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Attitudes and Knowledge of Adolescents in Jordan Regarding the Ethics of Social Media Data Use for Research Purposes

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Abstract

This study assessed the awareness and attitudes of adolescents in Jordan concerning the ethics of using their social media data for scientific studies. Using an online survey, 393 adolescents were recruited (mean age: $17.2 \text{ years} \pm 1.8$). The results showed that 88% of participants were using their real personal information on social media sites, with males more likely to provide their information than females. More than two thirds of participants (72.5%) were aware that researchers may use their data for research purposes, with the majority believing that informed consent must be obtained from both the adolescents and their parents. However, more than three quarters of those surveyed (76%) did not trust the results of research that depended on collecting data from social media. These findings suggest that adolescents in Jordan understood most of the ethical aspects related to the utilization of their data from social media websites for research studies.

Keywords

ethics; research; research	n ethics; social	media; adolescent	S

Introduction

Social media has become an efficient tool for research scientists to recruit study participants at minimal cost (Arigo et al., 2018; Brown et al., 2014), and to provide health promotion and interventions to the public (Cavallo et al., 2012; Frandsen et al., 2013; Harris et al., 2017; Napolitano et al., 2013; Pagoto et al., 2015; Paul et al., 2014). Social media is defined by the Cambridge Dictionary (n.d.) as "websites and computer programs that allow people to communicate and share information on the internet using computers or mobile phones." The

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Ethical Approval

Ethical approval was obtained from the Institutional Review Board (IRB) at King Abdullah University Hospital, Irbid, Jordan. Declaration of Conflicting Interests

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number of social media users around the globe is increasing, with an estimated 2.77-billion users expected by the end of 2019 (www.statista.com; Statista, 2020), reflecting the impact of social media on the lives of very large numbers of people. Facebook, Twitter, Instagram, LinkedIn, and YouTube are a few examples of frequently used social media applications.

Adolescents (young people between the ages of 10 and 19 years as per WHO, n.d. definition) use social media networks extensively, and as a result, social media websites are considered a rich source for data from this group (Anderson & Jiang, 2018). As social media websites are easily accessible, researchers may use personal data from adolescents without obtaining their consent (Spriggs, 2009). This practice has the potential to raise multiple ethical concerns, including the lack of standard ethical guidelines for institutional review boards (IRBs) to evaluate research projects conducted via social media. The lack of a properly informed consent process and problems related to data reliability and validity are examples of these ethical issues (Arigo et al., 2018; Samuel et al., 2018).

Adults are deemed mature enough to understand their rights and responsibilities; however, adolescents need special protection. They are a vulnerable population according to the International Council for Harmonisation (ICH) guidelines for ethics in research (ICH Harmonised Guideline, 2016, 2017) and the Code for Federal Regulations (CFR) Title 21 pertaining to the protection of human subjects involved in research (Electronic Code of Federal Regulations, 2018). Yet, there is a lack of information among this age group about the ethical considerations in using social media for research purposes.

A social media-based research approach may present an easy and convenient method for data collection regardless of the location or health status of the individual, and many researchers have previously utilized social media as a source of research data when studying adolescent populations (Hinduja & Patchin, 2008; Lunnay et al., 2015; Ringrose et al., 2012; Thelwall, 2008; Underwood & Card, 2013). However, this practice may compromise the data privacy of the individual (Zimmer, 2010), providing added challenges to the researchers, such as how to determine whether parental consent was obtained, or whether there is a need for a data anonymization strategy. Research methods and protocols must, therefore, recognize the unique challenges of collecting data from social media. Furthermore, in light of recent scandals related to the misuse of digital data, there is growing mistrust of how social medial data are being used or abused (Kang & Frenkel, 2018). Despite the existence of a large body of research on ethical conduct, knowledge about ethical guidelines for research using social media data is lacking (Moreno et al., 2013), and it is not clear what ethical guidelines researchers should follow when working with the online data of children or adolescents (Hokke et al., 2018). Furthermore, little is known about the views of adolescents regarding participation in this type of research (Moreno et al., 2012).

This study was conducted to assess the awareness and attitudes of adolescents in Jordan regarding the ethics of using their personal information from social media sites for research purposes. This has the potential to raise awareness about this issue and lead to a better understanding of how to address various ethical concerns raised by the individuals

themselves. To the best of our knowledge, this is the first such study involving adolescents from an Arab-speaking country in the Middle East or North Africa.

Method

Design and Participants

A cross-sectional study was conducted using an online survey targeting adolescents aged 10 and 19 years in Jordan. The survey was posted and distributed through social media pages on Facebook and Instagram commonly accessed by Jordanians in this age group (e.g., grade school and university-related pages) during August–September, 2018. In total, 393 participants were recruited. Inclusion criteria included individuals aged 10 to 19 years, being a Jordanian citizen and an active user of social media.

Items in the Questionnaire

Several meetings were held by the research team to prepare items to be included in the questionnaire. The questionnaire was piloted by 20 adolescents who were asked to complete it and provide feedback. They were qualified for inclusion in the study using the inclusion criteria provided above and were selected from the personal social network of the research team. The pilot-testing demonstrated high reliability of the questionnaire with a Cronbach's alpha score of 84. We also asked for input from colleagues regarding their assessment of the validity and comprehension of the questionnaire.

The survey consisted of six attributes including sociodemographic information, social media usage, knowledge and attitudes of users toward informed consent, utilization of their data on social media pages, and their trust in research data obtained via survey research utilizing social media pages. The questionnaire responses were rated based on a 5-point Likert-type scale.

Ethical Approval

Informed consent was obtained from all participants. Before data were collected by implementing an online survey, participants were instructed to obtain consent from at least one of their parents or a guardian before filling in the survey. As this research posed only minimal risk for participants, the IRB approved this consenting approach which relied on the research subject to obtain their parental consent. All study procedures were conducted according to the principles of the World Medical Association Declaration of Helsinki and its amendments. Privacy and confidentiality were taken into consideration throughout the study by ensuring that information collected from the survey was not shared with anyone other than the researchers who conducted the study. Participants were informed that their information will be used for research purposes only and no one other than members of the research team will have access to it.

Data Analysis

Statistical analysis was performed using SPSS v.20.0 (SPSS, Inc., Chicago, IL). Descriptive data analyses were carried out to determine means and percentages of responses according to population characteristics and the questions asked of the adolescents. Participants were

divided into three age groups: less than 16 years (early adolescence), 16–17 years (middle adolescence), and older than 17 years (late adolescence). The rationale behind this division refers to the difference in adolescents' physical, sexual, cognitive, social, and emotional changes during these age groups (Curtis, 2015). A chi-square test was used to compare the dependence level of subgroups based on the individuals' characteristics according to their answers to the survey questions. Fisher's exact test was used in cases where n < 5 leading to violation of chi-square assumptions. A p value of <.05 was considered statistically significant.

Results

This online survey included 393 adolescents aged between 10 and 19 years with a mean age of 17.2 years ($\pm SD = 1.8$ years). The majority of participants were female (73.3%). More than half of the participants (58.5%) were older than 17 years, 21.4% were between 16 and 17 years, and 20.1% were younger than 16 years. Also, most participants (90.3%) knew how to change the privacy status of their online profiles to private. Most (88%) were accessing their social media pages at least twice per day. The frequency of login times to social media increased with increased age (p = .002). About 62% of those who used social media two or more times per day were older than 17 years compared to about 27% and 11% for those aged less than 16 years and those aged 16–17 years, respectively. The demographic and social media usage characteristics of participants are illustrated in Table 1.

Responses to questionnaire items according to participant age are illustrated in Table 2. Half of those who used fake personal information were younger than 16 years (p < .001). With respect to gender, about 93% of females used fake personal photos for their profiles compared with only 7% of males (p < .001). Login frequency differed according to gender, but this difference was not statistically significant as shown in Table 3.

More than two thirds of participants (72.5%) were aware of the fact that researchers may use their personal data for research purposes. More than half of participants (55.5%) initially said they would not allow data from their social media pages to be for research; however, 71% would agree to share their data if the use of the data provided benefits to their community.

The majority of the participants (93.6%) believed that researchers must obtain informed consent, and this belief increased with increasing age. However, this difference was not statistically significant (p = .180). Moreover, 73.5% believed that informed consent must also be obtained from parents or guardians if the participant is younger than 18 years. Of those who had this belief, about 55% were older than 17 years, 16% were 16–17 years, and about 20% were younger than 16 years (p < .001). When participants were asked if researchers must obtain consent only from social media users whose profiles are private, more than half of those who agreed were older than 17 years (p = .023) as illustrated in Table 2. About 80% of those who objected to their data being used for research even without mentioning their names were females. This difference was statistically significant as shown in Table 3. Of those who thought consent from parents is necessary to use the information for those <18 years, more than 75% were females and 25% were males (p =

.008). More than three quarters of participants (76.8%) did not trust research that depended on data collected from social media, because they assumed that part of the data are not real. Moreover, 91% and 70% preferred the alternative collection of data using personal interviews and paper questionnaires, respectively.

Discussion

This study assessed the attitudes and knowledge of adolescents in Jordan regarding the ethical use of data acquired from social media for research purposes. Most of the study participants were using social media, and more than two thirds (72.5%) were aware that researchers can use their data presented under their profiles in social media applications. In addition, the majority were supportive of using social media for research purposes if it benefited society and involved the use of informed consent. According to ethical guidelines, such as General Medical Council (GMC, 2013), NIHR Research Governance (n.d.), or National Society for the Prevention of Cruelty to Children (NSPCC, n.d.), adolescents are considered to be a vulnerable group because they lack full decision-making capacity, and they may be vulnerable to coercion. Therefore, researchers must include adequate safeguards to protect their rights, prevent the abuse of the use of their data, and protect them from any physical or psychosocial harm. According to the Ethical Approaches to Gathering Information from Children and Adolescents in International Settings (Schenk & Williamson, 2005), the community, ethics committees, researchers, and funding agencies are responsible for ensuring proper participation of children and adolescents in research. Furthermore, the involvement of these individuals in research activities should be justified, as highlighted in the World Medical Association (2013) Declaration of Helsinki and they should stand to benefit from the knowledge, practices, or interventions that result from the research. Practical ethical guidelines related to the involvement of children and adolescents in scientific research include, among others, the GMC, NIHR Research Governance, or NSPCC. The researcher may also refer to Convery and Cox (2012), for aiding the initial discussions between researchers, online communities, and research ethics committees.

The awareness of research using social media data increased with age. This issue affirms the importance of increasing awareness among parents of individuals in this age group and the community, especially regarding the issue that some researchers may use their personal information in social media without their consent (American Sociological Association, 2018). There are few studies assessing the perception of social media users regarding research conducted through these online platforms (Eysenbach & Till, 2001; Golder et al., 2017; Moreno et al., 2012), especially among children and adolescents who are considered vulnerable populations (Monks et al., 2015). Although all international guidelines describe the safeguards needed for ethical conduct of research when it involves subjects under the age of 18 years such as the GMC, NIHR Research Governance, or NSPCC, these guidelines do not cover research using social media platforms, but there are several ethical guidelines and recommendations for internet research that have recently emerged (e.g., British Psychological Society, 2013; Ess, 2002). Although these guidelines have identified some of the ethical issues for researchers who use social media data to consider, they do not necessarily imply compliance and consistent interpretation. In addition, Markham and Buchanan (2012) recognized the need for a further and ongoing negotiation of online guides

to cover ethical issues of research involving human subjects that emerge in the dynamic evolution of the internet. Therefore, dedicated international recommendations regarding the use of publicly available personal data including that belonging to adolescents are needed.

In general, multiple ethical issues should be considered when designing an internet-based research study, including respect for the autonomy and dignity of individuals and the scientific value of their information, social responsibility, and maximizing benefits and minimizing harms (British Psychological Society, 2013; Flicker et al., 2004; Swirsky et al., 2014). Ethical standards of confidentiality (Moreno et al., 2008), and Löfberg (2003) have argued that the online and real-life identities of children and adolescents should be equally protected in research. Obtaining valid informed consent is one of the main problematic issues in this type of research. Some researchers believe that consent is mandatory for online data collection regardless of the status of the profile, while others believe that it is unnecessary especially for publicly available information. A study by Spriggs (2009) found that the issue of obtaining adolescents' or their parents' consent depends on groups of factors and considerations, such as the nature and the source of data, potential risks or benefits, and sensitivity of the topic. The study also reported that participants' or their parents' consent are not required if the research does not involve identifiable information. In addition, some researchers argued about the parental consent in particular and claimed that "it is not ethically required in all internet-based research involving young people but a researcher's decision to forgo parental consent needs to be clearly articulated" (Spriggs, 2009, p. 13), while other researchers argued that the investigator must justify the reasons for forgoing parental consent in any particular study and should not be justified only according to the benefits of the study or the type of data (public vs. private) (Spriggs, 2009). The infancy of internet research is aggravated by the lack of consensus among institutional guidelines (Carter et al., 2015).

The results of the current study showed that the majority of adolescents believed that the researcher must obtain both their approval and their parents' or guardian's consent to use their data. This result agrees with findings from another study that affirmed that "individuals in online environments such as chat rooms generally do not approve of being studied without their consent" (Hudson & Bruckman, 2004, p. 135). Similarly, Barnes (2004) confirmed that members of public discussion forums can become angry when their private communications are used for research. Informed consent of the participant remains a critical ethical consideration in every research project, especially for minors including adolescents. Parental involvement in informed consent represents an important issue for this age group to participate in the decision-making process and to prevent unwanted disclosure of any information. Legally valid consent should be obtained from the child's or adolescent's parent or guardian as appropriate (McIntosh et al., 2000).

It is important to assess the understanding and perception of the users themselves regarding participation in social media research. We observed a reluctance from about half of the participants in the current study to allow researchers to utilize their data from social media websites even if their names were not included. This result may be placed in the context of another study of older adolescents' views regarding participation in Facebook research where they were more supportive, and yet they seemed to not have a full appreciation of

privacy issues in social media research (Moreno et al., 2012). The willingness among the study subjects to participate in research would increase if the intended research was of benefit to the community. This finding agrees with the study by Elvira et al. (2019) which emphasized that internet-mediated research chiefly depends on the level of trust that people have in the research community. This trust in internet-mediated research can be achieved if researchers respect the privacy of the users and if the internet users feel that their informed consent is always sought. This finding agrees with Battles (2010) who emphasized that sharing the final results of the research (the published article or articles) with the participants will make them feel like partners in the research rather than objects of study. Barnes (2004) recommendations of "an acclimation process" and "a sharing mentality" for online social research are also in accordance with current findings. Continuous engagement with adolescents will allow their voices to be heard and will provide a greater understanding of online research methods in this age group (Spears & Kofoed, 2013).

The results of the current study indicate that the majority of the participants did not read the privacy terms and policies on social media pages and did not know that some social media sites can use their information according to the pages' privacy terms. This is because terms and conditions are usually too lengthy and require time to read. They were therefore not aware that important information regarding their privacy and the usage of their data by third parties was provided, and they gave their consent without reading. In this case, the adolescents' information will be available for the hosting site, within the network and also for third parties (from hackers to government agencies) (Gross & Acquisti, 2005). The hosting site and the network may use the information in different ways even if it is unknowingly revealed by the participant. Third parties also can access participants' information without the site's direct permission (Gross & Acquisti, 2005). In addition, privacy is increasingly networked and the control over personal data is complicated, as data can be tagged and shared (Boyd, 2012; Boyd & Crawford, 2012). One study recommended that social media organizations should continue to review terms so that the possible uses of data are easier to understand, and they suggested that these organizations can explore ways of incorporating opt out consent from research into their systems (Evans et al., 2015). Thus, awareness programs within schools and the community should focus on these policies and try to give examples, readings, and illustrations of what is present in these applications. It is worth mentioning here that most adolescents surveyed in the current study knew how to update their profiles from public to private, thus giving us a reliable indication that it will be a relatively easy task for the community to conduct awareness programs regarding the protection of information.

One limitation of the current study was the lack of gender and age representation where the majority of the participants were female and most participants were older than 17 years of age. Therefore, the results of this study are not representative of the Jordanian young population. A more representative sample is needed to confirm the present findings. Another limitation is the dependence on participants' honesty in reporting their age and other provided information, which cannot be verified as in the case of face-to-face designs.

Recommendations

Confidentiality is an important ethical consideration for adolescents using social media, and they must be assured that their personal data and information such as their names and locations will remain private and will not be disclosed according to general ethical recommendations.

Consenting users of social media for research is expected by users. Consent forms must, therefore, be offered and be clear and informative in a detailed manner. Understanding of these issues and the role of their involvement will lead to effective and active participation and will improve the quality of data and research.

Social media platforms have an ethical responsibility to inform users about how their data are being used repeatedly and should also involve the consent of parents when adolescents are involved.

Researchers can assist in this debate of online research by contributing their ethical challenges or certain case studies; thus, both participants and the researchers can benefit.

Conclusion

Many adolescents in Jordan were generally aware of the privacy of data and the need for consent, and they comprehended most of the aspects related to the ethics of utilizing their data from social media websites in research projects. Participants supported research if it served the community, but their preference was for face-to-face research because it was considered more accurate than research using social media platforms. There is a need to regulate research conducted via social media and follow ethical guidelines for responsible conduct of research, and to ensure that these guidelines are harmonious with human and research ethical rights, especially for this young age group. More research should be carried out to investigate users' attitudes and ethical needs regarding the use of social media for research purposes. The internet will continue to change and evolve ahead of any guidelines, and researchers will need to be informed about the ethical aspects of their online research. This study could be a foundation for further research in such an evolving setting, particularly in this vulnerable age group. Universal guidelines must be produced by taking into consideration the views of social media users.

Best Practices

There should be an increased awareness among adolescents regarding the privacy of their data on social media networks, through social media itself, schools, and their parents.

The privacy terms on any new social media website or application are important. Social media sites should try to minimize what is written on their pages regarding their service terms and conditions or include a few questions after the policy statements and before the sign-up process to ensure that everyone is adequately reading and understanding the terms and policies.

Every regulatory body in any country must protect the rights of adolescents in research through strict monitoring of ethical guidelines and the implementation of human rights.

Research Agenda

There is a need for research that illustrates the ethical considerations for social media—based research when dealing with vulnerable age groups such as adolescents to protect them from harm and to develop appropriate guidelines. The current research ethics agendas are disproportionately based on legal considerations compared with the widespread use of social media for research purposes.

Extra effort must be taken in formatting the informed consent to be more informative and easier for adolescents and their parents to understand both the research project objectives and their significant roles in the research process and to take their individual differences into consideration.

Educational Implications

As there are many interrelated terms in both human rights and ethical guidelines, such as informed consent, privacy, confidentiality, and justice, ethical guidelines for the social media research of all age groups must comply with these human rights and ethical principles.

Researchers must realize that adolescents have their rights as participants in all steps of the research, on an equal basis as adults, but with certain and special considerations as a vulnerable population.

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References

American Sociological Association. (2018, June). Code of ethics. http://www.asanet.org/sites/default/files/asa_code_of_ethics-june2018.pdf

Anderson M, & Jiang J (2018). Teens, social media & technology. Internet & Technology. https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/

Arigo D, Pagoto S, Carter-Harris L, Lillie S, & Nebeker C (2018). Using social media for health research: Methodological and ethical considerations for recruitment and intervention delivery. Digital Health, 4. 10.1177/2055207618771757

Barnes SB (2004). Issues of attribution and identification in online social research. In Johns MD, Chen SS, & Hall GJ (Eds.), Online social research: Methods, issues and ethics (pp. 203–222). Peter Lang.

Battles H. (2010). Exploring ethical and methodological issues in internet-based research with adolescents. International Journal of Qualitative Methods, 9(1), 27–39. 10.1177/160940691000900104

Boyd D. (2012). The politics of "real names": Power, context, and control in networked publics. Communications of the ACM, 55(8), 29–31.

Boyd D, & Crawford K (2012). Critical questions for big data. Information, Communication & Society, 15(5), 662–679. 10.1080/1369118X.2012.678878

British Psychological Society. (2013). Ethics guidelines for internet-mediated research.

Brown J, Kotz D, Michie S, Stapleton J, Walmsley M, & West R (2014). How effective and cost-effective was the national mass media smoking cessation campaign "Stoptober"? Drug and Alcohol Dependence, 135(100), 52–58. 10.1016/j.drugalcdep.2013.11.003 [PubMed: 24322004]

- Cambridge Advanced Learner's Dictionary & Thesaurus. (n.d.). Cambridge dictionary. Cambridge University. Retrieved January 6, 2020, from https://dictionary.cambridge.org/dictionary/english/social-media
- Carter CJ, Koene A, Vallejos EP, Statache R, Adolphs S, O'Malley C, Rodden T, & McAuley D (2015). Understanding academic attitudes towards the ethical challenges posed by social media research. ACM SIGCAS Computers and Society, 45(3), 202–210. 10.1145/2874239.2874268
- Cavallo DN, Tate DF, Ries AV, Brown JD, DeVellis RF, & Ammerman AS (2012). A social media based physical activity intervention: A randomized controlled trial. American Journal of Preventative Medicine, 43(5), 527–532. 10.1016/j.amepre.2012.07.019
- Convery I, & Cox D (2012). A review of research ethics in internet-based research. Practitioner Research in Higher Education, 6(1), 50–57.
- Curtis AC (2015). Defining adolescence. Journal of Adolescent and Family Health, 7(2), Article 2.
- Electronic Code of Federal Regulations. (2018, July 19). Title 45 public welfare. Government Publishing Office. https://ecfr.io/Title-45/
- Elvira V, Ansgar K, Christopher C, Daniel H, Christopher W, Lachlan U, Aislinn B, & Ramona S (2019). Accessing Online Data for Youth Mental Health Research: Meeting the Ethical Challenges. Philosophy & Technology, 32(1), 87–110. 10.1007/s13347-017-028
- Ess C. (2002). Ethical decision-making and internet research: Recommendations from the AoIR ethics working committee. https://aoir.org/ethics/
- Evans H, Ginnis S, & Bartlett J (2015). #SocialEthics: A guide to embedding ethics in social media research. Ipsos. https://ahrecs.com/resources/1342
- Eysenbach G, & Till J (2001). Ethical issue in qualitative research on internet communities. British Medical Journal, 323(7321), 1103–1105. 10.1136/bmj.323.7321.1103 [PubMed: 11701577]
- Flicker S, Haans D, & Skinner H (2004). Ethical dilemmas in research on Internet communities. Qualitative Health Research, 14(1), 124–134. 10.1177/1049732303259842 [PubMed: 14725180]
- Frandsen M, Walters J, & Ferguson SG (2013). Exploring the viability of using online social media advertising as a recruitment method for smoking cessation clinical trials. Nicotine & Tobacco Research, 16(2), 247–251. 10.1093/ntr/ntt157 [PubMed: 24127266]
- General Medical Council (GMC). (2013, March). Consent to research: Research involving vulnerable adults. https://www.gmc-uk.org/
- Golder S, Ahmed S, Norman G, & Booth A (2017). Attitudes toward the ethics of research using social media: A systematic review. Journal of Medical Internet Research, 19(6), Article e195. 10.2196/jmir.7082
- Gross R, & Acquisti A (2005, November). *Information revelation and privacy in online social networks (the Facebook case)* [Paper presentation]. ACM workshop on Privacy in the Electronic Society.
- Harris JK, Hawkins JB, Nguyen L, Nsoesie EO, Tuli G, Mansour R, & Brownstein J (2017). Using Twitter to identify and respond to food poisoning: The food safety STL project. Journal of Public Health Management & Practice, 23(6), 577–580. 10.1097/PHH.000000000000516 [PubMed: 28166175]
- Hinduja S, & Patchin JW (2008). Personal information of adolescents on the Internet: A quantitative content analysis of MySpace. Journal of Adolescence, 31(1), 125–146. 10.1016/ j.adolescence.2007.05.004 [PubMed: 17604833]
- Hokke S, Hackworth NJ, Quin N, Bennetts SK, Win HY, Nicholson JM, Zion L, Lucke J, Keyzer P, & Crawford SB (2018). Ethical issues in using the internet to engage participants in family and child research: A scoping review. PLOS ONE, 13(9), Article e0204572. 10.1371/journal.pone.0204572
- Hudson JM, & Bruckman A (2004). "Go away": Participant objections to being studied and the ethics of chat room research. The Information Society, 20, 127–139. 10.1080/01972240490423030
- ICH Harmonised Guideline. (2016, November 9). ICH E6 (R1): Guideline for good clinical practice. E6(R2). https://www.bing.com/

- images/search?q=ich+e6+r1+%3a+guideline+for+good+clinical+practice.+e6+r2&qpvt=ich+e6+(r1)%3a+guideline+for+good+clinical+practice.+e6(r2)&FORM=IGRE
- ICH Harmonised Guideline. (2017, August 18). ICH E11: Clinical investigation of medicinal products in the pediatric population.
 E11 (R1). https://www.fda.gov/regulatory-information/search-fda-guidance-documents/e11r1-addendum-clinical-investigation-medicinal-products-pediatric-population
- Kang C, & Frenkel S (2018, April). Facebook says Cambridge analytica harvested data of up to 87 million users. The New York Times. https://www.nytimes.com/2018/04/04/technology/mark-zuckerberg-testify-congress.html
- Löfberg C. (2003). Ethical and methodological dilemmas in research with/on children and youths on the Net. In Programme for applied ethics: Publication series no. 1. Applied ethics in Internet research (pp. 141–154). Norwegian University of Science and Technology.
- 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. 10.1177/1049732314549031 [PubMed: 25212856]
- Markham A, & Buchanan E (2012). Ethical decision-making and internet research: Recommendations from the AoIR ethics working committee (Version 2.0). https://aoir.org/reports/ethics2.pdf
- McIntosh N, Bates P, Brykczynska G, Dunstan G, Goldman A, Harvey D, Larcher V, McCrae D, McKinnon A, Patton M, Saunders J, & Shelley P (2000). Guidelines for the ethical conduct of medical research involving children. Archives of Disease in Childhood, 82, 177–182. [PubMed: 10648379]
- 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. The International Journal of Emotional Education, 7(1), 4–19.
- Moreno M, Frost N, & Christakis D (2008). Research ethics in the MySpace era. Pediatrics, 121, 157–161. 10.1542/peds.2007-3015 [PubMed: 18166570]
- Moreno M, Goniu N, Moreno P, & Diekema P (2013). Ethics of social media research: Common concerns and practical considerations. Cyberpsychology, Behavior, and Social Networking, 16(9), 708–713. 10.1089/cyber.2012.0334 [PubMed: 23679571]
- Moreno M, Grant A, Kacvinscy L, Moreno P, & Fleming MJ (2012). Older adolescents' views regarding participation in Facebook research. Journal of Adolescent Health, 51(5), 439–444. 10.1016/j.jadohealth.2012.02.001
- Napolitano MA, Hayes S, Bennett GG, Ives AK, & Foster JD (2013). Using Facebook and text messaging to deliver a weight loss program to college students. Obesity, 21(1), 25–31. 10.1002/oby.20232 [PubMed: 23505165]
- NIHR Research Governance. (n.d.). HR good practice resource pack. The research passport: Vetting and barring scheme guidance. https://www.nihr.ac.uk/
- National Society for the Prevention of Cruelty to Children. (n.d.). Ethical issues in research with children. https://www.nspcc.org.uk/
- Pagoto SL, Waring ME, Schneider KL, Oleski JL, Olendzki E, Hayes RB, Appelhans BM, Whited MC, Busch AM, & Lemon SC (2015). Twitter delivered behavioral weight-loss interventions: A pilot series. JMIR Research Protocols, 4(4), Article e123. 10.2196/resprot.4864
- Paul MJ, Dredze M, & Broniatowski D (2014). Twitter improves influenza forecasting. PLOS Currents Outbreaks, 1. 10.1371/currents.outbreaks.90b9ed0f59bae4ccaa683a39865d9117
- 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
- Samuel G, Ahmed W, Kara H, Jessop C, Quinton S, & Sanger S (2018). Is it time to re-evaluate the ethics governance of social media research? Journal of Empirical Research on Human Research Ethics, 13(4), 452–454. 10.1177/1556264618793773 [PubMed: 30141738]
- Schenk K, & Williamson J (2005). Ethical approaches to gathering information from children and adolescents in international settings, guidelines and resources. Population Council.

Spears B, & Kofoed J (2013). Transgressing research binaries: Youth as knowledge brokers in cyberbullying research. In Smith P & Steffgen G (Eds.), Cyberbullying through the new media: Findings from an international network (pp. 201–221). Psychology Press.

- Spriggs M. (2009). Consent in cyberspace. Internet based research involving young people. Monash Bioethics Review, 28(4), 321–315.
- Statista. (2020). Number of social network users worldwide from 2010 to 2021. https://www.statista.com/statistics/278414/number-of-worldwide-social-network-users/
- Swirsky S, Hoop J, & Labott S (2014). Using social media in research: New ethics for new meme? American Journal of Bioethics, 14(10), 60–61. 10.1080/1526516L2014.948302
- Thelwall M. (2008). 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. 10.1002/asi.20835
- Underwood M, & Card N (2013). Moving beyond tradition and convenience: Suggestions for useful methods for cyberbullying research. In Bauman S, Cross D, & Walker J (Eds.), Principles of cyberbullying research: Definitions, measures and methodology (pp. 125–136). Routledge.
- World Health Organization (WHO). (n.d.). Adolescents health. https://www.who.int/topics/adolescent_health/en/
- World Medical Association. (2013). WMA Declaration of Helsinki—Ethical principles for medical research involving human subjects. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
- Zimmer M. (2010). "But the data is already public": On the ethics of research in Facebook. Ethics and Information Technology, 12(4), 313–325. 10.1007/s10676-010-9227-5

Table 1.

Demographic Characteristics of Study Population (N=393).

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Characteristic	n (%)
Gender	
Male	105 (26.7)
Female	288 (73.3)
Age/year	
<16	79 (20.1)
16–17	84 (21.04)
>17	230 (58.5)
Use real info	
Yes	345 (87.8)
No	48 (12.2)
Use real photo	
Yes	236 (60.1)
No	157 (39.9)
Types of personal profiles	
Public	54 (13.7)
Private	164 (41.7)
Public and private	175 (44.5)
Changing their profiles fro	m public to private
Yes	355 (90.3)
No	38 (9.7)
Frequency of using social i	media
Once daily	34 (8.7)
Twice or more daily	346 (88.0)
Less than daily	13 (3.3)

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Table 2.

Responses to Questionnaire Items as per Age of 393 adolescents in Jordan.

	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \	Age/year n (%)	%),0)		
Questionnaire Items	<16	16–17	>17	Iotal <i>n</i> (%)	p value
Frequency of social media use					.002
Once daily	14 (41.2)	7 (20.6)	13 (38.2)	34 (8.7)	
2 times/day	93 (26.9)	39 (11.3)	214 (61.8)	346 (88.0)	
1–2 times/week	4^{a} (80.0)	$0^{a}(0.0)$	$1^a(20.0)$	5 (1.3)	
3 times/week	6 (75.0)	$0^a(0.0)$	$2^a(25.0)$	8 (2.0)	
Use real personal information					<.001
Yes	57 (16.5)	74 (21.4)	214 (62.0)	345 (87.8)	
No	22 (45.8)	10 (20.8)	16 (33.3)	48 (12.2)	
Use real photo					.275
Yes	49 (20.8)	56 (23.7)	131 (55.5)	236 (60.1)	
No	30 (19.1)	28 (17.8)	99 (63.1)	157 (39.9)	
Profile nature					.247
General	13 (24.1)	6 (11.1)	35 (64.8)	54 (13.7)	
Private	34 (20.7)	41 (25.0)	89 (54.3)	164 (41.7)	
Some private & some general	32 (18.3)	37 (21.1)	106 (60.6)	175 (44.5)	
The written comments reflect the real opinion					.002
Yes	52 (16.6)	68 (21.7)	194 (61.8)	314 (79.7)	
No	27 (34.2)	16 (20.3)	36 (45.6)	79 (20.1)	
Changing profile from general to private					<.001
Know	61 (17.2)	79 (22.3)	215 (60.6)	355 (90.3)	
Do not know	18 (47.4)	5 (13.2)	15 (39.5)	38 (9.7)	
Read privacy terms before registration					.012
Yes	41 (27.9)	28 (19.0)	78 (53.1)	147 (37.4)	
No	38 (15.4)	56 (22.8)	152 (61.8)	246 (62.6)	
Easy for others to get your info on social media					.017
Agree	45 (16.6)	56 (20.7)	170 (62.7)	271 (69.0)	
Disagree	34 (27.9)	28 (23.0)	60 (49.2)	122 (31.0)	

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	A	Age/vear n (%)	(%)		
Questionnaire Items	<16	16–17	>17	Total n (%)	p value
You were asked to give consent on using your info on social media for research purposes					.924
Yes	12 (21.1)	13 (22.8)	32 (56.1)	57 (14.5)	
No	67 (19.9)	71 (21.1)	198 (58.9)	336 (85.5)	
Researcher must get consent on using info of social media users for research purposes					.180
Agree	70 (19.0)	82 (22.3)	216 (58.7)	368 (93.6)	
Disagree	9 (36.0)	2^a (8.0)	14 (56.0)	25 (6.4)	
Parents consent is necessary to use information for those <18 years					<.001
Yes	56 (19.4)	46 (15.9)	187 (54.7)	289 (73.5)	
No	23 (22.1)	38 (36.5)	43 (41.3)	104 (26.5)	
Researcher must get consent on using info of social media users whose profiles are private only					.023
Agree	35 (22.2)	43 (27.2)	80 (50.6)	258 (65.6)	
Disagree	44 (32.6)	41 (30.3)	50 (37.1)	135 (34.4)	
You trust info collected from those <18 years					<.001
Yes	35 (26.7)	40 (30.5)	56 (42.7)	131 (33.3)	
No	44 (16.8)	44 (16.8)	174 (66.4)	262 (66.7)	
Do you mind if you know that someone will use your data in a research without mentioning your name?					.532
Yes	48 (22.0)	44 (20.2)	126 (57.8)	218 (55.5)	
No	31 (17.7)	40 (22.9)	104 (59.4)	175 (44.5)	
From now, I will pay attention to what I write on social media					.118
Yes	69 (21.6)	71 (22.3)	179 (56.1)	319 (81.2)	
No	10 (13.5)	13 (17.6)	51 (68.9)	74 (18.8)	

^aFisher's exact test was used.

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Table 3.

Responses to Questionnaire Items as per Gender of 393 adolescents in Jordan.

	Gende	Gender n (%)		
Questionnaire Items	Male	Female	Total n (%)	p value
Frequency of social media use				.458
Once daily	13 (38.2)	21 (61.8)	34 (8.7)	
2 times/day	89 (25.7)	257 (74.3)	346 (88.0)	
1–2 times/week	1 ^a (20.0)	$4^{a}(80.0)$	5 (1.3)	
3 times/week	2 ^a (25.0)	6 (75.0)	8 (2.0)	
Use real personal information				.325
Yes	95 (27.5)	250 (72.5)	345 (87.8)	
No	10 (20.8)	38 (79.2)	48 (12.2)	
Use real photo				<.001
Yes	94 (39.8)	142 (60.2)	236 (60.1)	
No	11 (7.0)	146 (93.0)	157 (39.9)	
The written comments reflect the real opinion				.082
Yes	90 (28.7)	224 (71.3)	314 (79.7)	
No	15 (19.0)	64 (81.0)	79 (20.1)	
Profile nature				.003
General	23 (42.6)	31 (57.4)	54 (13.7)	
Private	32 (19.5)	132 (80.5)	164 (41.7)	
Some private & some general	50 (28.6)	125 (71.4)	175 (44.5)	
Read privacy terms before registration				.015
Yes	29 (19.7)	118 (80.3)	147 (37.4)	
No	76 (30.9)	170 (69.1)	246 (62.6)	
Easy for others to get your info on social media				600.
Agree	83 (30.6)	188 (69.4)	271 (69.0)	
Disagree	22 (18.0)	100 (82.0)	122 (31.0)	
Do you mind if you know that someone will use your data in a research without mentioning your name?				<.001
Yes	44 (20.2)	174 (79.8)	218 (55.5)	
No	61 (34.9)	114 (65.1)	175 (44.5)	

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	Gende	Gender n (%)		
Questionnaire Items	Male	Female	Total n (%)	p value
From now, I will pay attention to what I write on social media				.035
Yes	78 (24.5)	241 (75.5)	319 (81.2)	
No	27 (36.5)	47 (63.5)	74 (18.8)	
You were asked to give consent on using your info on social media for research purposes				.122
Yes	20 (35.1)	37 (64.9)	57 (14.5)	
No	85 (25.3)	251 (74.7)	336 (85.5)	
Parents consent is necessary to use information for those <18 years				800.
Yes	71 (24.6)	218 (75.4)	289 (73.5)	
No	34 (32.7)	70 (67.3)	104 (26.5)	
Researcher must get consent on using info of social media users for research purposes				.278
Agree	96 (26.1)	272 (73.9)	368 (93.6)	
Disagree	9 (36.0)	16 (64.0)	25 (6.4)	
Researcher must get consent on using info of social media users whose profiles are private only				.056
Agree	34 (21.5)	124 (78.5)	158 (40.2)	
Disagree	71 (30.2)	164 (69.8)	235 (59.8)	
You trust info collected from those <18 years				1.000
Yes	35 (26.7)	96 (73.3)	131 (33.3)	
No	70 (26.7)	192 (73.3)	262 (66.7)	
Changing profile from general to private				.406
Know	97 (27.3)	258 (72.7)	355 (90.3)	
Do not know	8 (21.1)	30 (78.9)	38 (9.7)	

^aFisher's exact test was used.