an existing public forum with consent (passive research in public spaces) to investigate body image among young people</b></p> <p>University researchers wanted to find out about young people's body image. The researchers looked at an online forum where young people had posted their restrictive eating behaviours, excessive dieting and exercise, and concerns about their body image. The researchers saw the forum topic and created a post, describing their research and asking individual users of the forum whether they could have their permission to read and use their de-identified posts for research. By de-identified we mean that there are no names connected with the content. The researchers then read those comments they had permission to use, and used this information to write an article about how some young people have a negative body image and use harmful behaviours to change their body shape and size. This article was made available in online libraries worldwide and some de-identified comments from young people were used in a newspaper article that spoke about the study. The information was also used to develop a program about how to improve young people's body image.</p>
<p><b>Vignette (d) – Research on a designated site with consent and participants are active in the research (active research in a public space) to investigate bullying among young people</b></p> <p>The Speak Out Now organisation created a website with a forum for young people to share their experiences of being bystanders to bullying. The forum moderators post a new question on the forum every month, asking young people's responses to questions such as 'When you last saw someone being bullied, what did you do?'. Before posting on the forum, young people were asked to read an 'Instructions for Forum Use' document on the website, where it explained that their de-identified forum posts (i.e. posts with your name removed) may be used for research purposes. The researchers used the comments from young people as quotes in a research article that talked about experiences of bystanders to bullying, and recommended the need for more bystander programmes for young people.</p>

Each vignette presented different topics of research (different issues of mental health and wellbeing), varying levels of consent and anonymity, and different scenarios surrounding the dissemination of the research findings. The vignettes alternated between private and public online spaces (as perceived by the researchers) as the setting for the research, and featured scenarios where researchers utilised existing data from young peoples' online interactions (passive observational research) and where young people were actively engaged in the research as willing participants (active research). One half (n=4) of the total number of focus groups presented vignette (a) and (b), and the remaining half of the focus groups (n=4) presented vignette (c) and (d). The order of the vignettes were reversed in half of the focus groups [i.e. vignette (b) presented before vignette (a)] to ensure discussion would be devoted to each vignette in at least two of the focus groups, if there was insufficient time to reach the end of the protocol.

Questions were formulated to encourage discussion relevant to each vignette on the following topics: 1) overall perceptions of researchers using social media in that way including possible benefits and risks; 2) different online spaces that would be appropriate for researchers to use; 3) acceptability of the research method for exploring different topics of mental health and wellbeing, and; 4) issues of consent relevant to that research method. At the conclusion of the focus group young people were also asked what advice they would give to researchers who would like to conduct research with young people by means of social media.

The focus group protocol was reviewed by the chief and associated investigators, where appropriate, for content trustworthiness. The focus group protocol was also pilot tested with a convenience sample from the target group of Grade 9 students (n= 10, ages 11-14 years), to provide feedback on the flow of the protocol, skills of the moderator (Krueger, 1998), the development of questions and provide an assessment of the type of responses received (Delbecq, Van de Ven, & Gustafson, 1975).

### *Procedure*

A total of eight focus group discussions were held concurrently by trained researchers to address the aims of this formative project, with six students participating in each focus group. Focus group discussions were approximately 45 minutes in length, and consisted of six students participating in each, in addition to a facilitator and a scribe present at each focus group. As the research was not deemed to be gender-specific, heterogeneous focus groups (mixed gender) were used to allow for divergent thinking with the opportunity to gather different opinions and views (Stewart, Shamdasani, & Rook, 2007). The participants in each focus group, however, attended separate schools. With students' permission, digital audio recordings were made of each focus group. Confidentiality of responses was ensured and students were informed that there was no right or wrong answer, just their opinion, and if they wished to withdraw from the discussion at any time they could do so. Students were informed that for the purposes of the discussion, 'social media' refers to sites where someone can communicate with others online, for example Facebook, My Space, Twitter, YouTube, Skype and social games sites. A debriefing procedure was held immediately following the focus groups during which facilitators and scribes were invited to share overarching themes and key points from their discussions with students.



### *Data analysis*

Focus groups responses were transcribed verbatim and each transcript was reviewed for inconsistencies in tone, or errors in meaning prior to data analysis. Prior to formal analysis, the data were subject to reading and re-reading, to identify general patterns and contradictions emerging from the text, and to consider possible explanations. The data analysis process also involved simultaneously sifting and sorting information to inform the construction of categories of thought and behaviour (themes), to extract the essence of the raw data in a form that progresses new understanding (Fetterman, 2010; Hammersley & Atkinson, 2007; Kozinets, 2010; Miles & Huberman, 1994). Concrete and analytic categories emerging inductively through the data were then affixed to sections of text to sift and sort the remaining data into themes, adding new categories or sub-categories as necessary. Data analysis was facilitated using qualitative data management software Nvivo 10 and guided by the analytic method of Framework Analysis (Ritchie & Spencer, 2002), including:

- Familiarisation of the data through reading and re-reading, listing initial themes, and gaining an overview of the depth and diversity of information
- Constructing a thematic framework (Nvivo Framework Matrix) of key concepts emanating from the data and also drawing on a priori issues
- Indexing and charting – sifting and sorting the data into the identified themes of the Framework Matrix, with key supporting quotes
- Mapping and interpretation of the data set as a whole

### **Results**

Several main themes emerged from the eight focus group (FG) discussions with students about their perceptions of researchers using social media to conduct research about mental health and wellbeing among this population. As the general themes arising from discussions about researchers using social media were markedly similar to Eysenbach and Till's (2001) seven principles guiding ethical research online (privacy, intrusiveness, vulnerability, potential harm, consent, confidentiality, intellectual property), this structure forms the basis for discussion of the findings from the current project. However, as the topic of intellectual property was not raised in the focus group, this category was replaced by the theme of 'practical research issues and recommendations'. Also, the description of themes emanating from the study is preceded by findings about general social media use among young people.

### *Social media usage*

As an introduction to the focus groups, young people were asked about the types of social media they used to communicate with others. Commonly mentioned social media platforms included Facebook, YouTube, Tumblr, Instagram, Skype and iMessage. Other social media types used by young people were Viber (free messaging app), Twitter, Steam (gaming platform), E-modo (educational social networking site/interactive blog), Ninegag (image sharing site for memes), Voxer ('Walkie Talkie' and messaging app for team communication), Viber (free messaging and calling app), VYou (for interacting with celebrities online),

Flipboard (an integrated social media platform), specific gaming websites (Minecraft, Call of Duty), Kik (online texting program), and online forums including Reddit and Omeagle.

### *Privacy*

To understand how young people viewed online research in relation to privacy concerns, they were asked about their perceptions of specific social media as private or public. The perception of social media sites as public or private was largely dependent on users' ability to apply privacy settings to their profiles, which defines the level of access others can have to their information online. Also, young people noted that within certain forms of social media there may be private and public aspects - i.e. private messaging functions or posting publicly on shared pages. When referring to specific social media types, it was believed that Facebook could be both private and public (due to privacy settings). Twitter and online forums were seen as public, whereas iMessage and Skype were viewed as private spaces where young people had closed conversations with others.

Young people's initial reaction to scenarios about the use of social media to conduct research included some degree of discomfort, with some believing this as "like an exploitation of our enjoyment" (FG 7) and "an invasion of privacy" (FG2, FG5, FG6). Despite these initial reactions, several participants believed it was young peoples' responsibility to ensure their own privacy through their privacy settings on social media and what they post or do not post online, and as such they thought it was fair the researcher could use their information in this way; "I think it's the own person's fault for having a public profile because it's out there" (FG8). However, it was acknowledged that navigating the privacy settings of social media isn't always simple or straightforward; "in some ways you can't control all your privacy" (FG3). Further some people may not be aware of their privacy settings; "They might not have been aware that their profile was available to the world, so it's not entirely their fault that they did" (FG2). The complexity and tension between the issues was also noted; "I can understand both sides because like some people might think it's really rude because they didn't know how, but then if you purposely set it to public you can't get upset over it...." (FG2).

### *Intrusiveness*

Young people's reaction to being the subject of research conducted through social media varied according to the topic being studied and its personal or sensitive nature. For instance, topics were seen as less sensitive if "it's not really that embarrassing to share" (FG3). However, many topics were deemed okay to be approached by online research, including issues like cyberbullying and mental health. Young people suggested they would be less willing to be involved in research that was asking them about personal health behaviour rather than their general opinions about an issue, regardless of assured anonymity of the information they provide, for instance; "If I were to be getting bullied...I definitely wouldn't want anyone to know about that like that's something I would want to keep to myself" (FG4). "You can contribute a little bit more if it is less personal for you or you are less worried about being judged or whatever" (FG5).

However, another student believed it was young peoples' own responsibility to keep personal topics personal by not posting them online; "Well, if it was too personal then they shouldn't have posted it" (FG6). Some internet-based research may also be seen as intrusive because it infringes on the perceived anonymity

and freedom of expression on certain sites such as Tumblr; “Because sometimes Tumblr is where you just spill because no one really knows who you are” (FG1). “...People use Tumblr so much because it’s like a way to express how they feel” (FG5). “It’s kind of a place where everyone really just says what they want and be’s [sic] who they want to be” (FG1).

### *Vulnerability*

Some young people may be particularly vulnerable when using social media, such as those who are less informed of privacy settings; “There are quite a few people who are late to join to Facebook or are of a generation who don’t know how to use it” and “they shouldn’t be punished for that” (FG7). Additionally, specific social media sites may attract more vulnerable young people, specifically Tumblr. Young people indicated that “Tumblr is actually really intense”, “like really hardcore” and “some of the themes on Tumblr are dark” (FG7). However, some young people also felt this made the site a useful platform for online research; “Tumblr would be the best possible place where you could get researchers on” (FG7), and is “probably the biggest spot where cyberbullying happens” (FG8).

To help counteract the vulnerability of young people in relation to the use of their social media data for research purposes, it was recommended by focus group participants that respect for young people should be maintained in the use of this data:

...like having a trustworthy organisation that we know you're not going to like spin our words and make us look like bratty teenagers who just post because we can. Like try and understand it from our point of view I guess... (FG1)

Although research through social media may exploit young people’s vulnerability (when their data is used without permission), there is also the potential to empower young people through maximising their participation in research and develop more responsive solutions appropriate to young people: “By actually speaking to the young people then they get what’s actually going on and how to prevent it instead of spending money on things that aren’t going to work” (FG6). “I would be like really impressed and...I’d want to know about the company because it’s taking a step to involve young people” (FG7).

Whilst online research methods were seen as an ‘smart’ and ‘creative’ way to involve young people in research this was not without hesitation; “It’s really reassuring to see that people who are interested in stuff to do with teenagers are trying to get teenagers involved but at the same time I don’t think that teenagers are ready for it yet” (FG7).

### *Potential harm and benefits*

Young people’s perceptions of the acceptability of researchers using their social media information as data were dependent on the topic being investigated and its harmful nature, as well as the benefits for researching these issues. Another comment reiterated that acceptable use of their online data for research was determined by the potential benefits; “Well, as long as they are trying to help people...like not going against it, and saying young people are bad, they kind of do this... and not providing an answer to it” (FG3). Similarly, another student believed use of their information for research was more acceptable if “it’s going to a good cause” and “it’s going to help other people as well through something you’ve said” (FG4). Other

young people stated they would be encouraged to participate in research by “knowing that it would make a difference”, “knowing that it could help someone else” and “if the information was used wisely” (FG8).

Some topics of research were perceived to be particularly important among young people, which influenced their views of the acceptability of this method and their willingness to be involved in such research. Vignettes were presented to young people about cyberbullying and body image, and young people indicated these were particularly important issues for research. For some young people, whether the research was personally relevant (i.e. “you have gone through something”) would influence their willingness to participate more than the topic itself; “it would depend on personal experience; some people might react to it” (FG1).

Young peoples’ participation in online research was also relevant to the perceived benefits and costs of the research to them personally. For instance, use of incentives would increase their participation, as would minimal burden of the research, such as a short time commitment. Online research was seen as a creative way to access young people and the online nature of research “makes it easier for some people to do” because “you don't actually really have to do all that much effort to get your message through” (FG4).

### *Consent*

Young people were generally accepting of the use of their information on social media as data for research purposes, provided that their express permission was given for the use of their information in this way. It was believed that seeking consent ensures that people are only involved in the research if they want to be and they are fully informed of the use of their data for research purposes. The need for consent was seen as important regardless of the topic of the research, the perceived privacy of the site and whether the information was de-identified; “I reckon they should ask first ‘cos they have only posted on a public site like you are posting it for people to see not for them to take the information” (FG5). “Because I know it's not really your name and everything, but they should still have consent to use what you said, or post it” (FG3).

Young people recognised the difficulty in obtaining informed consent for research through social media channels. When consent is sought through a terms and conditions document upon entry to a particular social media site, young people may be unlikely to read it; “I don't think anybody reads them” (FG1). As such it was suggested by young people that these be made “short and punchy” (FG4) or contain a link to information on an external website. Young people also expressed a preference to be approached personally for consent either through an email or message on a social networking site, and ensure that the organisation establishes their credibility and trustworthiness.

### *Confidentiality*

Assurance of confidentiality and anonymity was perceived as crucial among young people when their personal social media data was being used; “As long as it's de-identified, that's all I really care about” (FG1). Although the use of direct quotations from their social media data was deemed acceptable given their consent, de-identification of social media posts was crucial to minimise negative ramifications; “If you do write something on there, it is going back to maybe someone you know, you could get bullied for that reason...” (FG3).

### *Practical research issues and recommendations*

Young people noted that the benefits of research using social media were limited because of lack of representativeness and quality of the data. For instance, the credibility of the research may be compromised given that “it’s so easy to lie about your age on the Internet websites, they won’t be getting a true reading.” (FG7). As such, research on young people’s public profiles is also likely to be biased and “give you a certain kind of response” (FG7). Young people in the focus groups also commented that actively seeking consent from young people to engage them in research through social media may be a more accurate form of research as participants may put more thought into their responses; “it’s important they know it’s a research thing because then they might be more honest and accurate” (FG8). Similarly, conducting research with the active engagement of young people may be more accurate than observing their use of social media where young people may not present an accurate or serious image of themselves; “they might be getting information that is not really true most of the time” (FG2).

Facebook was seen as the most appropriate space for researchers contacting young people because “it’s just used by so many people” (FG6). It was also added that “Facebook is probably one of the more practical ones...like a lot of the others ones just wouldn’t work because of what they are or how people use them” (FG6). Social media sites Twitter and Reddit were also seen as spaces suitable for researchers to contact young people for their opinions about topics of relevance. Young people also recommended that researchers should make the research as engaging and interesting as possible and with minimal complexity, such as the use of “interesting questions that you want to answer” (FG1) that are “short and sweet and easy for the young people to understand” (FG4).

### **Discussion**

When asked about the potential for their information on such sites to be used as research data, young people expressed some hesitation and concerns about their privacy, as related to their perceptions of specific sites as personal or private spaces. This finding is consistent with the suggestion by Hudson and Bruckman (2004) that users of social media may express some resentment to being studied particularly when disclosing personal information on these sites. However, the perceived acceptability of the use of social media data for research was dependent on the topic being investigated and the level of personal relevance, as well as the potential of the research to effect positive change among young people. Therefore, it appears young people may weigh up the risks and benefits of engaging in research through social media, including the personal risks to their privacy and the possible benefits of the research among their age group.

Young people were open to the use of social media for research if they were given an opportunity to provide consent and assured of confidentiality and anonymity of their information. This finding is in line with Kozinets (2010) assertion that researchers have an overriding ethical obligation of disclosure which is important to observe in online research. Whilst it is important to recognise young people’s desire to provide consent for use of their social media data, it is noted that in some cases, depending on the topic of the research and the risk posed to young people, this may not be feasible. For instance, the nature of online communication groups for anorexia (i.e. pro-anorexia websites) that may serve to maintain and promote these disorders is

considered quite hostile and exclusionary to outsiders, such that researchers may be inclined to pose as a community member whilst conducting covert online observation (Brotsky & Giles, 2007). As in Brotsky and Giles' (2007) study, the considerable degree of harm posed to users of pro-anorexia sites, and the lack of suitable alternatives to conduct such research may justify the use of covert observational data collection without consent.

When conducting research using social media, it is important for researchers to be aware of the vulnerability of users of this technology who may not be fully informed of privacy settings, and thus do not have reasonable opportunity to protect their data from inclusion in research. As Henderson et al (2013) discuss, despite the publicly accessible nature of online data, young people may not always intend their social interactions to be broadcast to a public audience. Similarly, findings from this study indicate that young people may not always be aware of their privacy settings on social media that are difficult to navigate. Accordingly, it cannot be assumed by researchers that young people who have publicly available social media information are passively consenting to the use of this information for research purposes. Young people's perceptions of the intrusiveness of social media research differed according to the sensitive nature of the topic being investigated, and whether they were asked about specific personal health behaviours as opposed to providing their general opinions about issues of health and wellbeing. However, the intrusiveness nature of the research was seen to be justified in some cases dependent on the importance of the research topic and the potential for the research to effect change. The intrusiveness and vulnerability of social media research also varied according to the type of social media site. For instance, some young people using Tumblr may constitute a particularly vulnerable population, given participants' comments about the potential for this to be a dangerous and negative online space. Young people also suggested that research on Tumblr may infringe on the perceived anonymity and freedom of expression that is associated with use of this specific site. Therefore, it is important for researchers to be aware of the wide-ranging differences between the various social media sites and the implications of this for online research, and to assess research in each of these spaces on a case-by-case basis.

Despite some precautions and concerns about the use of social media for research with young people, focus group participants, believed that social media is a 'smart' and 'creative' way to involve young people in research. Similarly, it has been suggested that young people's capacity for active participation in shaping the research process may be maximised through the use of innovative communications channels such as social media. Additionally, although current ethical frameworks may position young people as dependent and passive participants in the research process, the use of social media may also help to challenge the usual power relationship between participant and researcher (Clavering & McLaughlin, 2010; Hinton, 2013; Lunnay et al., 2015; Park & Calamaro, 2013; Spears et al., 2011). Accordingly it is important to conduct further research about the use of social media in research and ways this may be employed whilst being aware of issues such as privacy, intrusiveness, consent and vulnerability of the young people being studied.

While the decision of whether to use social media in research with young people is likely to be a complex one, certain guidelines have been proposed to help ensure an ethical approach to internet research. For instance, the Association of Internet Researchers Ethics Working Committee (Markham & Buchanan, 2012) recommend researchers consider the following fundamental issues when deciding to use online

research methods: the greater the vulnerability of the participant, the greater the obligation of the researcher to protect the participant; apply practical judgement attentive to the specific context when approaching ethical decision-making; consider principles related to research on human subjects; balance the rights of the participant with the social benefits of the research and the researchers' rights to conduct research; address ethical issues during all steps of the research process, and; consult as many people and resources as possible during the process of ethical decision-making.

The current study provides an important contribution to the existing literature on ethical online research, through providing a much-needed youth perspective in relation the use of social media research methods in the promotion of mental health and wellbeing. It is hoped that consideration of the key fundamental ethical, moral and practical issues raised by participants in this study will help guide researchers' decisions about the use of social media as a research tool in the promotion of mental health and wellbeing among this population.

### **Limitations**

The findings from this study should be considered with regard to several limitations. The Cyber Friendly Student Leaders who participated in the focus groups are a specific group of young people who are likely to be more informed about research due to their school's active involvement in the larger CFSP research study and this may have influenced their responses, particularly meaning they have greater understanding of issues of research and consent, and enhanced awareness of the importance of issues such as cyberbullying. This study asked about young people's use of social media platforms and their perceptions of privacy associated with each. However, it is important to note that due to the rapidly changing nature of ICTs, some of the various forms of social media mentioned in this paper may have been replaced by more popular social media platforms in the present day with different implications for privacy and the use of such data for research. Although the principles of ethical online research can help guide researchers decisions about whether to use social media as an online setting for their research, researchers' decisions may be restricted by the specific rules and regulations on certain types of social media that may prohibit the use of data uploaded to their site/application for research. This research project largely considered the implications of using social media with young people for qualitative research, and did not seek to explore the implications of quantitative methods with young people through social media.

### **Conclusions**

There will be ongoing challenges as technology progresses providing new opportunities and challenges for the use of social media in research about young people's mental health and wellbeing. Thus there is a need for constant discussion and renegotiation of ethical boundaries in light of these new developments. It is recommended that researchers continue to disseminate findings of studies employing online data collection and data analysis methods, and in doing so are encouraged to provide detailed information about their research challenges when using social media as a research tool. This will assist in furthering knowledge about the challenges and opportunities of social media research where this is deemed an acceptable, effective and appropriate means of research.

## Acknowledgements

The authors acknowledge the many staff at the Child Health Promotion Research Centre (CHPRC) who conducted focus groups and volunteers who acted as scribes. The CHPRC also thank the Western Australian secondary schools involved in the Cyber Friendly Schools Project. Thanks also go to the numerous stakeholders who participated in initial consultations for this project. The authors would also like to acknowledge the Edith Cowan University Avaya Development Fund as the funding source for this research.

## References

- Brockman, L., Christakis, D. & Moreno, M. (2014). Friending adolescents on social networking websites: A feasible research tool. *Journal of Interaction Science*, 2(1), 1-9.
- Brotsky, S. R. & Giles, D. (2007). Inside the “pro-ana” community: A covert online participant observation. *Eating disorders*, 15(2), 93-109.
- Clavering, E. K. & McLaughlin, J. (2010). Children's participation in health research: from objects to agents? *Child: Care, Health and Development*, 36(5), 603-611.
- Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.
- Cross, D., Shaw, T., Hadwen, K., Cardoso, P., Slee, P. & Roberts, C. (2014). Impact of a school-based online program on cyberbullying behaviour in adolescents. *Aggressive Behavior Journal*. Manuscript submitted for publication.
- Delbecq, A. L., Van de Ven, A. H. & Gustafson, D. H. (1975). *Group techniques for program planning: A guide to nominal group and delphi processes*. Glenview: Scott, Foresman and Company.
- Eysenbach, G. & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *British Medical Journal*, 323(7321), 1103.
- Fetterman, D. M. (2010). *Ethnography: Step-by-step* (Vol. 17). California: Sage.
- Hammersley, M. & Atkinson, P. (2007). *Ethnography: Principles in practice*. New York: Routledge.
- Henderson, M., Johnson, N. & Auld, G. (2013). Silences of ethical practice: Dilemmas for researchers using social media. *Educational Research and Evaluation*, 19(6), 546-560.
- Hinduja, S. & Patchin, J. W. (2008). Personal information of adolescents on the Internet: A quantitative content analysis of MySpace. *Journal of Adolescence*, 31(1), 125-146.
- Hinton, D. (2013). Private conversations and public audiences: Exploring the ethical implications of using mobile telephones to research young people's lives. *Young*, 21(3), 237-251.
- Hudson, J. M. & Bruckman, A. (2004). “Go away”: Participant objections to being studied and the ethics of chatroom research. *The Information Society*, 20(2), 127-139.
- King, S. A. (1996). Researching internet communities: Proposed ethical guidelines for the reporting of results. *The Information Society*, 12(2), 119-128.
- Kozinets, R. V. (2010). *Nemography: Doing ethnographic research online*. London: Sage.
- Kraut, R., Olson, J., Banaji, M., Bruckman, A., Cohen, J. & Couper, M. (2004). Psychological research online. *American Psychologist*, 59(2), 105-117.
- Krueger, R. (1998). *Analyzing and reporting focus group results*. Thousand Oaks, CA: Sage.



- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.
- Lunnay, B., Borlagdan, J., McNaughton, D., & Ward, P. (2015). Ethical use of social media to facilitate qualitative research. *Qualitative Health Research*, 25(1), 99-109.
- Madden, M., Lenhart, A., Cortesi, S., Gasser, U., Duggan, M., Smith, A. & Beaton, M. (2013). *Teens, social media and privacy*. Pew Research Center. Retrieved on 4<sup>th</sup> October 2014 from: <http://www.pewinternet.org/2013/05/21/teens-social-media-and-privacy/>
- Markham, A. N. & Baym, N. K. (2009). *Internet inquiry: Conversations about method*. California: Sage.
- Markham, A. & Buchanan, E. (2012). *Ethical decision making and internet research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)*. Association of Internet Researchers. Retrieved on 5<sup>th</sup> October 2014 from: <http://www.aoir.org/reports/ethics2.pdf>.
- Miles, M. B. & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. CA: Sage.
- Mitchell, A., Patrick, K., Heywood, W., Blackman, P. & Pitts, M. (2014). *5th National Survey of Australian Secondary Students and Sexual Health 2013*. ARCSHS Monograph series No. 97. Australian Research Centre in Sex, Health and Society, La Trobe University: Melbourne, Australia.
- Park, K. & Calamaro, C. (2013). A systematic review of social networking sites: Innovative platforms for health research targeting adolescents and young people. *Journal of Nursing Scholarship*, 43(3), 256-264.
- Ringrose, J., Gill, R., Livingstone, S. & Harvey, L. (2012). A qualitative study of children, young people and 'sexting': *A report prepared for the NSPCC*. National Society for the Prevention of Cruelty to Children: London, UK.
- Ritchie, J. & Spencer, L. (2002). Qualitative Data Analysis for Applied Policy Research. In A. M. Huberman & M. B. Miles (Eds.), *Qualitative Data Analysis for Applied Policy Research. The Qualitative Researcher's Companion* (pp. 305-330). Thousand Oaks, CA: Sage.
- Spears, B. & Kofoed, J. (2013). Transgressing research binaries: Youth as knowledge brokers in cyberbullying research. In P. Smith & G. Steffgen (Eds.), *Cyberbullying through the new media: Findings from an international network* (pp.201-221). London: Psychology Press.
- Spears, B., Sleep, P., Campbell, M. & Cross, D. (2011). *Educational change and youth voice: Informing school action on cyberbullying*. Paper presented at the Seminar Series #208. Centre for Strategic Education: Victoria.
- Stewart, D., Shamdasani, P. & Rook, D. (2007). *Focus groups: Theory and practice* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Thelwall, M. (2008a). Fk yea I swear: Cursing and gender in a corpus of MySpace pages. *Corpora*, 3(1), 83-107.
- Thelwall, M. (2008b). Social networks, gender, and friending: An analysis of MySpace member profiles. *Journal of the American Society for Information Science and Technology*, 59(8), 1321-1330.
- Underwood, M. & Card, N. (2013). Moving beyond tradition and convenience: Suggestions for useful methods for cyberbullying research. In S. Bauman, D. Cross & J. Walker (Eds.), *Principles of*

*cyberbullying research: Definitions, measures and methodology* (pp. 125-136). New York: Routledge.

United Nations. (1989). UN Convention on the Rights of a Child. Retrieved on 4<sup>th</sup> November 2014 from:  
<http://www2.ohchr.org/english/law/pdf/crc.pdf>

Wong, N. T., Zimmerman, M. A. & Parker, E. A. (2010). A typology of youth participation and empowerment for child and adolescent health promotion. *American Journal of Community Psychology*, 1-15.