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Older Adolescent Perspectives on the Use of Research within Online Communities

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Abstract

This study explores the attitudes of older adolescents (aged 16 to 19) regarding researchers collecting personal information from Social Networking Sites (SNSs) through passive observation to support research on pro-Non-Suicidal Self-Injury (NSSI) communities. The aim of this study is to add to the ongoing discourse in the scientific community, by providing a unique perspective on how researchers can uphold ethical conduct throughout their research process. This study adopts a mixed-methods approach and incorporates a Qualtrics^{XM} survey and online focus groups (FGs). The findings reveal that participants have reservations toward passive, hidden observational researchers. Despite their concerns, participants support researchers using their findings to support individuals within pro-NSSI communities, provided that privacy and confidentiality are prioritized and there are no personal or social repercussions resulting from the research. This study provides valuable insights for researchers aiming to uphold ethical standards, emphasizing the need to actively incorporate the perspectives of adolescents in the formulation of clear guidelines for Social Networking (SN) research.

Keywords: Research Ethics, Social Networking Sites, Observational Research, Older Adolescents, pro-Non-Suicidal Self Injury Communities

Abbreviations

NSSI: Non-suicidal self-injury

SNSs: Social Networking Sites

SN: Social Networking

SNA: Social Network Analysis

R&D: Research and Development

TCPS-2: Tri-Council Policy Statement 2

REB: Research Ethics Board

FGs: Focus Groups

Summary for lay audience

There are worries about how young people can keep their independence and stay private on social media. Some adolescents are known to access hidden online communities known to researchers for promoting behaviors like Non-Suicidal Self-Injury (NSSI). Researchers are interested in these behaviours and can also use social media and specialized research tools to study these groups of young people. This research explores older adolescents' attitudes concerning the use of their social media data for research purposes. Youth aged 16 to 19 were recruited through social media and mass recruitment emails to participant in a survey and a FG. This study described what we found in our study on exploring older adolescents' perspectives about passive researchers observing their social media behaviours, often without explicit knowledge, to better understand NSSI and associated behaviours.

The findings from the study show that participants are sensitive to the risks of engaging with content about NSSI online. Participants are aware of potential long-term consequences, influencing their opinions towards researchers using personal social media data for research purposes. While some participants trust researchers' ability to portray their experiences in online communities, others felt uncomfortable with researchers studying their online activities without explicit knowledge of or consent for. Still, participants understand that social media is causing the world to change quickly, and they agree that it is important to keep studying hidden NSSI communities online.

Keywords: Research Ethics, Social Networking Sites, Observational Research, Older Adolescents, pro-Non-Suicidal Self Injury Communities

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Chapter 1

1 Introduction

This chapter serves as an introduction to the thesis, contextualizing the aim of this research. In this chapter, I first describe the current context of non-suicidal self-injury (NSSI). I then describe how the dynamic landscape of Social Networking Sites (SNSs) create opportunities and ethical dilemmas for research within hidden, online NSSI communities.

1.1 Background

Non-suicidal self-injury (NSSI) typically emerges during adolescence and is characterized by activities like "cutting, scratching, or burning the skin" (Hasking et al., 2019, p. 218). NSSI is often overlooked by mental health professionals, as adolescents might feel ashamed and hesitant to disclose their struggles. In such situations, adolescents may consider Social Networking Sites (SNSs) and associated anonymous channels to obtain support (Clarke & Kuosmanen, 2015). While there are benefits to adolescents accessing online support groups to find mutual support, research also suggests that a subset of adolescents might be using SNSs inappropriately. This subset engages with pro-NSSI communities that either encourage or reinforce NSSI behaviours (Breen et al., 2013).

Researchers can enhance their understanding of NSSI through a form of passive observation by leveraging publicly available SNS data. Many SNSs are viewed as public domains, allowing users to adjust their privacy settings to manage their online identities (Sloan & Quan-Haase, 2016). However, boyd (2011) highlights that despite SNSs being considered public domains, a covert observer, not the intended recipient of NSSI content, might be perceived as a "lurker." The term "lurker" is typically used to refer to someone who takes on a passive, anonymous role, with limited personal interaction with the poster. When examining the influence of passive observers, including researchers, it is crucial to recognize the diverse roles played by researchers in various settings. University-affiliated researchers, dedicated to upholding ethical standards like those outlined in the TCPS-2 guidelines conduct meticulous research to ensure adherence to established rules (Government of Canada et al., 2018). It is worth noting that researchers in industry, especially those in Research and Development (R&D) roles for companies, may have different objectives and priorities.

Still, the term lurker could also be applied to researchers studying pro-NSSI communities in situations where the users are largely unaware of how their behaviour is being monitored. Concerns about the ethical implications of such research were raised by boyd (2011) and are echoed in the literature by researchers such as Carter et al. (2012) and Marotzki et al. (2013). They contend that accessing user information carries unethical implications for managing user autonomy and confidentiality. While many SNS users engaging in pro-NSSI communities use aliases, researchers can still uncover valuable demographic information by observing these SNS communities, such as age and gender (Cavazos-Rehg et al., 2017). Additionally, not all SNS users take precautions towards anonymization, as observed in the study conducted by Cavazos-Rehg and colleagues (2017) investigating suicidal ideation on Tumblr. Ideally, researchers work hard to ensure integrity and rigour in their work; however, it falls on the researcher to comply with research standards. In SNS communities, the absence of clear guidelines especially with regards to protecting privacy, can make this process challenging. With the wealth of data from SNSs, passive observational researchers now face the challenge of navigating the online landscape without structured regulatory oversight.

This current study presented in this thesis stems from a broader investigation titled "*A Community of Practice Approach to Understanding Non-Suicidal Self Injury,*" (PI: Dr Gerald McKinley, who is also an advisory committee member on this work), which pooled qualitative and quantitative data from Instagram and Tumblr to explore hashtags and locate pro-NSSI communities, which are anonymous and frequented by youth (Guccini & McKinley, 2022). Investigators used discourse gathered from hashtags to construct a natural language processing methodology that located NSSI communities (Guccini & McKinley, 2022). Researchers then documented the structure, nature, and size of communities during data collection and identified accounts posted in several communities using Social Network Analysis (SNA). Naturally, the team developed a deep appreciation for the significance of this research (Guccini & McKinley, 2022). However, researchers from this study felt uneasy due to the inherent ambiguity surrounding negotiating consent and protecting the privacy of adolescent users.

While preparing their results for publication, the researchers made significant observations. Research Ethics Boards (REBs) do not mandate approval for online, covert observational research, as the TCPS-2 guidelines specify that data collected online is public (Government of Canada et al., 2018). However, this raises the need for additional guidelines and increased researcher literacy regarding the ethical use of data from SNSs. The publication of research findings carries the potential risk of subsequent identification of participants, putting confidentiality and safety at risk. Throughout this endeavour, the research team remained vigilant, steering clear of opportunistic or coercive practices (Warrell and Jacobsen, 2014). However, concerns arose later due to the need for explicit protocols or regulatory oversight from the Western University REB when determining the appropriateness of the content to publish.

As of today, researchers from this study are actively contributing to ongoing efforts to define ethical research in this domain. Consultations with the literature also reveal that researchers in the UK, such as Winter and Lavis (2020), are propositioning ways to navigate covert observational research ethically. Therefore, the aim of this study is to contribute to the ongoing discourse, by providing an additional perspective on how passive observers can uphold ethical conduct throughout their research process (Winter & Lavis, 2020). In light of this, adolescents, frequently overlooked and underrated stakeholders in research on pro-NSSI communities, have prompt consideration of whether valuable insights might lie within their perspectives.

1.2 Research Question and Objectives

For this research, adolescents were engaged in meaningful discourse on their experiences with NSSI content, individual privacy concerns, views on autonomy, and degrees of trust towards researchers. The following question guided the study: What are the attitudes of older adolescents towards researchers collecting personal information through SNSs to support health promotion research?

The objectives of this project were to:
1. describe the current research practices for collecting data on youth engaged in online communities, specifically pertaining to NSSI groups;

2. explore older adolescent attitudes toward research practices used to drive health promotion research;

3. determine how the older adolescent perspective on research practices can inform health promotion research.

Pro-NSSI communities provide a unique opportunity for researchers to peer into maladaptive behaviours that are particularly common among vulnerable adolescents (Guccini & McKinley, 2022). As I engaged in discussions with older adolescents, I brought up pro-NSSI communities as a foundational example to illustrate the concept of hidden online communities.

1.3 Rationale

Research is needed to understand adolescent perspectives towards researchers using their public SNS data, as health promotion research can unintentionally become paternalistic. In a qualitative study conducted by Schmeichel et al. in 2018, the researchers examined language and discourse surrounding adolescent behaviour. They found that the language used in the literature often underestimates the sophistication and maturity of older adolescents (Schmeichel et al., 2018). There was a tendency to inadvertently confine adolescents to specific roles and expectations potentially leading to heightened discrimination against individuals whose behaviours were deemed unusual by societal standards (Schmeichel et al., 2018).

Many people who die by suicide have previously engaged in NSSI, so there is obvious value in researchers conducting such inquiries (Klonsky et al., 2013). However, there are additional questions about the ethics of targeting vulnerable communities as it can be invasive and unknowingly damaging (Tengland, 2012). Negative comments concerning mental illness or potential hazards may exacerbate the stigmas individuals already face (Carter et al., 2012; Hasking et al., 2019). Therefore, by exploring older adolescent perspectives from a pragmatic point of view and through employing triangulation, I hoped to provide deep and nuanced accounts of the older adolescent's perspectives on social networking (SN) data usage beyond the "well-intended" health researcher view (Schmeichel et al., 2018).

1.4 Structure of thesis

The purpose of this section is to provide context for the rest of the study and prime the reader to think deeply about ethical data practices and the difficulties regarding SNS-driven research. In Chapter 2 of this thesis, I present the literature and the current tools researchers leverage to access hidden pro-NSSI communities. I describe the complex nature of SN research, examining a range of topics such as the unique opportunities offered by SNSs, prevailing standards for conducting SN research, factors that might influence older adolescent attitudes, and the core practices implicated in researching pro-NSSI communities. This literature review highlights the importance of dedicating more time and commitment to this field.

Chapter 3 highlights the methodology, including the exploratory survey and focus groups (FG) used to comprehend the subject matter. It also describes the inductive, thematic approach used for analyzing qualitative data, along with the methods employed for survey data analysis. In Chapter 4, the study results from the survey and FGs are triangulated using a convergent, parallel design (Fetters et al., 2013). These results are further examined and interpreted in Chapter 5, aligning closely with the existing literature. Chapter 6 discusses the research's implications, offers suggestions for future work, and summarizes the findings.

Chapter 2

2 Literature Review

This chapter highlights the benefits of observational Social Networking Site (SNS) research, delves into ethical challenges, and explores the dynamic methods used in this domain. The primary goal of this study was to understand the perspectives of older adolescents regarding researchers collecting their personal information for the advancement of health promotion research in pro-non-suicidal self-injury (NSSI) communities.

2.1 The affordances of SNSs

The different prospective applications of SNSs are known as their affordances. Relational affordances explain how a seasoned researcher might utilize SNSs differently compared to adolescent users. Functional affordances explain how each platform possesses distinct capabilities and potential uses that can either enable or hinder a SNS user in accomplishing their goals (boyd & Ellison, 2008; Burgess et al., 2008).This range of prospective applications of SNSs between users and platforms is encapsulated by a term coined by Madianou & Miller (2013) known as 'polymedia.' Polymedia has afforded boundless amounts of pre-existing naturalistic data, allowing researchers to study populations at risk for NSSI (Ellison & boyd, 2007, p. 2013). This availability of information is due to adolescents now utilizing various SNSs to accomplish specific goals, employing certain platforms to selectively share sensitive aspects of their lives, such as involvement in NSSI.

SNS research provides insights into vulnerable demographics outside the structured academic environment. Researchers such as Eynon and colleagues (2017) highlight the advantages of covert observational research in providing access to hidden groups and amplifying their voices. They delve into how personal factors hinder individuals from openly discussing their experiences, potentially affecting their participation in research to improve their lives. Additionally, within the literature, SNSs are recognized as a medium for researchers to tap into the voices of the overlooked, by providing anonymity and unrestricted insights without participants' explicit awareness (Ponterotto, 2005). This sentiment is echoed by other researchers who assert that "mainstream research practices are generally implicated in the reproduction of systems of class, race, and gender oppression" (Ponterotto, 2005, p.130). Also, adopting a covert role minimizes the researcher's "influence" on the data, resulting in increased external validity

(Ponterotto, 2005). Overall, covert observational SNS research has helped foster healthy communication in adolescents, enhanced community knowledge, and driven behavioural change in harmful communities (Korda & Itani, 2011). Therefore, researchers can gain insights into designing outreach strategies for health promotion by passively studying pro-NSSI communities through SNSs.

2.2 Current standards for passive SNS research

Researchers contend with numerous ethical challenges as passive observers when navigating SNS data. The literature describes them as "lurkers," therefore holding more negative connotations than researchers conducting observational studies from the offline setting (boyd, 2011; Madianou & Miller, 2013). It is worth noting that researchers in industry, especially those in Research and Development (R&D) roles for companies, may have different objectives and priorities from university-affiliated researchers, whom have different guidelines to follow (Government of Canada et al., 2018). The intricacies of data stemming from polymedia is marked by its complexity, fluidity, and multiplicities, and pose challenges in aligning with the existing online SNS research standards outlined in the Tri-Council Policy Statement for Ethical Research Conduct (TCPS-2) (Government of Canada et al., 2018). These standards include respect for persons, concern for welfare, and justice, serving as social guiding frameworks for researchers. Respect for persons is the recognition that everyone deserves a basic level of 'respect' before being included in the research, acknowledging their autonomy accordingly (Government of Canada et al., 2018). In this context, autonomy is the capacity of a person to decide whether they want to partake in a research study (Government of Canada et al., 2018). Good qualitative research centers on building trust and rapport with the participant, where researchers can actively negotiate power dynamics. This process is dynamic and iterative and factors in the inclusion of member reflections in the research process (Tracy, 2010). It is important to consider how, unlike conventional research practices that involve deliberating, obtaining and renegotiating consent to participate in a research study, the covert *lurking* researcher must consider different factors to conduct research ethically.

Researchers in the traditional Research Ethics Board (REB) process outline their data collection methods, analytic approach, and plans for prospective publications. This process serves as an

opportunity for introspection, allowing researchers to reflect on the ethics behind their work. However, as covert observers, researchers must assess whether the scope of their study falls under human subjects' research, needing additional oversight from the REB (Moreno et al., 2013). Hence, researchers may be exempt from this rigorous review process if the data from the SNS is considered public and is non-identifiable. Researchers do not have to undergo a strict REB process if the information is publicly available, because when sharing information through SNSs, there is a reasonable expectation that users will exercise the appropriate privacy settings to regulate their publicness (Moreno et al., 2013). However, this seemingly straightforward solution addresses only a fraction of a complex issue. The existence of polymedia, characterized by its fluidity and complexity, blurs the lines of private versus public spaces (Townsend & Wallace, 2016). Although SNS data is publicly available, the definition of the public and private domain is complicated by variations in privacy standards across different SNSs, and that the expectations and affordances of the platforms also differ among users (boyd & Crawford, 2012). Unlike the well-defined guidelines for researchers conducting in-person observational research, passive observation often neglects a crucial step, negotiating consent or providing the opportunity to withdraw from the study (Townsend & Wallace, 2016). The literature also highlights the need for researchers to think more reflexively about the ethical usage of SNS data (Hokke et al., 2020).

While adolescents on SNSs have access to individual Terms and Conditions regarding the use of their data, the degree of their consent requires clarification. Their compliance with the Terms and Conditions is more likely driven by the desire to be part of a community and leverage each platform's relational affordances for personal purposes. When adolescents are online, passive observational researchers are typically not the intended recipients of such information. This situation introduces uncertainty about consent, especially when individuals sharing content within pro-NSSI communities take measures, such as using covert hashtags, to prevent identification from outsiders to the community (Guccini & McKinley, 2022). Given these concerns, there is now increasing discourse about the issue of negotiating consent as some researchers, like the "Association of Internet Researchers" are beginning to suggest ways to navigate the use of NSSI data that has been gathered and presented from the online landscape

(Winter & Lavis, 2020). While this discourse is helpful, the absence of a general course of action adds complexity to navigating polymedia's dynamic yet complicated realm.

As users frequenting pro-NSSI communities tend to be younger and more vulnerable, researchers must exercise due diligence when using their information. A growing challenge in passive observational research online is the potential harm introduced to participants through the publication of research results. From a theoretical standpoint, lurking researchers must ensure they minimize risks by safeguarding anonymity and avoiding introducing "unintended consequences of research" (Eynon, 2017, p. 4). Therefore, when collecting personal information, researchers should carefully assess the risk of data leaks, ensuring it does not render the user recognizable to others. However realistically, despite their due diligence, the nature of SNS content might still make users identifiable through the traceability of online information between polymedia (Thompson et al., 2021).

Potential risks in SN research also include misrepresenting research identities and a lack of reflexivity during research, particularly when considering ethical research practices. Furthermore, when researchers amass large volumes of online data, there is a risk of unintentionally distorting adolescent perspectives due to individual biases. This misrepresentation could amplify the stigmatization of vulnerable groups (Chiauzzi & Wicks, 2019). The absence of opportunities for member checks and a lack of a humanistic lens when employing artificial intelligence in data analysis could further perpetuate the paternalistic perspective (Schmeichel et al., 2018). Therefore, the varying levels of expertise and standards of practice within the community of practice contribute to the blurred lines in ethical research. This ethical ambiguity serves as the backdrop for this study, as this thesis is deeply concerned with incorporating the voices of older adolescents into the conversation about ethical SNS research.

2.3 SNSs as a catalyst for adolescent-centric research

With the advancement of the internet, SNSs have become a platform for agency and activism due to a shift in how knowledge spreads online. The evolution of the internet aligns with the concept of "technogenesis," suggesting that humans evolve alongside the tools available to them (Kozinets, 2015). A study by Young and Garett (2018) mentions that about 94% of youth in

Canada have access to a SN account. SN apps like Tik-Tok, Instagram, Snapchat, and Tumblr, have become avenues for adolescents to express themselves (Montag et al., 2021). Therefore, the rapid adoption and evolution of SNSs are transforming adolescent behaviours, surpassing researchers' capacity to capture these swift changes in this dynamic landscape without utilizing the internet (Wood, 2013). boyd (2011) characterizes these landscapes as the "networked public" spaces where individuals can connect and communicate with one another, irrespective of their circles (boyd, 2010). The current generation of adolescents may harbour unique perspectives on data usage, being integral members of the networked public (boyd, 2010). Therefore, this generation may feel differently towards the passive researcher, as they may view the risks of engaging with SNSs differently from their predecessors. Their perspectives might be different from adults due to their heightened technological expertise, owing to growing up with easy access to internet-connected devices (Wood, 2013).

Adolescents are experiencing multiple pressures from the online landscape that increase their vulnerability to mental health issues (Gabriel, 2014). As a result, some adolescents turn to virtual wellness accounts to better understand how to cope with their struggles (Clarke & Kuosmanen, 2015). Research indicates that SNSs appeal to adolescents under mental pressure because it allows them to share personal information without the fear of repercussions (Yeo, 2021). Many adolescents prefer online, non-traditional engagement methods because they are convenient, non-confrontational, and perhaps even peer-approved (Oh et al., 2009). The anonymity and reciprocal engagement in online forums, social media posts, and comment sections explain why adolescents are more inclined to disclose personal information online to strangers versus their family or friends, a phenomenon known as the "online disinhibition effect" (Singleton et al., 2016). In line with this phenomenon, adolescents often use social media to express their issues with self-image and rationalize why they may engage in NSSI (Brown et al., 2020). Adolescents leverage the added comfort of anonymity on the internet to access pro-NSSI communities, away from disapproving adults (Arigo et al., 2018; Warrell & Jacobsen, 2014). According to Somerville et al. (2013), these feelings could be linked to a developmental stage in older adolescents between the ages of 15 and 18, which is marked by a heightened sense of self-consciousness when regarded by their peers. In this 2013 study by Somerville and colleagues, participants (between the ages of 8 and 22) participated in a cognitive neuroscience experiment that examined the

emergence of self-consciousness in adolescence. Participants in the study were informed that a member of their peer group was observing them on a live video feed. During this task, she observed that, when compared to their child (8- to 12-year-old) or adult (16- to- 22 year-old) counterparts, older adolescent's Medial Prefrontal Cortex, a portion of the brain known for processing emotional and social cues, showed higher activation. Overall, the results showed a continuous rise from infancy (Ages 8 to 14), and feelings of humiliation and self-consciousness peaked in adolescence (15 to 18) (Somerville et al., 2013).

Therefore, this study defines older adolescents as biologically and developmentally different from youth 15 and under. In the literature, adolescents between the ages of 16 and 19 have demonstrated complexity in navigating their interpersonal relationships, experimenting with privacy, and determining the level of information they deem worthy or acceptable to the public (Schmeichel et al., 2018). Older adolescents are also described as behaving proactively, thinking critically, and consciously engaging with social media (Schmeichel et al., 2018). Older adolescents partaking in pro-NSSI communities often strive to hide their identities using hashtags, code words, or anonymous personas to expand their reach. Essentially, they intend to be "public without being public" (Marwick & boyd, 2014, p. 1054). Despite wanting to share certain content with their peers online, they will take extra measures to hide content from the paternalistic voyeur, which might be adults within their circle. If their primary objective is to evade detection by the seemingly paternalistic observer, it raises ethical concerns about respect for consent or respect for vulnerable persons (Government of Canada et al., 2018). Despite the researcher's good intentions, older adolescents balancing their privacy expectations, who are at risk for NSSI, might not feel so kindly to the lurking researcher.

2.4 Methods for investigating pro-NSSI communities online

Passive observational researchers have an array of raw data, offering valuable insights into the supportive connections, hierarchical interactions, and common behaviours among pro-NSSI communities. SNS data is dynamic, and researchers can organically observe "special roles or actors in a social context" and how culture, social positioning, and marginalization are represented online (Marotzki et al., 2013, p. 10). The next part of the literature review positions the study within the rapidly evolving technological landscape and describes some of the

available data and approaches to studying and interpreting pro-NSSI content online. This brief descriptive review addresses Objective 1, which is to describe various approaches to researching pro-NSSI communities.

2.4.1 Diverse data sources

Textual and natural language data aid researchers in discerning sentiments, exploring themes, and uncovering intentionally hidden information related to NSSI (Kim & Yu, 2022). Natural language data encompasses any information communicated through language, whether orally or in writing. While this data is typically unstructured, the application of natural language processing (NLP) algorithms allows for deeper insights into adolescent behaviors and meaningful categorization of information (Kim & Yu, 2022). Data collected in textual, numerical, or structured forms can be analyzed using NLP, undergo content analysis, or be subjected to other interpretations by the researcher (Luscombe et al., 2022).

Another type of data is network data, which unveils intricate patterns of relationships among community members. Social network data provides a window into the dynamics of information exchange by revealing the connections between different individuals and observing how information travels between people. Social network data considers different connections and the hierarchical classifications within a user's network (Wester et al., 2015). Additionally, researchers can harness temporal data to identify periods when adolescents may be more susceptible to exhibiting heightened online activity (Griep & MacKinnon, 2020). Researchers carrying out passive observational studies incorporate predictive models to anticipate behaviours and employ temporal data to monitor changes in the frequency of posts, engagement metrics, and preferences of adolescents. They can also use temporal data to detect anomalies in individual posting patterns (Griep & MacKinnon, 2020).

Data about user demographics, encompassing age, name, gender, and location, can also pose substantial risks (Luscombe et al., 2022). Researchers must exercise caution and adopt stringent privacy safeguards when handling sensitive information, so the individual is not identifiable during publication. The responsibility lies with researchers to meticulously assess the quality of the data, ensuring it faithfully represents the phenomena under examination. Navigating the

digital landscape, researchers must remain vigilant against data breaches and inadvertent privacy violations that could harm participants. Therefore, though SNSs present vast information and opportunities, they also demand diligent adherence to TCPS-2 guidelines.

2.4.2 Methods for uncovering pro-NSSI communities

Netnography is a branch of ethnography that delves into the interactions and relationships among individuals within online communities (Kozinets, 2010). This approach explores how people interact within their online cultural environments and investigates connections or exchanges related to specific topics. For example, regarding pro-NSSI communities, netnography sheds light on the affordances of SNSs and their influence on initiating harmful behaviours among adolescents (Marchant et al., 2018). This method has contextualized NSSI by explaining the etiology of the behaviours, like the desire for control, relief from mental distress, and the pursuit of attention (Chandler & Powell, 2016). Netnography has implications for advocacy and education, offering an additional nuance to clinical data, which is known to capture more structured information through employing diagnostic tools, medical tests, and personal interaction within a controlled environment (García-Nieto et al, 2015; Marchant et al., 2018).

Another key method used to study pro-NSSI communities is, Social Network Analysis (SNA) which offers insights into the bidirectional or unidirectional connections among individuals using SNSs (Knoke & Yang, 2008). This method has proven effective in understanding hierarchical social group structures, the diffusion of ideas, knowledge transmission modes, and more (Wasserman & Faust, 1994). For instance, Zinoviev and colleagues (2012) utilized network analysis to explore semantic networks of interest and personal characteristics among users discussing NSSI behaviours, revealing insights into user correlations and cluster analyses. In health promotion research, SNA aids in the discovery of pro-NSSI communities through the analysis of purposeful hashtag usage, facilitating the identification of influencers, groups, and idea dissemination (Eynon et al., 2017; Korda & Itani, 2013). Researchers also leverage artificially intelligent models to delve into the content of online forums using phrase detection as part of their network analyses (Arigo et al., 2018). For instance, NLP can be used to swiftly analyze linguistic patterns in social media texts, allowing for a faster assessment of a person's mental state than traditional methods (Alfonso, 2020). Researchers can develop models flagging

harmful NSSI content more accurately, facilitating the exploration of behavioural trends and identification of vulnerable groups that seek to be hidden (Baclic et al., 2020). Furthermore, researchers can employ user behaviour analysis to evaluate posting activity and monitor relationship shifts over time (Baclic et al., 2020). Additionally, sentiment analysis, a component of opinion mining, enables the assessment of an individual's prevailing emotional state, whether positive or negative, offering insights that can be quantified or interpreted (Jung et al., 2017).

Given the rapidly changing SN landscape, newer and more effective processes, primarily developed for marketing purposes, can be reconfigured, and leveraged by researchers to investigate pro-NSSI communities. Researchers venturing SNS research must consider the core principles of ethics like respect for persons, concern for welfare, and justice (Canadian Institutes of Health Research [CIHR], 2014).

2.5 Summary

The aim of this study is to add to the ongoing discourse in the scientific community, by providing a unique perspective on how passive observers can uphold ethical conduct throughout their research process. The literature review serves as a foundation for this investigation, emphasizing the need for a more comprehensive exploration of older adolescents' perspectives on using the personal information they post to SNS. It highlights the disconnect between research in hidden online communities and the standards to protect users in the public social media domain. The literature review also points out a critical gap in the existing body of work, emphasizing the necessity of ethical practices in online research, particularly through collaboration with directly affected populations such as older adolescents.

In line with Objective 1, this exploration raises considerations such as informed consent, information privacy, and the fine line between public and private domains, underscoring the significant ethical challenges researchers encounter during their investigations involving online SN data and the need for researchers' guidance.

Chapter 3

3 Methods and Methodology

This chapter details the study's methodological approach, outlining the preparations for the research, including the research design, paradigmatic approach, ethical considerations, research setting, participant distribution, and sample size. The data collection process, encompassing survey and focus group (FG) procedures, recruitment strategies, data analysis approach, quality criteria, and contingency plans, is discussed in greater detail. The aim of this study is to add to the ongoing discourse in the scientific community, by providing a unique perspective on how passive researchers can uphold ethical conduct throughout their research process.

3.1 Research Design

This study followed a mixed method, convergent parallel design where the qualitative and quantitative data was compared, related, and interpreted jointly (Creswell & Clark, 2011; Fetters et al., 2013). As there is limited literature guiding researchers on how to navigate ethical research on hidden NSSI communities, and since this topic is relatively new, I adopted an explorative approach in the form of 1) a survey administered through Qualtrics[XM] and 2) a semi-structured FG between the researcher and older adolescents, between the ages of 16 to 19. Data collection for the survey and FGs occurred at the same time, and the findings were analyzed independently before being integrated and presented in Chapter 4 as part of the convergent mixed-methods design (Fetters et al., 2013).

3.1.1 Paradigm

The existing literature for qualitative research discusses how acknowledging paradigmatic identity can affect the rigour and quality of research work (Tracy, 2010). *Pragmatism* allowed me to embrace the diversity of mixed-methods research (Kaushik & Walsh, 2019). *Pragmatism* bypasses the concerns of the competing nature of paradigms in quantitative and qualitative research by suggesting there may be singular or several realities to investigate (Kaushik & Walsh, 2019). Essentially, this means that in our social experiences, different versions of those social realities are more consistent depictions of the individual experience over the other (Morgan, 2013).

3.1.2 Ethics

The Non-Medical Research Ethics Board at Western University approved the study before starting this investigation (Project ID 121308). Participants were given thorough explanations of the study's goals and the potential risks and benefits associated with the research endeavour with an information letter. Individuals also gave their permission to be audio-recorded during the FG sessions.

Throughout the study, a series of measures were implemented to ensure the ethical integrity of the research. A notable example lies in effectively communicating the researcher's responsibility to promptly report instances of NSSI and child abuse to participants before embarking on the FG discussions. Some preparations included undergoing a comprehensive curriculum with preparations for potential challenges, underscoring my commitment to conducting ethically sound research. In this case, knowledge regarding the concept of ethics in practice, which delves into appropriate responses to intricate ethical dilemmas researchers encounter when engaging with adolescents during research, was helpful (Guillemin & Gillam, 2004). This knowledge particularly pertains to situations like the potential disclosure of NSSI by a participant, as might occur in the context of this study. I also considered Guillemin and Gillam's (2004) proposal of "ethically important moments." These moments typically arise when dealing with sensitive populations and introducing challenging and nuanced situations. In preparation for these scenarios, I embraced the concept of reflexivity, a process that cultivates ethical research practice. This involves critically analyzing various aspects, including participant responses, the research context, and the role of the researcher (Guillemin & Gillam, 2004). Per ethical guidelines, this approach ensures that participant dignity, autonomy, and privacy are respected (Government of Canada et al., 2018).

A series of measures were implemented to ensure participants were well informed about potential risks and topics of discussion. Each FG had at least two researchers present; the second researcher was available and prepared if needed to support individuals needing help. Throughout this journey, both the research assistant and I closely monitored participant well-being. Adopting a reflexive approach enabled me to acknowledge participant's challenges empathetically and respond with compassion.

A fundamental tenet of reflexivity and "ethics in practice" is recognizing when to seek guidance from a more experienced source. Consequently, during FG interviews, although the more seasoned Principal Investigator (PI) or co-investigator might have been absent from the room, they remained on standby and available. This arrangement ensured that if a participant revealed sensitive information, I could discreetly signal the research assistant to inform the PI for further action promptly. I prepared for such situations using techniques described by Biddle and colleagues (2013), including:

1. monitoring of participant well-being
2. inclusion of patient information letters with warnings about potential distress from participation
3. debriefing
4. referral to mental health resources/follow-up care

Despite preparing, the situation did not arise during the discussion, rendering the application of this technique unnecessary. However, it is important to acknowledge and address potential risks in the research process to uphold ethical standards and fulfill my duty to ensure the well-being of participants. In ensuring a coherent framework, I conducted a thorough assessment of the suitability of the chosen methods, considering the previously established rationales tied to accessibility, convenience, and the pursuit of triangulation, this deliberate approach aimed to establish meaningful connections and enhance the interplay of the findings.

3.1.3 Setting

This research was positioned within the online landscape, a deliberate choice guided by the study's overarching aim to understand adolescents' perceptions within NSSI communities towards passive research. This was a cost-effective approach and offered access to a participant community that would have been challenging to engage within a traditional in-person context (Eynon, 2017). Participants received a $10 'Everything' gift card, which they could use to choose a gift card from a diverse range of brands such as Tim Hortons, Amazon, Indigo, Uber, Cineplex, and more. Compensation was delivered via email for each FG.

3.1.4 Participants

The FGs comprised individuals aged 16 to 19 who regularly engage with others on SN platforms. Given the observed link between NSSI and suicidal attitudes, I adopted a broader participant recruitment strategy to reduce potential risks (Muehlenkamp et al., 2018). The aim of this study is to add to the ongoing discourse in the scientific community, by providing a unique perspective on how passive researchers can uphold ethical conduct throughout their research process. Therefore, I did not single out individuals specifically partaking in NSSI communities during recruitment. Hence, the recruitment criteria encompassed individuals aged 16 to 19 who would actively participant on SNSs and were English-speaking.

Participants were not allowed to partake in the study if they were (1) below or above the ages of 16 to 19, (2) Unable to communicate in English, (3) were unable to connect with the researcher using an internet-connected device.

Participants were recruited through a (1) mass recruitment email specifically to Western University undergraduate students (Appendix E) and through (2) social media posts made on Instagram, LinkedIn, and Facebook (Appendix F). The email and posts contained a link to the Qualtrics^{XM} survey platform and upon clicking the provided link, participants viewed a consent form with details about the study where they provided their informed consent. After completing the Qualtrics^{XM} survey, participants indicated their interest in participating in an online qualitative interview to understand their experiences better. Individuals who expressed interest were contacted via email to coordinate FG sessions.

The recruitment process for the FG interviews was parallel to the survey recruitment. A minimum of two and a maximum of five people participated in each FG. Though FGs typically have four to twelve individuals, some have been even smaller (Tang & Davis, 1995). Smaller FG sessions made more sense in the case of this study, as it encouraged all participants to participate freely. It made also made it easier for the student researchers to mitigate and respond to unforeseen situations regarding discussions about NSSI.

3.1.5 Sample Size

Determining the sample size for the survey was guided by an a priori sample size calculation. This calculation utilized a 95% confidence level and a 5% margin of error. Considering a population size of 2,050,000 older adolescents in Canada, with the most recent poll from Statistics Canada indicating that 92.2% of older adolescents between the ages of 15 and 19 use SNSs regularly, the minimum sample size was expected to be 111 participants with an actual sample size of 113 participants. This approach ensured the findings balanced precision and feasibility within the provided context.

Marshall (1996) elaborates that researchers should adapt their strategies to the specific circumstances and ensure that their chosen sample size aligns appropriately with the study's objectives. The emphasis lies on exercising *pragmatism* and *flexibility* when determining the sampling approach to adequately address the study's goals (Marshall, 1996). The point at which collecting additional data no longer offers novel insights eliminated the need for further participant recruitment to progress the study (Saunders et al., 2018). When it came to determining the sample size for the FG sessions, since the data from each interview was rich, I reached data saturation after conducting four FG sessions and sampling the target population through the survey.

3.2 Data Collection

3.2.1 Survey

Convenience sampling was used for participant recruitment which unfolded from January 27, 2023 to April 12, 2023. Surveys are an efficient way to involve a large group of participants and as most older adolescents have access to mobile or Wi-Fi-enabled devices, this was a strategic decision to reach a wider pool of participants. Participants were not screened for having a history of engaging in NSSI, given that the information letter encompassed comprehensive details about the study, empowering participants to make informed decisions regarding their participation. The survey was administered via Western University's 'MySurveys' Qualtrics[XM] and took participants approximately 20 minutes to complete. Using the online link, participants received a consent form and indicated their agreement by checking a designated box, thus showing their willingness to partake in the study. Upon survey completion, participants responded to questions about interest in engaging in a subsequent FG interview centred around the research theme. Respondents who

opted for this shared their email addresses for coordination purposes. Importantly, all email addresses collected were maintained separately from the survey data, safeguarding the integrity of participant information. The distribution of electronic gift cards and coordination related to the timing of FG interviews occurred through email.

The aim of Objective 2 in this research study was to gain insights into the attitudes and perspectives of older adolescents toward passive research practices. My supervisor and I developed closed and open-ended survey questions after consulting the literature and addressing the questions from the larger study. These questions covered general SNS use, posting habits, and overall trust towards researchers. Additionally, specific questions were adapted from an established survey addressing information sharing, information seeking, mental health, NSSI, and SNS use (Akhther & Sopory, 2022; Li et al., 2018; Pretorius, 2019).

Measurement scales were established during the survey development phase, with sentiments such as "No," "Uncertain," and "Yes" recoded as 1, 2, and 3, respectively, on an ordinal and gradient scale (negative to positive attitudes). Additionally, another set of survey items utilized a sentiment scale ranging from 1 to 5, representing sentiments from "Definitely not" to "Definitely have" and from "Extremely uncomfortable" to "Extremely comfortable", with each sentiment assigned a numeric value (Appendix G). Responses such as "Prefer not to answer" or skipped responses were excluded from coding. Using ordinal, categorical scales were intentional to identify unobservable individual qualities, which are difficult to quantify because of behavioural variances in people. Scaled responses were treated as ordinal data during analysis, recognizing the ordered nature of responses without assuming precise intervals between them.

3.2.2 Focus Groups

Each FG session lasted approximately 50 minutes and was semi-structured, involving participants responding to six open-ended questions and prompts (Appendix C2). Participants were encouraged to expand on their perspectives as they provided more detailed responses. Participants were redirected to steer the conversation appropriately when the discussion veered away from the study's aim. I was accompanied by an undergraduate assistant and a Ph.D. candidate throughout the interviews, each performing distinct roles. As the master's candidate, I was responsible for

facilitating the discussion, the undergraduate student acted as an observer and note taker, and the Ph.D. candidate was there to aid in case ethical concerns, like participants disclosing past experiences with NSSI, arose during the discussion. I used the emails provided from the surveys to organize and schedule FG sessions. Before the online FG commenced, I obtained participants' consent by sending them an independent consent form through Qualtrics[XM]. I reviewed the forms with the participants to confirm their understanding of the study and address any questions. The FGs were conducted securely through a designated Zoom link.

A subset of participants from the initial survey were recruited for FG discussions about various domains, including:
 a) General use of SNSs
 b) Prior engagement or attitudes towards risky online content
 c) Attitudes toward targeted research practices
 d) Personal involvement with research.

During the Zoom sessions, participants frequently utilized the chat feature, which offered a distinct and unforeseen capability that reflected their comfort level. Interestingly, some individuals felt they could express their thoughts and emotions more effectively through text, enabling them to reflect more profoundly on the subject. This data was transcribed alongside the oral responses from the FG sessions and were interpreted inductively. Additionally, this feature allowed participants to have more chances to self-reflect throughout the sessions and better articulate their thoughts. All the discussions were recorded and transcribed, all identifiers removed, and the original recordings deleted. The transcriptions and survey data were stored in a secure OneDrive location to maintain confidentiality and data integrity.

3.3 Data Analysis

3.3.1 Survey Data Analysis

Initial data processing was conducted using Microsoft Excel, while LucidChart was utilized to visualize patterns within the data. Statistical analyses were performed using SPSS Inc (version 29.0.2.0). To present participant demographics, variables such as age and gender were summarized using frequency and percent responses, offering a comprehensive snapshot of the sample. Raw

scores from survey responses underwent thorough analysis, including frequency distribution, mode identification, and determination of minimum and maximum values. Statistical significance was assessed using a significance level of 0.05, employing specific tests tailored to the nature of the data.

It was observed that the data did not meet the assumption of normality, indicating a nonparametric distribution. To measure the strength of associations between response items, Kendall's Tau correlation coefficient was employed, providing insights into the bivariate relationships, focusing on both nominal variables (gender and age) and ordinal variables (e.g., ranked survey responses from Q11 to Q16) using Kendall's Tau (Appendix A4). Tables A3 and A4 from the appendix summarize the direction and strength of correlations that were found to be statistically significant when tested. Impressions of relationship strength are informed by guidelines established by Chan et al., 2003, which highlight the significance of various correlation coefficients. According to their guidelines, correlations between 0.3 to 0.5 or -0.3 to -0.5 suggest a fair relationship, but those between -0.3 and 0.3 indicate a weaker relationship. Statistically non-significant responses with a p value below 0.05 indicate that there is not enough evidence to reject the null hypothesis, meaning the observed relationships are most likely due to chance.

Additionally, 95% Confidence Intervals were computed to provide a level of precision around relationships identified in the data. Systematic comparisons of responses were conducted to discern relationships between items, contributing to a comprehensive understanding of the dataset. The raw data was exported from Qualtrics and were then imported to Excel. Raw data was organized and cleaned such as removing duplicates, majority missing values, or when majority of answers were chosen as 'prefer not to answer.' A codebook was created to recode the raw choice text into numeric values so they could be used for the ranked correlational analysis in SPSS (Appendix G). The results of the analysis are included within the appendix. Each response option was assigned a specific numeric value to represent the range of sentiments expressed by participants. Responses from participants who did not identify as male or female were excluded, as the majority of participants fell within these two categories, thus facilitating a more focused and interpretable examination of the data.

3.3.2 FG Data Analysis

After completing the qualitative FG sessions, the sessions were transcribed. I adhered to a process influenced by the methodologies of Gale et al. (2013) and Thomas (2003). This process began with thoroughly familiarizing the data, involving a meticulous review of questions and responses from the semi-structured FG sessions. This immersion aided me in establishing an initial coding round where I delved into the transcripts, capturing the essence of each conversation.

Open coding was an inductive process generating approximately 425 codes that captured a wide range of concepts and perspectives in the data: for example, participants' care towards their public image or participants' individual appreciation of NSSI research (Williams & Moser, 2019). Following this initial phase, there was a transition to axial coding, focusing on discerning connections and relationships among the codes (Williams & Moser, 2019). For example, there was an overlap in responses suggesting the feelings of trust towards researchers was largely dependent on the individual researcher's intent. This step brought about a more structured arrangement of the data, leading to the grouping of codes under overarching themes, enhancing clarity and coherence. Overall, this approach aligned with the framework method, as qualitative responses were inductively coded by myself and another graduate student. We coordinated team meetings to discuss our independently derived themes, where we found points of agreement and disagreement. Following this, my supervisor and committee were engaged in team meetings where there was a collaborative effort to review the appropriateness of the themes. An iterative cycle was at play throughout these phases, fostering a dynamic and immersive exploration. This approach facilitated a nuanced analysis of the qualitative data, ensuring an understanding of the study's underlying intricacies.

Findings from the survey and FG responses were then compared and contrasted to reveal patterns and subtle discrepancies between findings.

A framework matrix was utilized for this purpose, guided by Gale et al.'s (2013) outlined steps:

Figure 1: Inductive coding approach to data analysis adapted from Gale (2013)
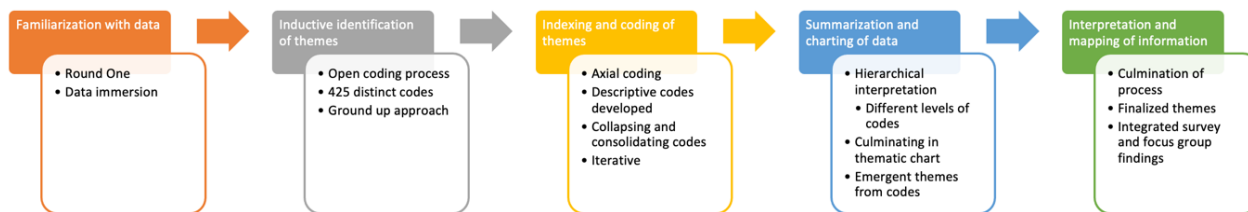
3.4 Quality Criteria

To assess the quality of this study, a series of benchmarks presented by Tracy (2010) in their article "Qualitative Quality: Eight-Big Tent Criteria for Research" were used. Throughout the evaluation, the topic's worthiness, the research's sincerity and credibility, its ethical integrity, and overall coherence was considered (Tracy, 2010).

I incorporated quality checks for coherence and accounted for my role as a researcher to decrease conflict between quantitative survey data grounded in post-positivism and qualitative FG sessions grounded in a more constructivist paradigm (Ballinger, 2006; Guba & Lincoln, 1994). Concurrent with data collection processes and specifically the FG interviews, I engaged in a process of reflexivity, which involved a journaling of my perceptions and their potential impact on participant' responses before and after each conversation.

This study was born out of a significant contextual development given recent technological advancements in methods used to access and study pro-NSSI communities. According to Tracy (2010), a worthy qualitative study distinguishes itself by its relevancy and need, thereby addressing a specific need that warrants scientific inquiry. During the initial NSSI study by Guccini and McKinley (2022), concerns surfaced about safeguarding user privacy. After identifying this gap, a brief literature search highlighted the uncertainty surrounding researchers' steps to ensure ethical practices. The literature search highlighted the significance of investigating this topic, as it revealed that REBs have yet to establish appropriate guidelines for researchers conducting studies dealing with sensitive materials from pro-NSSI communities.

In pursuing robustness and credibility, I incorporated triangulation, another element of Tracy's (2010) comprehensive framework (Figure 2). The purpose of methodological triangulation was to

uncover potential convergence or divergence in opinions and to investigate the possibility of generalization among a spectrum of adolescents (Heale & Forbes, 2013). Data analysis occurred concurrently with the Principal Investigator and another dedicated master's candidate to substantiate the study's rigour. This research also made a substantial moral contribution, emphasizing the principles of ethical research practices, which Tracy (2010) also highlights as a critical criterion for good quality research.

Figure 2: Triangulating data between FGs and survey
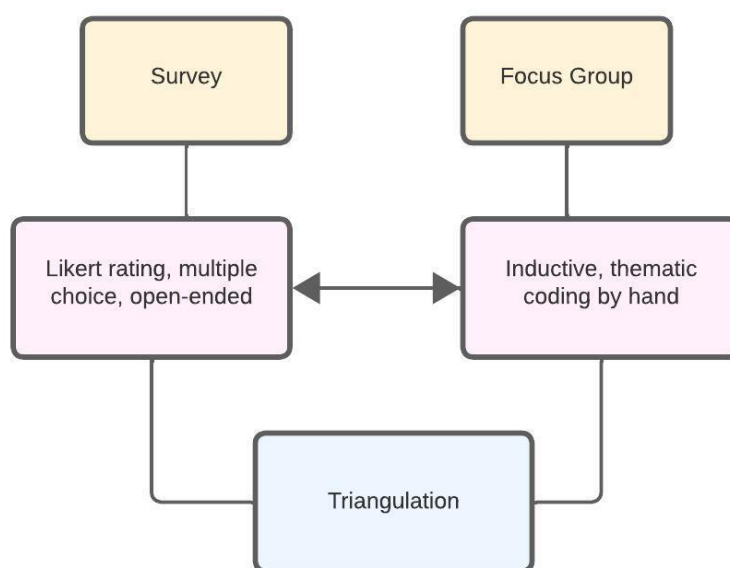
3.5 Summary of Methods

The concurrent use of FGs and survey methods served to triangulate results and strengthen the quality of findings. Results from the survey were organized, interpreted, and visualized using LucidChart, Microsoft Excel, and SPSS. Qualitative data from the FGs and surveys were iteratively and inductively coded. As data analysis progressed, themes that emerged were refined to reflect the growing understanding of the material. Findings from the survey and FG responses were processed concurrently to review patterns and subtle discrepancies.

Chapter 4

4 Findings

These findings address the following research question: What are the attitudes of older adolescents towards researchers collecting personal information through social networking sites (SNS) to support health promotion research? First, I provide an overview of the demographic data. Subsequently, I discuss each theme, integrating the survey results with the focus group (FG) themes, as part of the analysis process. The study's objectives included 1) describing the current research practices for collecting data on older adolescents engaged in online communities, 2) exploring the attitudes of youth towards research practices used to drive health promotion research on NSSI, and 3) determining how the older adolescent perspective on research practices can inform health promotion research.

From 122 survey responses, a data-cleaning process resulted in 113 qualifying entries. This involved excluding incomplete submissions and those beyond the specified age range. The inclusion criteria for both the survey and FG participation were as follows: (1) proficiency in English, (2) the ability to provide informed consent, (3) between 16 to 19 years old, and (4) having access to an internet-connected device. In the context of the four online FGs, 13 participants engaged in discussions, each session accommodating a minimum of two and a maximum of five participants.

Five themes and ten sub-themes were identified from the FGs (Table 2), and the results from the survey and the FG were triangulated and presented alongside each other. The themes from the FGs include: A. The permanence of online information, B. Nurturing safer online communities, C. Information overload, D. Respecting ethical boundaries, and E. Youth considerations for research.

4.1 Participant demographics
4.1.1 Survey gender and age composition

Figure 3: Response distribution by gender and age from survey (Total n= 113)
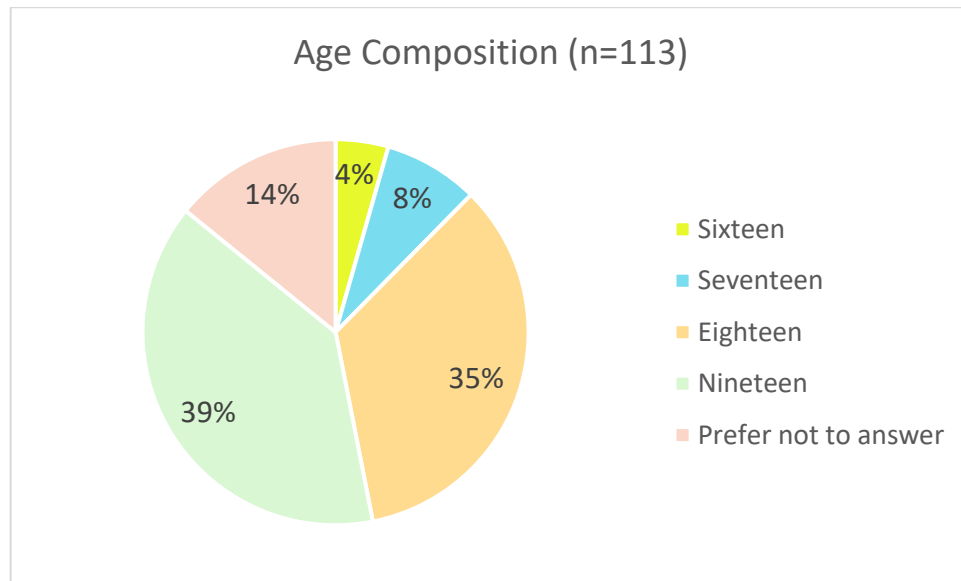
The age composition of the survey shows the relative distribution of each age category, where individuals between the ages of 18 (n= 39, 34.5%) and 19 (n= 44, 38.9%) made up the majority of the study's respondents.

Gender Composition (n=113)
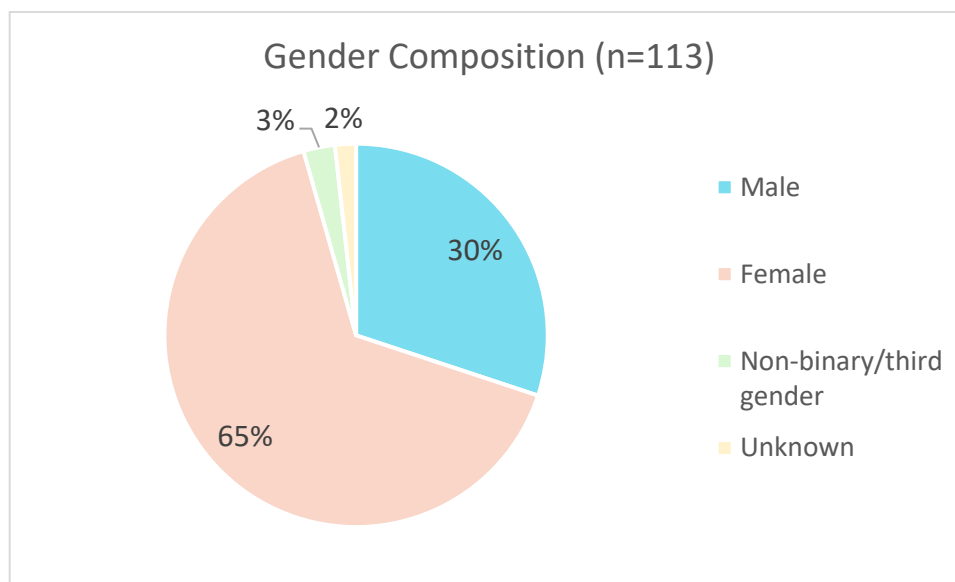
65.4% of the 113 participants from the survey identified as female (n=74), and 30.1% (n=34) identified as male. 2.65% of the participants (n=3) identified as non-binary or third gender, and 1.77% of participants did not disclose their gender orientation.

Table 1: FG demographic details

Participant characteristics	n= 13 (%)
Age (years)	
16	2 (15.4%)
17	3 (23.1%)
18	5 (38.5%)
19	3 (23.1%)
Gender	
Male	10 (76.9%)
Female	3 (23.1%)

4.2 Results

This section presents the survey findings alongside the five primary themes and their corresponding ten sub-themes, which emerged through the inductive coding of FG data.

Table 2: Themes and sub-themes from FG

Themes	Sub-themes
A. The permanence of SNSs	Digital self-consciousness
	Vigilance towards resurfacing posts
B. Nurturing safer online communities	Empathy as a driver for enhancing community health
	Habituation to harmful online content
C. Information overload	Regulating pervasive NSSI spaces online
	Information inundation
D. Respecting ethical boundaries	Trust is dependent on intention
	Balancing privacy concerns
E. Youth's considerations for research	Potential for bias or misinterpretation
	Valuing anonymity and confidentiality

4.2.1 The permanence of SNSs

Adolescents show a deep concern for how others view them and a heightened self-awareness regarding their public image. They also recognize the permanence and consequences of their online presence and are aware of their digital footprint, considering how their peers might perceive them. Within this theme, two subthemes emerged: 1) digital self-consciousness and 2) vigilance towards resurfacing posts.

Digital self-consciousness
The survey findings and FG discussions indicated a notable trend towards adolescents dedicating more time and effort to carefully curating their online identities. Survey participants were asked about their time spent thinking before posting SNS content online. As depicted in Figure 4, 35.3% (n=40) of participants reported spending 10 minutes or less contemplating their posts before sharing. Conversely, 45.1% (n= 51) of participants spent between 10 minutes to more than a day contemplating their online content. Other participants (n=22, 19.5%) highlighted how their posting patterns depended on context, corresponding to the different functional affordances dictated by each platform.

Figure 4: Posting time intervals on SNSs
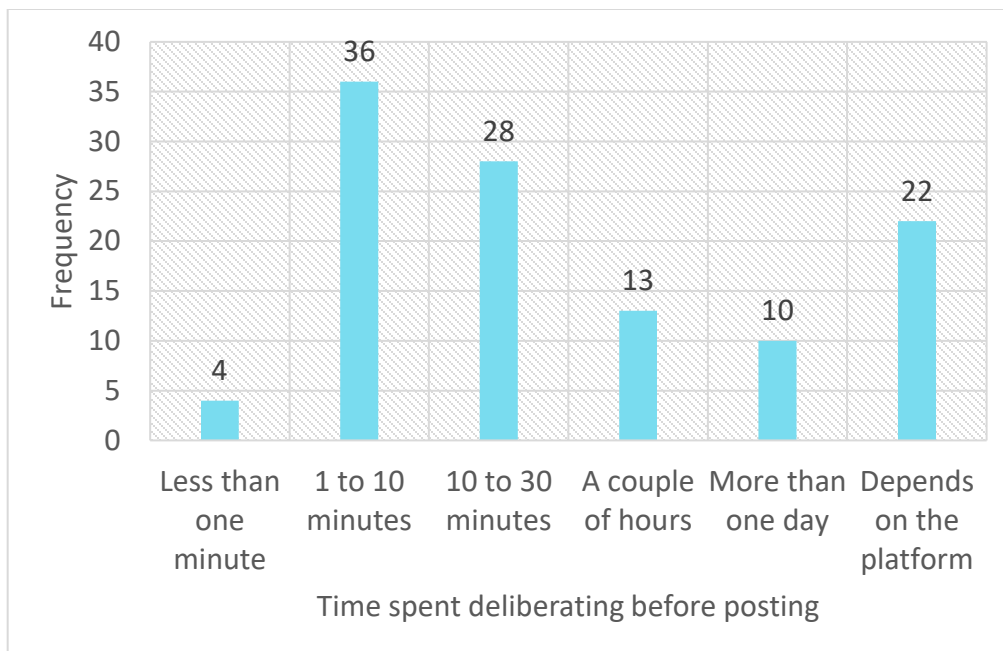
The insights gained from the FGs can offer a deeper understanding of why survey participants spent time contemplating or relying on context before sharing their posts on SNSs. Participants from the FGs stressed the importance of taking time, describing a process where they anticipated their emotions post-sharing and contemplated how others might perceive the content they posted. They mainly considered how their messages would be perceived by their audience, accounting for the active or passive observer.

> *"I'll really think about what I'm posting to see if this is something that I want people to see" (Female, 19, FG1).*
>
> *"I spend a lot of time because I care about what people are going to think... I'm concerned with other people's attitude and other people's decisions on what I'm going to post. If I think it's going to affect others, I don't post." (Male, 17, FG2).*
>
> *"Each time before I post, I think who's going to see this and how it will affect me tomorrow or the next day" (Male, 16, FG4)*

A prevailing sentiment among participants was their concern about the social repercussions of their posts. Participants highlighted how they would carefully evaluate the appropriateness of the content before sharing it with others. These observations collectively underscore the balancing act

that participants engage in, driven by a desire to manage and control the perceptions that others may form of them.

Vigilance towards resurfacing posts

Though participants were not certain of who exactly might be viewing their SNS content, they displayed a certain vigilance towards resurfacing posts that had become ingrained *"because of the generation [they had] grown up in"* (Female, 18, FG3, 010). Participants' discomfort and unease toward researchers viewing their content were frequently highlighted. They expressed apprehension about sharing problematic content online, driven by the enduring nature of online posts.

> One participant even shared a valuable lesson learned: *"As a rule, you should not post anything that you don't feel is safe to be out there" (Male, 18, FG2, 008).*

Therefore, most participants from the FGs had been shaped by their generational awareness, and expressed vigilance about how they might be perceived by others based on the content they were posting. This supports the survey findings where participants were asked about their perceived impact of SN posts on future outcomes (Figure 5). Many participants refrained from sharing online content they believed could have adverse implications for their future, opting to avoid engaging with harmful content. The majority, comprising 57.5% (n=65), included a combination of those who selected "Definitely not" (30.1%, n=34) and "Probably not" (27.4%, n=31). Additionally, 24.8% (n=28) of participants expressed uncertainty about the potential impact of their shared content on their futures, while a smaller number 17.7% (n=20) acknowledged having posted content that could negatively impact their future if discovered.

Figure 5: Perceived impact of SN posts on future outcomes
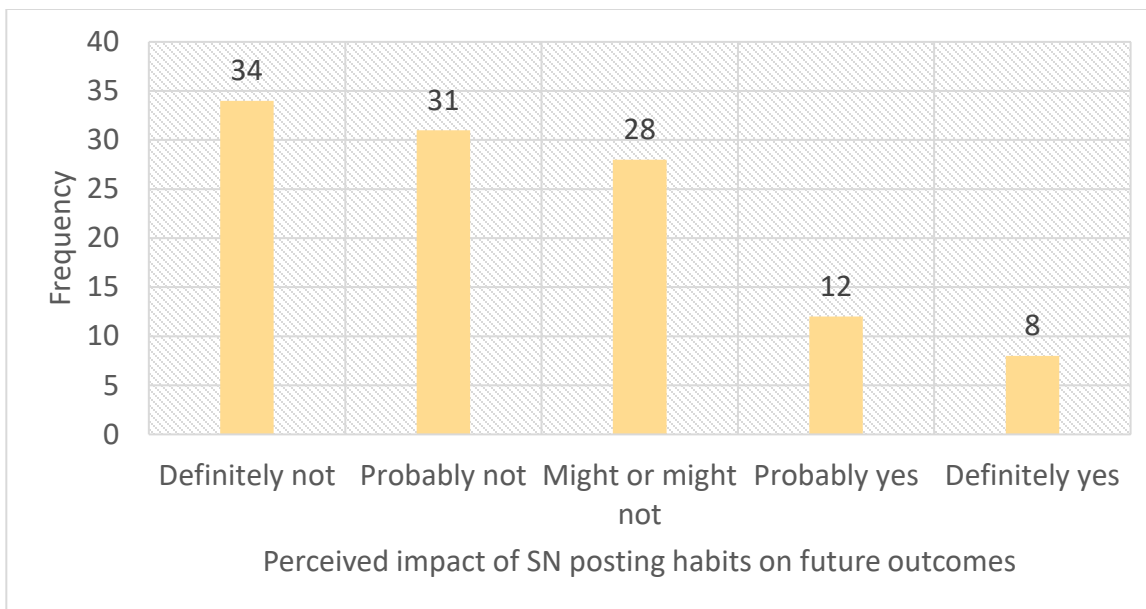
When conducting a correlational analysis, it was noted that among participants who acknowledged having a harmful digital footprint, there was a weak correlation with those who had previously engaged in harmful hidden online communities (Kendall's tau_b = 0.268, p = 0.001, 95% CI [0.148, 0.380]). This suggested a relationship between individuals posting content in hidden online communities and the perceived implications towards their digital footprint (see Appendix A, Table A4).

FG participants also described how an emotional resonance persisted even in the absence of regrettable posts, highlighting the psychological implications of digital permanence.

> *"I feel unease[y] because it is impossible to fully draw back from a post that I'd regret (Male, 16, FG2, 006)."*

> *"I'm aware of when I post that nothing ever really goes away. But it does still, even if you've never posted anything that you think you'd regret, get you a little anxious." (Female, 18. FG3, 010)*

FG participants acknowledged the potential for something seemingly harmless to swiftly turn controversial, drawing unwelcome attention and negativity. There was an awareness of the potential for SNSs to damage their image not only online but within their personal lives.

> *"People will screenshot a person's post if it's controversial– and then share it on different streaming apps… a lot of people will try to get them cancelled. I think the internet is a scary place because when things resurface, it can look bad on a person." (Female, 17, FG4, 012)*

One individual shared their experience of being trolled in the past after posting something emotional online: *"People will troll me and take me for granted, and then sometimes they insult me. I feel so bad this happens. It has changed me a lot because I think twice before I post things about myself because I might get trolled again, and I won't like that to happen"* (Male, 17; FG2, 005).

Being the target of trolling made this individual more aware of how they were perceived by others and highlights the potential repercussions of being an SN user as part of the networked public.

FG participants also exhibited greater mindfulness towards the possible ramifications of their online activities, specifically concerning their prospective career paths. Their worries exceeded their immediate peers and included their professional environment.

"I am a little anxious and conscious about what I'm going to post, what I have posted in the past, and who all can see it. For example, if I am applying for a job, your employer might look at your LinkedIn or even just background research on you. So, you have to be conscious about that." (Male, 19, FG3, 011).

There was a recognition amongst participants that one's online presence may be scrutinized by external individuals, highlighting that participants are aware of passive observers, though they might not always be considering researchers within this context. Regardless, participants are mindful of how lurker might interpret them on the internet, and this affects how they behave online.

Overall, these quotes from the FGs demonstrate how participants are conscious of the potential for their information to be used by lurkers on SNSs. The survey findings also indicate that adolescents recognize the potential repercussions from their digital footprint and demonstrate a capacity to recognize its implications.

4.2.2 Nurturing safer online communities

Two sub-themes emerged regarding adolescents' sentiments regarding the importance of understanding the scope of pro-NSSI content in hidden online communities: a) empathy as a driver for enhancing community health and b) habituation to online content.

Empathy as a driver for enhancing community health

Participants from the FGs exhibited a strong sense of empathy toward individuals dealing with NSSI and expressed an understanding of the motivations behind seeking support or validation.

> *"I have seen quite a few comments that have promoted self-harm and I feel sorry for the victims, it is very disturbing to see such comments." (Male, 16, FG2, 006)*

Participants were introduced to the concept of pro-NSSI communities as a foundational example and prompted to reflect on personal encounters with such content on SNSs.

> For instance, participants emphasized the regularity of encountering such content, expressing, "*I think it's almost every day that I come across something related to [NSSI] online (Male, 19, FG1, 004)."*

Participants also showcased their empathy towards others accessing pro-NSSI communities.

> *"I try to be more empathetic and to put myself in some other person's shoe and try to digest how the information is going. So, I think, for me, being at such point, I feel bad. I think I am also a victim of such circumstances. (Male, 17, FG2, 005)."*

In the survey, participants with a more detrimental digital footprint (Q11) and a history of involvement in hidden communities (Q12) exhibited a weak positive correlation in their confidence regarding researchers' abilities to convey their personal experiences (Q11 Kendall's tau_b = 0.183, p = 0.026, 95% CI [0.059, 0.301] & Q12 Kendall's tau_b = 0.202, p = 0.021, 95% CI [0.078, 0.319]). There was also a weak correlation among those with a history of involvement in hidden communities and trust toward researchers safeguarding privacy (Kendall's tau_b = 0.193, p = 0.027, 95% CI [0.070, 0.311]) (Appendix A, Figure A4).

An explanation for why participants with a history of a detrimental digital footprint or involvement in hidden communities felt more positively inclined towards researchers might explained by the FGs sessions. Participants showcased the capacity to empathize with individuals who actively sought out pro-NSSI communities, but also described them as more sensitive and less resilient. For instance, one participant discussed how hearing advice about NSSI from someone detached or unfamiliar is helpful to individuals who lack support from those close to them. They also discussed

how their frequent encounters with harmful online content would make them more empathetic towards others.

> *"[Accessing pro-NSSI groups] is kind of like a cry for help when you don't have support from home or like support from friends or support from your school maybe. Sometimes I feel like some people feel like it's better to engage with strangers who may encourage them to just keep going." (Female, 17, FG4, 012).*

In addition to these details, the quotes below reflect how participants from the FG demonstrated preventive or protective behaviours to shield themselves and others from such exposure, like blocking or reporting content, so that it would decrease in frequency. Participants also expressed a degree of habituation to the routine of either reporting or scrolling through harmful content. With repeated exposure, they characterized this habit of blocking and reporting as becoming almost instinctive.

> *"I always just remove the post, reporting spam. It's just, the algorithm doesn't work 100 percent of the time. I still use [social media], I'm just quicker to like report or scroll." (Male, 19, FG3, 011)*

> *"If it's not like that big of a deal, I'll just keep scrolling. But if it is something that was very harmful or I think could potentially be harmful to somebody else who may see it, I'd report the post to try to get it down." (Female, 19, FG3, 010)*

Overall, while all participants in the FG acknowledged the impact of NSSI, it is noteworthy that individuals experiencing such challenges and with a history of struggle showed greater receptiveness towards researchers. This receptiveness could be attributed to their empathetic stance and past encounters with similar harmful content, which was elaborated further during the FG sessions.

Habituation to harmful online content

Both in the survey and FG discussions, participants consistently displayed significant usage of social media, establishing it as an integral element of their networked public. For instance, SNSs were deeply ingrained in their daily lives, with 71.4% (n=80) indicating daily usage and 25.9% (n=29) reporting use multiple times a day (Figure 6).

Figure 6: Frequency of engagement with SN content
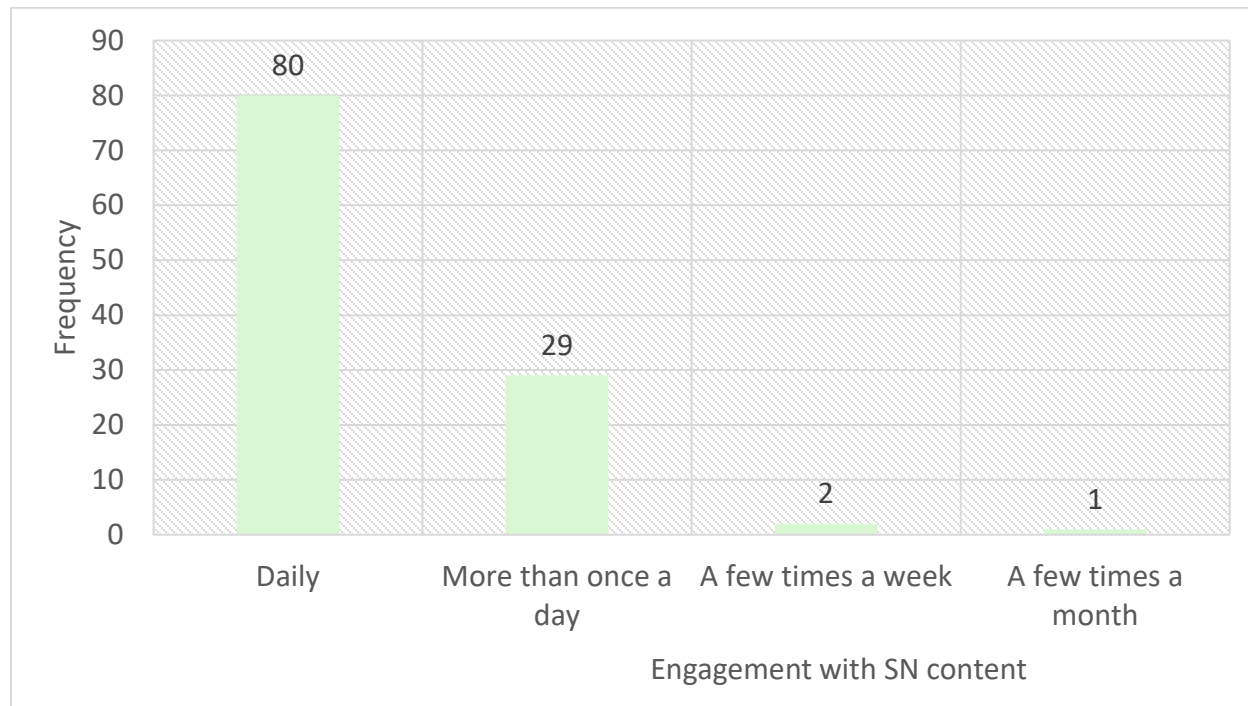
Participants from the FG sessions described how spending significant time online could diminish perceived risk due to exposure to a high volume of content. They drew a connection between repeated exposure to pro-NSSI content and a habituation process, suggesting a gradual reduction in the perceived level of risk over time. Notably, significant time spent online lead to a dwindling sense of risk due to the volume of content encountered.

> *"We're spending so long every day online, people don't really think twice about what they're doing. It doesn't seem like a big deal if you are seeing 100s or 1000s of posts a day, to comment on one of them, it's just people not really thinking about the consequences." (Female, 18, FG3, 010)*

When encountering harmful content that could potentially evoke negative feelings or encourage a negative self-image, participants demonstrated resilient determination to persist in their engagement with online platforms. However, they did so while implementing strategies to safeguard their well-being. Consequently, participants credited reasons for why other adolescents might access harmful hidden online communities to personal factors, such as a perceived lack of resilience or intentional ignorance. When adolescents described encounters with pro-NSSI posts on SNSs, they noted how some individuals find resonance and a sense of connection with such

risky content, whereas others may feel detached and choose to ignore the content entirely. This individual resilience was seen as a critical factor distinguishing those who internalized or ignored such harmful content, as illustrated by the quote below.

> *"People are different. Some are sensitive and other quite insensitive. When people come across such posts, others may feel like they can connect with the people who have posted them and others may feel like they do not, so they just ignore the blog." (Male, 18, FG2, 008)*

4.2.3 Information overload

Platform preferences among older adolescents shift over time as they are drawn to more attractive platforms with unique features. These platforms, in turn, often present a higher likelihood of encountering Non-Suicidal Self-Injury (NSSI) content. There were two sub-themes that emerged in this section: 1) Regulating pervasive pro-NSSI spaces online and 2) Information inundation.

Regulating pervasive pro-NSSI spaces online

Figure 7: Personal preferences for polymedia
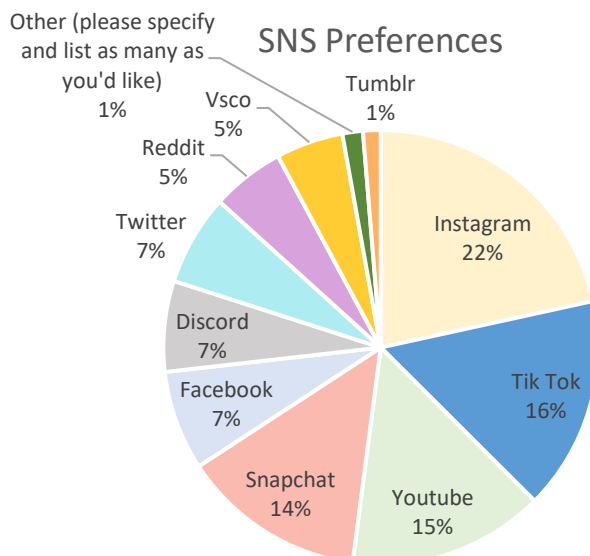
Between the survey and FG, there was overlap in the preferences for certain SNSs due to their affordances. TikTok emerged as the second most prevalent platform among survey participants (Figure 7), with FG discussions shedding light on its role as a space where individuals may come across pro-NSSI content. Participants frequently encountered unexpected pro-NSSI content on TikTok, a platform gaining popularity among adolescents. While contributing to the platform's widespread use, the algorithm also posed challenges to participants as it led to regular exposure to pro-NSSI content. Participants noted TikTok as a space where the predictability of content, a feature they found more prevalent on Instagram, was lacking. The familiarity with followed accounts on Instagram provided a greater sense of content control, as they primarily saw posts from friends and family. The differences in functional affordances between Instagram and TikTok were highlighted by participants, who expressed concerns about younger users potentially encountering posts through TikTok's *For You Page* feature. This disparity in affordances on TikTok was believed to expose them to unexpected content interactions, illustrating the nuanced impact of different polymedia on each participant's networked public.

> *"I think I am more likely to come across [pro-NSSI content] on TikTok because it is the platform I spend most of my time on and, compared to Instagram, you can't really control what you're seeing. I feel on Instagram, you know who you're following. And I personally don't really scroll through my feed, like through my explore page, so I can just see who I*

want to see and what I want to see, whereas TikTok you're just continually scrolling, and you don't know what you're coming across." (Female, 19, FG1, 001).

"TikTok is probably the biggest, most prevalent one, in my opinion, on most social media— especially eating disorder type, videos and posts and things like that. There is the algorithm that caters things to you. But I think that it's never perfect, and a lot of people see things that they weren't expecting, and that can be potentially harmful." (Female, 18, FG3, 010).

While acknowledging the existence of an algorithm that adapts material to user preferences, participants remarked that this algorithm could be better. They noticed that people frequently encounter content they were surprised to find out, which could have unfavourable outcomes.

Information inundation

Participants considered the ubiquity of pro-NSSI content on SNSs and even highlighted the transformative impact of the COVID-19 pandemic on individuals' regular posting behaviours. Notably, this increased online engagement was particularly pronounced in discussions about engaging with NSSI content or other sensitive topics online.

"I think I've seen a lot of, like different posts that I'm not expecting, like, in the middle of the day that are risky or harmful." (Female, 18, FG3, 010).

Due to the potential for information to spread far beyond one's initial intentions, participants emphasized the need for caution while sharing information online. Participants emphasized the need for people to reflect carefully before sharing content, understanding their potential reach and impact.

"I think people should be considerate and think deeply before dropping any information as they will know that this information will spread wide, even far beyond their imaginations. (Male, 17, FG2, 005)

In line with the idea of information overload, participants noted that the frequency of their encounters with pro-NSSI content was affecting their mental health. They discussed how the sheer volume of daily content contributed to such negative feelings and being inundated with information affected them personally despite not seeking such content.

For example, *"talking about [pro-NSSI content] on social media, I actually come across it so many times, especially on Facebook and Twitter, and those times, I feel depressed and bad, and I don't feel happy at all. It actually had gotten to a point where my friend had to discuss this with me." (Male, 18, FG2, 007)*

The notion that adolescents are overwhelmed by pro-NSSI content resonates with the survey findings discussed in Section 4.2.2, where participants with a history of engagement in hidden communities (Q12) showed a weak positive correlation in their confidence regarding researchers' ability to understand their personal experiences and trust in researchers safeguarding privacy (see Appendix A4). However, no statistically significant relationship was observed between their history of engagement and their level of comfort when being observed by researchers. This suggests that the inundation of pro-NSSI content they encounter online may influence their attitudes towards researchers, as adolescents recognize the necessity of such research to address this rapidly transforming environment.

4.2.4 Respecting ethical boundaries

Participants recognized the ethical challenges that researchers must navigate when dealing with passive, observational research. They emphasized respecting privacy and prioritizing safety when conducting research. Concerns were raised about negotiating consent, respective privacy, and the potential for bias and misinterpretation in studying online behaviour. Participants recognized the value of research in understanding and addressing the challenges of online behaviour, building safer online communities, and preventing harm. Subthemes included: 1) Trust is dependent on intent and 2) Value of research.

Trust is dependent on intention

Participants in the FGs viewed research as a safeguard amidst a dynamic landscape where the precision of algorithms targeting youth posed a shared concern. One participant described how

important passive observers, such as researchers, are to improving the quality of interactions within the networked public. They viewed such oversight as important in protecting adolescents by reducing contact with pro-NSSI content through research and regulation.

> *"It may be a good thing because they can see how we interact online, what we find engaging, what we disengage in when we are on social media. And they may help prevent us from interacting with things that may be harmful to us, and they can find ways to improve our feed so that we are not looking at things that may be negative and may impact our mental health." (Female, FG4, 17, 012)*

Having been personally affected by pro-NSSI content and having experienced trolling in the past due to posting unconventional content online, another FG participant emphasized the usefulness of passive observation in fostering a networked public where adolescents feel free to express their feelings. They asserted that researching pro-NSSI groups online could help establish supportive communities, creating an online landscape that is more compassionate and understanding overall.

> This participant expressed enthusiasm about the potential outcome, envisioning increased comfort in sharing emotions on social media and the possibility of receiving help if needed, stating: "*I feel that this great because I will be very comfortable to share my emotions with people because that's what social media is for. If this research holds, I believe that most people like me will be able to share our emotions and actually get help from other people if necessary." (Male, 17, FG2, 005)*

As presented in Figure 9, survey participants were asked whether they approved of researchers conducting research into pro-NSSI communities through passive observation. Approximately 49.6% (n=56) of participants agreed, stating that it was acceptable for researchers to study their SNS behaviors (see Figure 9 and Appendix, Table A2). However, despite many FG participants expressing that it was okay for researchers to conduct netnographic research, survey results also revealed another sentiment. Approximately half of the respondents (49.1%, n=54) expressed discomfort towards researchers when questioned about their comfort with this practice, while only 26.3% (n=29) indicated comfort with it, and 24.5% (n=27) expressed indifference when asked this question (refer to Figure 8). Therefore, although the majority of participants were accepting of

passive observation (49.6%), it did not necessarily mean that most adolescents were comfortable with it.

Figure 8: Overall comfort towards SNS observation
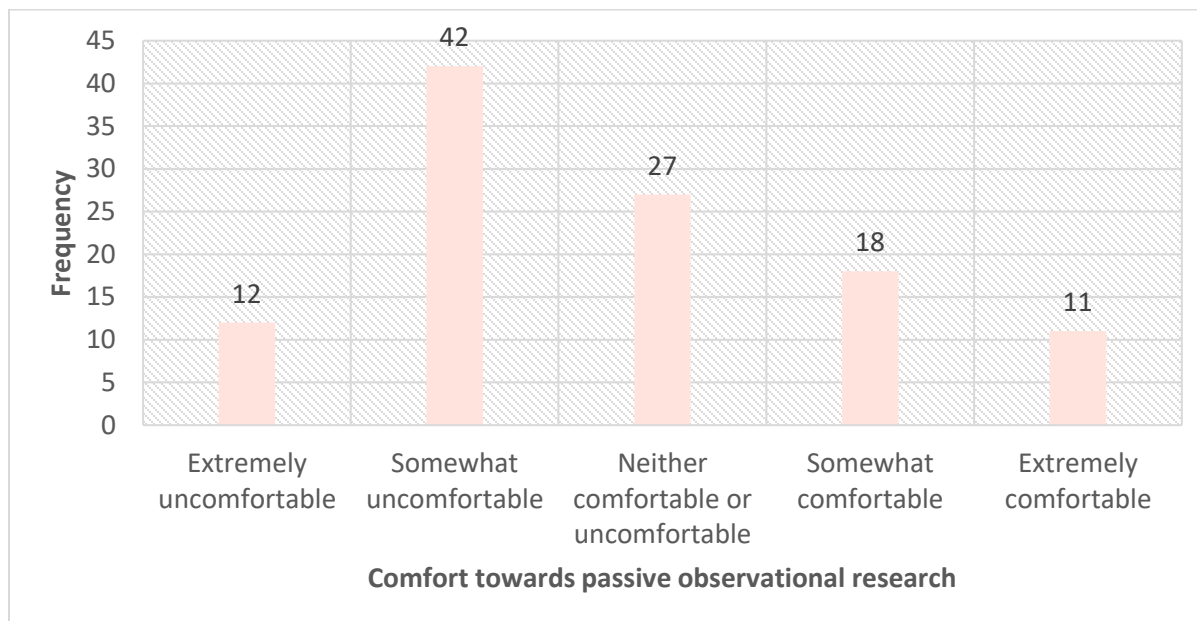
Figure 9: Distribution of responses when assessing dimensions of attitudes towards data collection
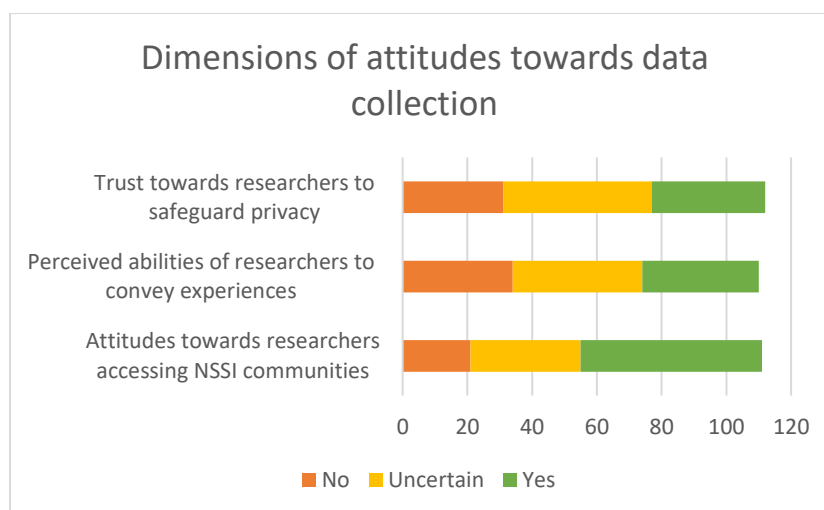
Participants in the FG acknowledged that sharing data online, in any form, implied making information public. Hence, adolescents' trust in passive observers depended on the motivations of these observers. In discussions, participants explored the difference between scientists conducting research with altruistic intentions and those within R & D roles. They were conscious of researchers aiming to advance scientific understanding. Some participants felt more at ease after understanding that researchers operate with the intent to advance the scientific field.

> *"My first reaction to your question before you expanded on it and tried to explain what you mean by researchers was first, I don't like anyone overseeing what I'm doing online... But since you have clearly defined the researchers are people that will engage the people who try to maybe self-harm, I think yes, that gives them a value and I can pretty much accept it. (Male, 19, FG1, 004)*

> *"I feel like researchers are trying to do their work in the name of science, right, but some people are motivated by financial gain and– I think if it's that kind of situation where someone – like they're trying to look at trends to help their sales or something—I'd rather not have them have access to that." I feel if it is researchers looking at my stuff, I don't really care because like they're trying to help (Male, 16, FG4, 013).*

Participants were more wary of people with self-regarding or materialistic goals. If the goal is rooted in monetary gain or to gain personal advantage, they expressed reluctance to allow access to their online presence, especially if the analysis were aimed at discovering trends for profit-related endeavours.

Balancing privacy concerns

Participants from the FGs frequently highlighted the importance of respecting privacy, obtaining consent, and prioritizing safety when conducting research. For instance, they discussed the need for researchers to obtain proper consent, given the nature of the study.

> *"I wouldn't say it's that ethical because obviously consent is very important. And you can't really get their consent even if they want to be unseen." (Male, 19, FG3, 011).*

Participants also displayed an awareness of the risks of sharing content online, and discussed how the act of posting online is an autonomous decision, and there is a reasonable expectation that the post might be observed by an unintended recipient.

> "*It is something that you posted for the whole world to see. So, there is no problem with people studying it since you posted it online. You should know the risks of posting.*" (*Female, 19, FG1, 001*)

Despite highlighting the potential benefits of passive observational research, most participants also expressed some reservations. They felt it was intrusive for someone to scrutinize their online activities; though, they stressed that the researchers' good intentions may outweigh this possible interference with privacy. Essentially, they recognized the paradox of the situation by expressing concerns about the degree of scrutiny applied to such research while simultaneously acknowledging the potential advantages of improved online experiences.

> "*It is more of the fact that someone is analyzing the way that you are on social media. I feel like it may seem invasive but there is a good intention for it possibly.*" (Female, 17, FG4, 012)

> "*I think it can be effective at ultimately building safer online communities and prevent such incidents. I think it is ethical in moderation.*" (Male, 16, FG2, 006).

Overall, the balance between researcher intent and unease towards facing repercussions was what affected participant attitudes towards the passive, hidden researcher.

The correlational analysis conducted on the survey findings unveiled a potential relationship between gender and various dimensions of attitudes (refer to Appendix, Table A4). It was observed that male respondents in the survey were more confident in researchers safeguarding their privacy (Q2 - Q16). Namely, a statistically significant weak negative association was identified, with a correlation coefficient of -0.200 (p-value = 0.029). These findings underscore the potential influence gender on individual perceptions of researchers' abilities and trust in privacy safeguards, emphasizing the importance of considering gender-specific nuances in interpreting these aspects within the research context.

Another significant and fair correlation was found between perceived abilities to convey experiences and trust towards researchers to safeguard privacy (Kendall's Tau_b = 0.363, p < 0.001), as well as between comfort with researchers and trust in their ability to safeguard privacy (Kendall's Tau_b = 0.341, p < 0.001). These correlations show that participants are more likely to trust researchers to protect their privacy if they have greater faith in their ability to understand their experiences and feel more at ease around them. This implies that when participants consider researchers' involvement in monitoring pro-NSSI communities, they may balance their privacy concerns against their opinions of the researchers' qualifications and reliability. This was also articulated in the FG sessions, where participants discussed the challenges, researchers face in obtaining consent for such research, while also emphasizing its importance in building safer online communities.

4.2.5 Youth's considerations for research

Participants questioned researchers' ability to capture the adolescent experience, particularly when the researchers themselves are not part of the community. Participants believed there is potential for bias and a lack of comprehension from researchers with limited first-hand experience with NSSI. Two sub-themes were explored in this section: 1) Potential for bias or misinterpretations and 2) Valuing anonymity and confidentiality.

Potential for bias or misinterpretation

Participants were asked whether they believed researchers can accurately convey the experiences of adolescents accessing online communities (Section 4.2.4, Figure 9). When looking at the response distribution: a. 31.9% of respondents (n=36) answered "Yes," and 30.1% of respondents (n=34) answered "No," suggesting that they did not believe researchers can accurately convey the experiences of adolescents in online communities, c. 35.4% of respondents (n=40) answered

"Uncertain," implying that they were unsure or had mixed beliefs about researchers' ability to convey adolescents' experiences in online communities accurately, and d. 2.7% of respondents (n=3) preferred not to answer the question.

These survey findings displaying participant uncertainty can be explained by the FG sessions, where participants in the FG expressed skepticism about researchers' ability to understand if they are not part of the community or are closer in age to the participants. Participants felt that researchers might need more knowledge or a deeper comprehension of such groups since they were not a part of the communities they were studying. Older adolescents feared the researcher's perception would be biased and their actions misconstrued.

> *"You are only a small portion of yourself online. So, if they are studying people, that can't be done through only online observation… It's never going to be perfect if they don't fully understand. I do think that they can do justice with just interpreting trends and things like that. I don't think they're ever going to really get it in a way of like a 12-year-old who's posting online, understanding why they're doing the things that they're doing." (Female, 18, FG3, 0010).*

Participants emphasized the different viewpoints between younger and older generations in this statement. They argued that adolescents may be misunderstood by adults who did not have the same upbringing because they were raised in a different socio-cultural landscape. To improve the accuracy of researchers understanding, they emphasized the value of having researchers from similar circumstances.

> *"I feel it depends because the way that younger people think is very different from adults. They didn't grow up with the same stuff as us so I feel like they may misinterpret us. So, if you were going to be doing research on a certain age group, you would need to be maybe closer to that age group in order for them to be able to understand you a little better" (Male, 16, FG4, 013).*

> *"I would be a little bit skeptical if they aren't a part of that community. Just engaging with people your age or similar to age. I feel like sometimes it may be a bit weird if they're older*

people. I think that analyzing younger people online– just something doesn't settle with me when I hear that." (Female, 17, FG4, 012).

Participants were also concerned about the temporal nature of social media, as participants acknowledged how the evolving online landscape shapes user behaviors and how older adolescents might present themselves online. They noted that social media posts, sometimes dating back months before, might not correctly reflect current attitudes, emphasizing how temporality could affect the credibility of findings.   They emphasized the difficulty in authentically portraying such behaviours, and the time commitment necessary for a thorough comprehension. Analyzing articles, photos, and broad behavioural trends demands significant time and effort. In essence, these concerns revolved around the challenge of maintaining the integrity and credibility of online research in the face of rapidly changing networked public. There was a belief that results should be interpreted with the awareness that they may reflect a past situation over a current moment.

"The time taken to analyze someone's post, their overall pattern of behaviour to get an accurate representation, I think that may take quite a time. At the end when researchers publish their results, it may represent something in the past, and maybe not a current accurate representation of someone. It depends on someone's pattern of behaviour– so if they took their time to research said post or said person for quite a while, it may accurately represent. But if they just saw one post and it took them like six months to publish then I don't think it will accurately represent." (Male, 19, FG1, 004)

Despite the high levels of uncertainty noted in Figure 9, moderate positive correlations were found between general attitudes towards researcher access and perceived abilities to convey experiences (Kendall's tau_b = 0.248, p-value = 0.004). Similarly, as mentioned in Section 4.2.1, participants with a history of involvement in hidden communities exhibited a weak positive correlation in their confidence regarding researchers' abilities to convey their personal experiences (Kendall's tau_b = 0.268, p = 0.001, 95% CI [0.148, 0.380]). It is noteworthy to observe the more positive inclinations demonstrated by those more deeply affected by such research.

These findings also indicate that confidence in researchers' capabilities might be linked to other factors like gender (Appendix A, Table A4).   Additionally, when examining gender-related

perceptions, statistically significant correlations were identified in two dimensions. Regarding the perceived abilities of researchers to convey experiences, a weak but notable shift in perceptions was observed between male and female participants (Kendall's Tau= -0.290, p= 0.002). This statistically significant relationship suggests that male participants demonstrated greater confidence in researchers' abilities to convey their experiences online, thereby providing additional evidence of gender-specific nuances in the findings (see Appendix A, Table A4).

Valuing anonymity and confidentiality

Respondents displayed high awareness and consideration towards their digital footprint, signifying mindfulness regarding their online persona (Section 4.2.1, Figure 5). In line with their apprehension about how others perceive them, participants were willing to share information without reservations, as long as their identity remained hidden. The primary source of participants' anxiety revolved around how they were perceived externally, indicating that if researchers maintained their anonymity throughout this process, adolescents would be more comfortable with being studied online.

An open-ended question probing participants about their preferences for anonymity led to the creation of a flowchart (Figure 10). This visual representation illustrates the underlying principles that drive adolescents to create anonymous accounts to persist in engaging with harmful online content.

Figure 10: The value in privacy, curiosity, and freedom associated with posting to hidden online communities
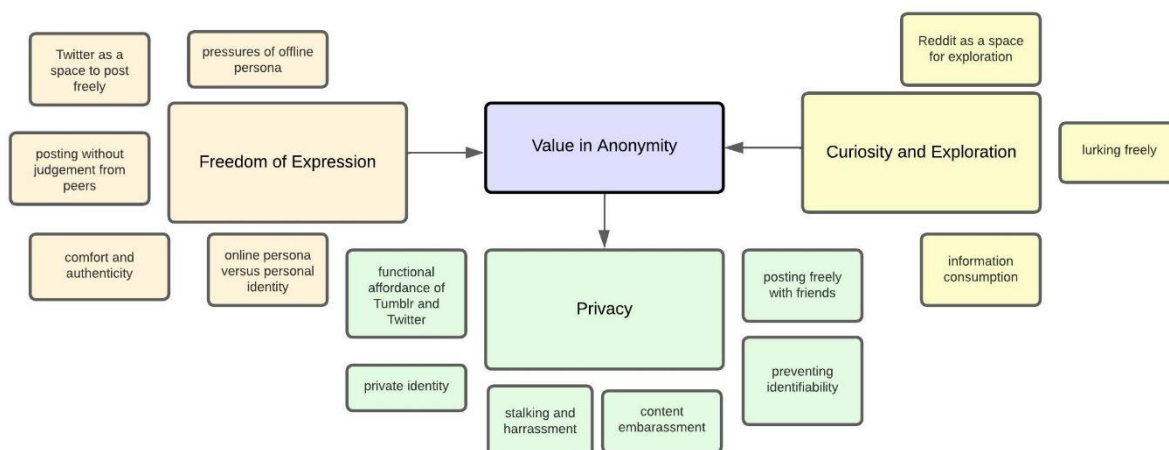
Participants in the survey acknowledged the potential harm or offensiveness of the content they engaged with or uploaded (Figure 10). Participants often opted to share content privately with friends and family using anonymous or private accounts. This strategy allowed them to exert control over information transmission and maintain distinct online personas. Anonymization also provided them with a shield against unwanted attention and safety concerns, particularly regarding possible harassment. Another prominent idea among participants, 'Curiosity and Exploration,' highlighted that anonymity fosters a sense of worldly curiosity among participants. They felt more liberated to explore beyond their immediate social networks when interacting with content without disclosing their identity, underscoring the importance of respecting their space for free and uninhibited exploration. 'Freedom of Expression' emerged as another crucial subject, with participants expressing that when the fear of criticism is alleviated, they can be more genuine and comfortable in their online interactions.

Preferences for anonymity were also highlighted in the FG sessions, where participants provided ways in which researchers can continue this research ethically and mainly cited that any identifiable information should not be made available during publishing. One member viewed online behaviour and privacy as always in opposition when utilizing the internet. They stated that people should be aware that their online behaviour is fundamentally public and that others may view their material and behaviours. Therefore, most participants highlighted the value in protecting privacy by advising researchers to only involve subjects with public accounts in their studies. They

suggested that even when using publicly accessible accounts, researchers should retain anonymity by not revealing the usernames of the study participants. They asserted that upholding these standards would allow researchers to ethically leverage such data in their investigations.

> *"I think one of the most ethical things to consider would be, if somebody's account is private, don't use them in the research and only use people whose accounts are public and then don't, like even still don't name their usernames. Keep everything confidential, with whom exactly you're studying. If things are kept completely anonymous, and no individual is being named, their privacy is protected." (Female, 18, FG3, 010)*

Summary of Findings

This study contributes to the ongoing discourse in the scientific community by providing a unique perspective on how passive observers can uphold ethical conduct throughout their research process. These findings address the question of older adolescents' attitudes towards researchers collecting personal information through SNSs to support health promotion research. These findings reveal statistically significant correlations between participants' attitudes towards researchers and the inductively derived themes from the FGs, enhancing the triangulation of data. The main findings revolve around specific themes, including the permanence of social media, nurturing safer online communities, dealing with information overload, respecting ethical boundaries, and considering collective adolescent insights.

Chapter 5

5 Discussion

  5.1 Summary

The aim of this study is to add to the ongoing discourse in the scientific community, by providing a unique perspective on how passive researchers can uphold ethical conduct throughout their research process. This research addressed the following research question: What are the attitudes of older adolescents towards researchers collecting personal information through social media to

support health promotion research? The objectives of the project included: 1) describing the current research practices for collecting data on older adolescents engaged in online communities, 2) exploring the attitudes of older adolescents towards research practices used to drive health promotion research on NSSI and 3) determining how the older adolescent perspective on research practices can inform health promotion research.

This discussion strengthens the cohesive findings obtained from both the FG sessions and survey data, elucidating their relevance and contributions to the existing literature. The themes included: A. The permanence of online information, B. Nurturing safer online communities, and C. Information overload, D. Respecting ethical boundaries, and E. Youth's considerations for research.

The first three themes highlight the need for research to match the spread of information through polymedia. Older adolescents are intensely aware of the importance of studying pro-Non Suicidal Self-Injury (NSSI) communities and exhibit a natural tendency to think critically about their online identities. Adolescents' consciousness of their digital footprint signifies their awareness of the repercussions associated with making personal information accessible to the public. The last two themes contextualize the nuanced responses from participants in response to researchers passively studying pro-NSSI communities. They provide examples as to how researchers can confront the paradox of protecting adolescents in pro-NSSI communities whilst maintaining their ethical integrity and respecting their boundaries.

5.2 Significant Findings

Adolescents in this study shed light on how online activities influence their decision-making processes, particularly regarding their engagement with potentially harmful online content. They are cautious about the threat of resurfacing posts, affecting their overall attitudes toward researchers accessing personal data for research into pro-NSSI communities. The three most significant findings reveal that adolescents demonstrate heightened vigilance towards safeguarding their public image, emphasize the importance of fostering empathetic online communities, and care primarily about researchers' intent when handling their social networking (SN) data.

5.2.1 Adolescents' vigilance towards safeguarding of their public image

Social Networking Sites (SNSs) play a heavy role in participants' daily lives, making them members of a networked public, as observed in Figure 6 where most participants reported using social media daily or multiple times a day. Participants also displayed an awareness of their public image and digital footprint, as mentioned in Section 4.2.1, aligning with a previous study by Karabatak and Karabatak (2020), which reviewed qualitative and quantitative literature exploring Gen Z individuals' digital footprint awareness. Their findings revealed an increased consciousness of the consequences linked to digital presence. Although their study had a broader demographic inclusion criterion than the current one, they noted that participants exhibited greater awareness of how their digital footprints could shape their futures. Likewise, participants demonstrated maturity in discussions about their public image by contemplating the potential consequences of posting harmful content online. This highlights their capacity for critical thinking, by Schmeichel and colleagues' (2018) assertion that researchers should view adolescents as decision-makers with the capacity for self-reflection.

Participants in the current study actively curate their online presence and are conscientious of how they are perceived by their passive audience, particularly their peers. This finding is consistent with the literature, as indicated in a 2018 article by Adorjan & Ricciardelli which delves into the behaviours of adolescents online. Their article highlights that the widespread concern towards adolescent's online activities is frequently exaggerated, and youth can discern the harmfulness of the content they engage with. The current study reinforces such findings, as participants articulated their critical perspective and heightened awareness of the risks within the social landscape. Participants even discussed the necessity of cultivating resilience to counter the negative feelings stemming from regular exposure to harmful NSSI content on social media in their experience of growing up in a digitally interconnected world. The vigilance expressed by participants towards regulating their public image resonates with insights from the cognitive neuroscience literature on adolescent development, as articulated by Somerville and colleagues (2013). Their work suggests that the medial prefrontal cortex, a brain region responsible for processing emotional and social cues, exhibits higher activation in older adolescents when they believe others perceive them. This heightened vigilance can extend into the online realm as discussed in Chapter 4, Figure 8, where

most participants from the survey expressed discomfort or uncertainty towards the passive researcher. The FG discussions provided additional explanations of how this discomfort likely stemmed from the fear of negatively perceived by others. These adolescents displayed an awareness that by partaking in the "network public" they were at risk for being perceived negatively by others (Lewis & Seko, 2016). These findings underscore participants' acute awareness of passive observers, prompting them to safeguard their privacy and prevent directly linking embarrassing content to their identity.

Participants mainly stressed the importance of researchers taking precautions to prevent their subjects from becoming identifiable through publication. They highlighted the vigilant safeguarding of their public identity by anonymizing problematic accounts to escape potential consequences and judgment. Participants recognized that managing online identity is a complex process, influenced by various factors such as privacy, curiosity, freedom of expression, and selective sharing, which are noted in Section 4.2.5 (Figure 10). The intricate relationship that older adolescents maintain with their online presence and their contemplation of future implications influence their attitudes toward researchers accessing their personal information. This phenomenon, commonly called the "privacy paradox," occurs when SN users exhibit discrepancies between their intentions and actions regarding their expectations of privacy (Adorjan & Ricciardelli, 2018). This is manifested by disclosing personal information online, even when the users aim to maintain a public presence while safeguarding certain aspects of their lives from public scrutiny (Hibbin et al., 2018; Marwick & boyd, 2014).

Participants' unease with the enduring presence of their online information is linked to situations where they anticipate potential consequences. Participants deliberated on the potential repercussions of posting questionable content to SNSs such as facing cancellation or being trolled (Section 4.2.1). There are also recorded instances where older adolescents have faced repercussions like being ignored and blocked as consequences for their online posts (Yar & Bromwich, 2019). A correlation is observed between the increasing prevalence of this phenomenon and participants expressing fear of potential alienation or ostracism due to their online activities. While participants are open to sharing certain content with their peers online, they proactively implement measures to hide it, aiming to mitigate the risks of stalking, harassment, or potential embarrassment. Participants expressed concerns about how others would

perceive them and took measures to protect themselves from external scrutiny (Section 4.2.2). They feared the potential for identification and the ensuing repercussions, which added to their unease. At its core, it reflects participants' vigilant safeguarding of their public image in relation to their "need for social approval and acceptance" (Adorjan & Ricciardelli, 2018, p. 37). Participants realize that their content can wield a lasting impact and are attuned to the risks of harmful posts. This two-fold perspective underscores the complex lens through which participants grapple with the enduring nature of their online content with the potential drawbacks of posting something that will not be forgotten.

The variability in levels of information sharing implies that there is no universal perspective, as adolescents approach online content with differing degrees of caution and consideration. If the researcher respects the boundaries of their private lives and the carefully curated personas they present publicly, participants remain relatively open to researchers accessing their personal data (Section 4.2.4 & Section 4.2.5). However, despite the efforts made towards anonymization, introducing artificial intelligence tools poses new challenges to participants' safety (Nassar & Kamal, 2021). Concerns arise regarding the possibility of being identified through published studies or study results despite attempts to anonymize data. Many of the worries participants shared are valid, echoing concerns highlighted in a 2021 article by Nassar and Kamal. A key worry for participants centred around the potential violation of their privacy and confidentiality. While expressing openness to such research and underscoring the significance of safeguarding their privacy, Nassar and Kamal (2021) cautioned that risks of cyber threats and data breaches persist, even with publicly available data and large datasets. This concern is echoed in a separate 2021 article from the UK by Thompson and colleagues (2021), who delved into the issues surrounding privacy leaks related to the publication of SN content obtained through online ethnographic research. It underscores the need for researchers to ensure that individual profiles remain detached from personal identifiers to prevent harm or embarrassment to participants in case of a breach.

5.2.2 Adolescents' emphasis on fostering empathetic online communities

Participants demonstrate a heightened sense of empathy towards individuals grappling with NSSI and actively attempt to curtail the harmful content available online. Their efforts are evident in their proactive approaches to blocking and reporting harmful content, which, in turn,

influences the platform algorithms and helps create safer online spaces (Section 4.2.2). This inadvertent collective movement to improve community health highlights why participants recognize such research as important in promoting the well-being and safety of online communities. Furthermore, despite the apparent risk or inability to avoid this content, these encounters with harmful posts do not prevent app usage. This is consistent with the shifting landscape, where older adolescents' personal lives are a part of the networked public, and polymedia makes it hard for them to escape the use of SNSs (boyd, 2010). Empathy and compassion are powerful driving forces compelling participants to curtail their exposure by reporting and shielding others from interacting with harmful content. Participants are keenly aware of their exposure to harmful online content and take proactive steps to protect their safety while interacting with this information. These activities strongly connect to risk resiliency, defined in the existing literature as a person's ability to recover skillfully from experiences with difficulties and adversity (Daniel et al., 2020). This notion of risk resiliency is multifaceted, requiring individuals to confront challenges and triumph over them. Participants felt that spending substantial time online could diminish the perceived risk of posting and interacting with harmful online content, making them more resilient (Section 4.2.3).

Participants also discussed how information inundation increased individual exposure to harmful content. This understanding is pivotal for developing an 'adolescent-centric' approach to health promotion, acknowledging older adolescents' autonomy and capacity to influence observational research practices (Schmeichel et al., 2018). The participants strongly emphasized personal responsibility when posting on SNSs. The responses and decision-making pathways undertaken by the adolescents in this study underscore a significant interplay with their self-perceived identities in the context of external observations. They stress that anything uploaded online becomes part of the public domain, accessible to anyone with internet access. Increased interactions with the internet in this digital age has heightened their awareness of being observed by external parties. This aligns with boyd (2010), who highlights how older adolescents manage their complex social landscape as they grow up alongside it.

Overall, many participants recognize each platform's functional and relational affordances and participants' apprehension towards researchers studying their online content is closely linked to

their awareness of the ubiquity of NSSI content and becoming habituated to encounters with harmful content online. They recognize that the availability of such content may lead them to engage in online activities without fully recognizing the repercussions. In line with their view of the problematic nature of engaging with this content, participants highlight the importance of establishing comprehensive guidelines to conduct effective health promotion research on platforms like Instagram and TikTok, where they believed a concentrated youth demographic is prevalent and there is high risk of exposure in these locations (Section 4.2.3). TikTok has faced criticism in the literature for its inadequate content moderation and privacy safeguards. Logrieco and colleagues (2021) emphasize these concerns, shedding light on TikTok's addictive nature by captivating people with engaging short clips operating within an algorithmic feedback loop. The study reveals that once adolescents encounter such content, they are more likely to be repeatedly exposed to similar content, posing risks when the content promotes NSSI (Logrieco et al., 2021).

Participants understand the rapidly changing nature of the internet and the inevitable need for passive observational SNS research. This awareness significantly shapes their attitudes toward researchers accessing their personal information online for research purposes. They believe such research is crucial to comprehending contemporary concerns and behaviours. The participants emphasized the research's value in offering a broad perspective on the influence of SNSs on people's lives. They recognized the significance of researchers studying pro-NSSI communities, considering it an avenue to foster a safer online community (Section 4.2.4). Participants view passive observational research as an opportunity to gather invaluable insights into sensitivity and potential remedies. The participants acknowledge the research's role in building secure online communities, averting incidents, and mitigating exposure to pro-NSSI content online.

5.2.3 Adolescents' care towards researchers' intent

Attitudes towards researchers are nuanced; many participants were hesitant towards researchers observing their internet behaviours and worried about privacy invasion and potential exploitation of their personal information for monetary or other gain. However, most participants also saw value in research and appreciated the efforts to understand and help individuals in pro-NSSI communities. They acknowledged that research could contribute to minimizing pressure in online communities and providing recommendations for improving such spaces (Chapter 4,

Section 4.2.3). Mainly, adolescents acknowledged that university researchers were motivated by a commitment to enhance health and well-being, framed as being "in the name of science," leading them to perceive these research practices as more acceptable. This observation is consistent with earlier research, specifically in the study by Monks (2015), which unearthed a parallel theme where younger adolescents 13 and 14 years of age stated that research is more acceptable when conducted for a "good cause" like improving community guidelines to protect older adolescents from harm. This underscores a shared belief among adolescents that research is acceptable when the intent is pure (Golder, 2017).

Essentially, the researcher's intent when using SN data affects participants' overall trust towards them (Section 4.2.4). For instance, when questioned about the boundaries of trust, comfort, and ease with researchers accessing lurking online, participants demonstrated diverse opinions regarding their feelings, as displayed in Appendix A, Tables A3 and A4. In Appendix A, Table A4, the fair correlations among various dimensions of attitudes suggest that positive attitudes were associated with higher confidence in researchers' capabilities and increased comfort with researchers studying personal content. However, the lack of strong significant correlations across attitudes toward researchers accessing sensitive online communities underscores existing uncertainties and emphasizes the need for further trust-building between the community of adolescent participants and researchers. While participants possess a degree of self-awareness regarding their digital behaviours, they may need timely reminders to reflect on the potential implications and ethical considerations associated with their online activities. Trust in researchers' portrayal of experiences is linked to trust in their ability to protect privacy, indicating a connection between participant comfort with researchers studying posts and trust in privacy protection. Thus, fostering a community built on transparency and ongoing dialogue between researchers and participants becomes imperative in addressing these concerns and cultivating a relationship built on mutual trust and ethical conduct.

The ambiguity around the researchers' intents and prospective goals brought similar hesitation and uncertainty during the FGs. participants elaborated on this uncertainty highlighting how attitudes and considerations regarding the intersection of research, online communities, and privacy concerns. When asked about their belief in researchers to accurately portray their experiences, participants, although leaning towards uncertainty, did convey some belief that

researchers could accurately represent their experiences. Participants expressed concerns about invading privacy and the need for respect and consent, and despite not having read the TCPS-2 guidelines, they highlighted many of the factors that often might be compromised or considered grey areas in this line of work, including respect for persons, concern for welfare, and justice (Government of Canada et al., 2018). Participants highlighted the importance of researchers considering their privacy, consent and building trust. The participants also acknowledged that people should consider safety first and be aware of the risks of posting online. In the literature, researchers have discussed how the concept of public good outweighs individual privacy concerns, indicating a belief that serving the broader social good holds more significance (Golder et al., 2016). This was further asserted by participants in this study, who regarded research as uncomfortable but also essential for comprehending and addressing the complexities of online behaviour. This highlights the importance of intent in fostering trust and influencing participants' willingness to grant researchers access to their online presence. These findings highlight the complex relationships that exist between digital behaviours and attitudes toward researchers. They also highlight the need for more study to fully understand these relationships and to inform future studies passively conducted in hidden online groups.

5.2.4 Summary of Significant Findings

Adolescents are vigilant about their public image and consider the permanence of their digital footprints. Their empathy towards people who suffer from NSSI motivates them to proactively limit offensive material and foster safer online spaces. Participants exhibit diverse attitudes toward researchers, expressing concerns about privacy invasions while also highlighting the importance of passive observational researchers' dedication to improving the health and wellbeing of their research subjects. This study also establishes that building trust and promoting open communication are essential for effectively navigating the challenges of observational research in online settings. The findings underscore adolescents' complex landscape as part of the networked public and the measures researchers should take to ensure they do no harm to their participants.

5.3 Study Implications

Given the versatility of the networked public through polymedia, it is vital that researchers also consider the affordances of individual platforms and their attractiveness to youth, as the SN landscape is constantly changing (boyd, 2010). I addressed Objective 1 by summarizing and

highlighting the wide range of methods available to study hidden NSSI communities through the descriptive search. This underscores the importance of considering a future scoping review or systematic meta-analysis to thoroughly explore the approaches to accessing such communities. Such an exploration can promote a deeper understanding of these methods and their associated ethical considerations, paving the way for more ethical research practices in the future.

Participants pointed out issues stemming from using artificially intelligent tools to analyze their behaviours, which are also noted in the literature, including algorithmic bias, lack of transparency, privacy worries, consent and autonomy, and security and trust (Nassar & Kamal, 2021). Participants had reservations about the researchers' ability to precisely capture the nuances of polymedia. Skepticism emerged among participants regarding researchers' capacity to fully grasp their perspectives and experiences, mainly if the researchers are separate from the same online community or are further in age to the participants. This skepticism was rooted in concerns about potential bias and limited understanding stemming from the researchers' lack of firsthand involvement (Section 4.2.5). Participants emphasized the need for accurate trend interpretation and cautioned against adopting paternalistic approaches in research practices, such as framing young individuals as autonomous stakeholders rather than portraying them as vulnerable individuals needing rescue. Participants voiced doubt about the ability of researchers to truly understand their opinions and experiences, mainly when researchers themselves are outside the online community. They contended that researchers outside the online community might need help comprehending the studied individuals' perspectives due to their lack of firsthand experience. Participants suggested that observation through a lurker could only partially capture the nuances of online behaviour, bias could seep into research practices, and trust-building necessitates accurate and ethical trend interpretation. They highlighted how this demographic mismatch could skew the results of the study. These worries are in line with the literature, as a systematic review by Golder and colleagues (2017) revealed that SN users expressed concerns about the validity of research due to inadequacies in the scientific approach, authenticity, and quality of data.

As described in section 4.2.5, participants were concerned with the temporal nature of SNS, acknowledging how SN posts, sometimes dating back months before, might not correctly reflect current attitudes. One participant suggested integrating long-term behaviour analysis to

comprehensively understand pro-NSSI data, enabling accurate trend analysis and bias prevention. Incorporating the study of temporal data is a feasible solution to this concern, as it accounts for the dynamic nature of SN data. Addressing this concern involves incorporating temporal analyses, such as time series analysis, a statistical method identifying patterns and trends related to pro-NSSI communities. Passive observational researchers use temporal data to track shifts in posting frequency, engagement metrics, and preferences among adolescents, facilitating the identification of anomalies in individual posting habits. Additionally, they may employ predictive models to forecast future trends (Griep & MacKinnon, 2022).

Ultimately, research focusing on online behaviour assumes significance as it aids in comprehending the intricacies of individuals and communities. Researchers must modify their approaches to reflect the interests and life experiences of the young people they are studying, not relying on artificially intelligent tools solely in their interpretations. Therefore, despite using these tools, which can be both qualitative and quantitatively driven, researchers should consider incorporating reflexivity when representing participants.

5.4 Research implications for current study within larger program of research

Participants noted that by sharing content through SNSs, they were likely consenting to the risks and potential consequences of disclosing personal information online. This viewpoint aligns with Moreno and colleagues (2013), who discussed the reasonable expectation that information posted on SNSs are available for use by others. Consequently, researchers may not be required to undergo a rigorous ethics review if the material is considered public. Still, researchers are expected to exercise due diligence, and current discussions on consent affirm that researchers should use such data per TCPS-2 guidelines (Government of Canada et al., 2018).

In the larger study titled "*A Community of Practice Approach to Understanding Non-Suicidal Self Injury,*" (PI: Gerald McKinley) the researchers highlighted that despite there being a theoretically straightforward answer, there were also complications such as securing consent or guaranteeing anonymity. This study, which was later translated to a publication highlighted challenges in securing consent, even with applying ethical protocols such as Townsend's and Wallace's (2018) guidelines for SNS ethics (Guccini & McKinley, 2018). Researchers faced

difficulty in member checking due to the sensitive nature of the content, an issue participants acknowledged. Their vigilance in managing resurfacing posts was closely tied to a fear of facing repercussions, with an awareness that being perceived by researcher could exacerbate the harms of NSSI.

The researchers noted how Tumblr's privacy policy states that whatever is published online is deemed public unless stated otherwise (Tumblr, 2021; Guccini & McKinley, 2022). The researchers adopted the perspective that users, mindful of the public nature of blog posts, inherently signal an intent to share content publicly. Researchers from the larger study mainly emphasized Tumblr users' meticulous deidentification practices, meaning that researchers did not have ready access to personal information due to measures participants would take prior to posting online. However, it is also apparent from these study results that most adolescents do not engage with Tumblr and instead operate using more easily identifiable public profiles on TikTok, Instagram, and Twitter, which are heavily tied to their identities. Hence, there is a distinct advantage to diversifying our focus to include other platforms and establishing independent research standards for them, as they are the primary hubs of these communities. The findings from this study underscore significance of meticulously assessing the distinctive affordances of each platform, as these characteristics play an essential role in determining the extent to which information may become publicly accessible, especially in terms of individual identifiability within research outcomes It is crucial to acknowledge and differentiate the unique affordances of each platform. Therefore, these concerns hold significance given the complex ethical terrain of data collection.

5.5 Reflexivity

As a budding researcher, my status and preoccupations influence my paradigmatic identity. Having navigated diverse social circumstances about identity and image online, I related to my population of interest, particularly older adolescents. I view social media as a safe space through which I often advocate for different ideas and regularly as a platform to speak on social justice and change (Benjamin & Hoang, 2020). Therefore, when undertaking a virtual research study, my history, values, and cultural experiences position me within a historical realist framework, potentially influencing how I approach the research process (Benjamin & Hoang, 2020). Upon careful reflection, I acknowledge my inherent bias as a researcher involved in a team conducting

research within the online realm. There is profound value in employing observational research methods to gain insights into the experiences of marginalized and frequently neglected groups, exemplified by adolescents facing vulnerabilities like non-suicidal self-injury (NSSI). Therefore, during each discussion, I took a series of steps to safeguard against my internal dialogue influence and maintain a balanced perspective within the study. These measures included having a separate moderator, facilitator, and an undergraduate student to assist in the FG discussion. A notable challenge often encountered during FG discussions involves inadvertent researcher responses that could skew the study outcomes. Therefore, I also adhered to a semi-structured interview guide, developed in collaboration with my supervisor, to ensure that the discussions remained focused and aligned with the research objectives.

When following a pragmatic approach, throughout the research process, particularly the FG sessions, I realized that my paradigmatic views primarily fell under a *constructivist* paradigm, as the data collection and ensuing interpretation of the results grew as a co-construction. Participants felt comfortable speaking about their experiences, mainly because of my age and how I presented myself. Participants perceived me as an individual who, like them, routinely encounters such hidden online communities in my daily interactions. My presence appeared less authoritative and 'paternalistic' and was easily integrated into the dialogue, fostering heightened openness during discussions. Also, by incorporating reflexivity, I enhanced the integrity of the study by providing insight into the dynamic between myself, as the researcher, and the participants, encouraging a more transparent and nuanced analysis.

The rich and deep data challenged me to let go of preconceived structures to be receptive to new connections and themes. To enhance the robustness of my analysis, I considered how my findings from my bottom-up approach aligned with the existing literature. For example, as I delved into the theme of adolescents' consideration of intent as a key factor shaping their attitudes, I discovered its resonance with existing research, a connection I thoroughly explored in Chapter 5 when consolidating my findings (Monks, 2015). I also considered the role writing also played in the analysis of my data, as it allowed me to process my themes to create a coherent narrative. Getting feedback from my thesis committee and supervisor helped to ensure a

balanced analysis, which encouraged the study's general robustness by encouraging the evaluation of data inconsistencies.

5.6 Summary of Discussion

This thesis adds to the literature by highlighting the need for further investigation into potential ethical research methodologies and revising the ethical approach guide. The descriptive review of the literature and research practices guiding Objective 1 suggests that a detailed scoping review or meta-analysis of methodologies could facilitate the identification of ethical practices adopted by researchers. Though an attempt to understand all practices was made, the search could have been more comprehensive, and a better understanding of the various methods would have made it easier for researchers to establish guidelines for reporting results as more information is made available through innovative methods. The growing concern around privacy and the potential long-term ramifications of digital interactions highlights a need for researchers to be more aware of their data collection practices and how they can shape personal and professional trajectories.

Adolescents show compassion for those struggling with NSSI, acknowledging the significance of observational research practices for health promotion. However, concerns were raised about privacy invasion, potential bias, and misinterpretation in the study of online behaviour. Participants were deeply concerned about potential ostracism resulting from their posts. They reflected their apprehension about how others, from those in their inner circle or the external community, might perceive them based on their online presence. However, they also recognized the value of research in addressing online behaviour challenges, fostering safer online communities, and preventing harm.

When addressing Objective 2, it was apparent that participants all displayed diverse levels of trust in the researchers' capacity to safeguard their privacy. This mirrors a spectrum of privacy concerns and confidence levels in researchers, while the majority remains uncertain about researchers accurately portraying the experiences of adolescents in online communities. Though adolescents are aware that their content is being viewed externally, they sometimes experience

discomfort and distrust towards researchers viewing their personal information, despite it being for an intended altruistic reason.

With Objective 3, the participants highlighted the significance of protecting privacy by employing careful measures to guarantee anonymity and highlight the public aspect of online conduct. After consulting the literature, to guarantee that participants are not unintentionally harmed by their publications, researchers must establish a framework to prevent traceability. This might involve consulting with experts and understanding their tools, so they do not inadvertently harm their participants. The participants' perspectives underscore the intricate interplay between methodological adaptation, ethical considerations, trust-building, and the evolving online landscape in shaping research practices and understanding online behaviour. These insights resonate with the notion that researchers must align their approach with the evolving platform preferences of adolescents in response to the dynamic social media landscape. This diversity underscores the subjectivity and complexity of documenting and presenting adolescent online experiences.

The significance of this study, future directions, and a study conclusion are described in the next chapter.

Chapter 6

6 Conclusion
6.1 Strengths and Limitations

This study was born out of a significant contextual development within Social Networking Sites (SNS) research and polymedia. Given the increase in the use of artificially intelligent tools to support research into pro-Non Suicidal Self-Injury (NSSI) communities, this topic is deeply relevant, timely, and significant (Tracy, 2010). Participants were probed further whenever additional clarification was needed during the interview. Also, to ensure this process was coherent and executed appropriately, multiple members were involved, including an undergraduate student to take notes and a Ph.D. candidate to ensure the consideration of the

safety and well-being of participants throughout the study. Throughout the analyses, various team members actively participated in the thematic development process to evaluate the robustness and appropriateness.

Another study strength was the diversity in participant distribution between male and female participants, notably more males in the FG and a higher number of females in the survey. A central concern in research is the observed feminization of participants, leading to disproportionately more female than male participants (Schmeichel et al., 2018). This discrepancy may have given male participants more opportunities to express their ideas and perspectives during the FGs. The divergent composition of respondents on each side highlighted the benefits of incorporating triangulation into the research methodology, allowing participants with diverse backgrounds to have their voices heard.

A few limitations regarding the survey might have generated mistakes in the findings. Out of the initial 122 responses received from the survey, 113 (91.9%) respondents remained engaged throughout. The loss of data occurred as some participants exited the survey prematurely. Another limitation is sample representation, where while many participants acknowledged regularly encountering pro-NSSI material, none actively sought out such content. This lack of proactive engagement might have resulted in the loss of crucial information about NSSI. Since the participants were not directly involved in these behaviours, even though all participants from the FGs indicated previous exposure to such content, individuals who actively engage in NSSI might hold different opinions. In future research, it would be beneficial to seek out the perspectives of those engaging in NSSI to gain a more comprehensive understanding.

With survey research, there is a risk of respondents not being a part of the intended population. However, regarding this study, it is known which channels this survey was distributed through; therefore, there is a reasonable belief that the intended recipients responded. There is a potential response bias, as most participants were Western University students contacted by a mass recruitment email encouraging them to participate in the study. Given that this community is primarily made up of young students who might have a greater level of literacy and education than the overall population of older adolescents, it is crucial to consider this when interpreting

the survey questions. As Andrade (2020) stresses, it is important to note that researchers must use caution when assessing studies conducted with participants who are interested enough in the subject to warrant devoting time and effort to crafting a response. Respondents were asked questions about their Social Networking (SN) habits, including their posting habits, considerations about privacy, and SNS preferences, to see if responses align with what is expected from older adolescents in this age range in the literature.

The potential for response bias by participants influencing each other in FGs is a potential shortcoming of this research. Participants frequently responded in a manner that conveyed an understanding of the other participant's reaction, which might have required less thought. The discussion sometimes veered off course since the moderator had to be objective in their comments and avoid deviating from the topic. Under these circumstances, participants were redirected or prompted to revisit the question.

6.2 Future Directions

Given the growing prevalence of natural language processing and artificially intelligent methods to understand pro-NSSI communities, a future directive should consider the development and implementation of more robust ethical frameworks. This includes acknowledging that while researchers often approach their work with integrity and good intentions, the absence of clear ethical guidelines with SNS research may impede researchers' ability to uphold the highest ethical standards. This study's discussion of older adolescents' awareness of the evolving SN landscape revealed different nuances about the older adolescent perspective. Participants in this study displayed an awareness of the harmfulness of pro-NSSI communities and proposed ways in which researchers could improve the accuracy of their findings, like implementing temporal analyses and member-checking. Therefore, to increase trust and address the priorities of older adolescents, researchers should continuously seek their feedback throughout the research process and identify ways to incorporate participatory voices.

Additionally, future directions should also include a systematic review of all the current research practices to access pro-NSSI communities and explore ways to ensure there is sufficient anonymization and protection of participant identities and sensitive information. By

incorporating privacy conserving methods into the research design, researchers can minimize harm while extracting important insights. Furthermore, cultivating conversation with important stakeholders like SNS researchers, ethicists, mental health professionals, and pro-NSSI community members can help with refining research protocols to ensure that comprehensive measures are put in place to protect participant safety. By integrating multiple perspectives, and prioritizing the adolescent point of view, from within these communities, researchers can advance knowledge of NSSI while safeguarding the wellbeing of individuals from within the community.

It would also be advantageous to carry out this study among different cohorts. For instance, future research endeavours could also potentially delve into the experiences of individuals engaging in NSSI individually. This study focused on the everyday experiences of older adolescents. Thus, there is a chance for deeper investigation into the distinctive sentiments of individuals who engage in NSSI. Another potential cohort could be youth between the ages of 12 and 15 who differ from the older adolescent population in terms of development but also regularly engage with pro-NSSI content (Esposito et al., 2023). A comparative analysis can be used to discover developmental differences, environmental influences, and fluid changes in how kids understand the study of their digital identities if another survey of the same capacity and with identical questions is conducted among the younger population. Additionally, researchers should explore the integration of participatory action-based youth community advisory boards when developing techniques for studying hidden pro-NSSI communities. Feedback from youth engaged in these communities could offer valuable insights and solutions to ethical complexities.

As we deliberate about the ethics of using sensitive data on youth, we must also consider the changing SN landscape. Despite Tumblr being a location where research on NSSI is normally conducted, most respondents described coming across harmful NSSI content through other platforms, mainly through TikTok, which is more versatile and contains more personal details, putting them at a greater risk for identification, including their face, and voice likeness. Therefore, researchers should look more closely into SN sites that adolescents are actively using. It is essential to broaden the scope of the investigation to include additional platforms that could be less popular among older adolescents because prior studies have primarily concentrated on

sites like Tumblr, Instagram, YouTube, and Facebook. Each platform provides unique affordances that influence how people connect and share content. Researchers may paint a more nuanced picture of young people's online experiences and behaviours by investigating these understudied sites at the forefront. TikTok is a platform that warrants extra attention as it is trendy among older adolescents. Researchers should actively investigate how young people use TikTok and other emerging SNSs. By ignoring these platforms in their investigation, researchers would be missing out on a plethora of relevant data as these newer platforms have extraordinary potential for health promotion research. By engaging in more profound and targeted dialogues with adolescents about their experiences using these platforms to thoroughly understand their viewpoints, researchers can learn more about the intricacies of content consumption and possible areas for health promotion interventions. Additionally, researchers should consider improving their personal polymedia literacy to enhance their familiarity with diverse research methodologies and the ethical dilemmas they might impose. By promoting personal education and broadening their horizons, researchers can enhance their ability to use context effectively in decision-making and interpretation across diverse polymedia platforms.

6.3 Conclusion

As the social media landscape evolves, it is essential to recognize the dynamic nature of online identities and the challenges associated with content exposure, privacy expectations, and thoughtful posting habits. This study explored adolescents' online behaviours, driven by privacy awareness and personal identity, influence their attitudes towards researchers accessing their online data, underlining the importance of researchers respecting individual online personas and considering diverse posting preferences and contextual factors. Acutely aware of the lasting impact of their online presence and potential consequences, participants exhibited cautious attitudes towards researchers accessing their personal information, emphasizing the need for respecting online boundaries. Additionally, participants displayed empathy and compassion by actively contributing to safer online communities and supporting researchers' access to personal online content to improve community well-being. Participants' top concerns were privacy and confidentiality, and they pushed for measures to stop identifiability in research data. They

recommended involving young people from vulnerable communities to offer more genuine insights. The study highlights varied attitudes among participants regarding researchers studying their online behaviour, emphasizing the role of transparent communication and the value of research in addressing the complexities of online behaviour in today's digital landscape. Researchers should adapt their methodologies to align with adolescent preferences, recognizing the dynamic nature of social media, safeguarding privacy, and incorporating participatory perspectives from older adolescents in the studied communities.

The older adolescent perspective highlights the careful balance researchers must strike between gathering valuable insights from SN platforms and respecting the privacy and anonymity of the studied individuals. When conducting ethically sound research, participants place significant trust in researchers, attributing positive motives that contribute to the greater good. Nevertheless, this underscores the paramount responsibility of researchers to honour this trust and uphold their work to the highest standards of ethical conduct. The TCPS-2 guideline state that researchers have the right to academic freedom, which includes the freedom to discuss ideas without limitation, undertake research to challenge established norms and distribute knowledge generated from studies. Researchers should leverage technological advancements responsibly in the context of the evolving social landscape to foster knowledge expansion and draw conclusions that would benefit society. With this freedom comes the obligation to conduct research ethically and responsibly, particularly when it comes to safeguarding more vulnerable groups that are more susceptible to suicide or NSSI. Ultimately, our research underscores that while adolescents may experience discomfort about being studied online, they recognize its importance. Their ability to comprehend the benefits of such research underscores the trust they place in researchers. Therefore, it is on us, as researchers, to diligently uphold our responsibilities in conducting ethical and impactful research.

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Appendices

Appendix A: Additional Data Tables

Table A1: Participant details from FGs

Participant Number	FG Session	Age	Gender
1	1	Female	19
2	1	Male	17
3	1	Male	18
4	1	Male	19
5	2	Male	17
6	2	Male	16
7	2	Male	18
8	2	Male	18
9	2	Male	18
10	3	Female	18
11	3	Male	19
12	4	Female	17
13	4	Male	16

Table A2: Responses to Digital Footprint Awareness, Hidden Communities, and Researcher

Question	Dimension	N	Mode	Mode Frequency n (%)	Minimum	Maximum
Q11. Have you ever posted something online, that you believe would affect your future if it were discovered?	Existing digital footprint	113	1 Definitely not	34 30.1%	1 Definitely not	5 Definitely have
Q12. Have you ever posted content online in a hidden online community?	Participation within hidden communities	111	1 No	68 60.2%	1 No	3 Yes
Q13 Do you think it is okay for researchers to access these online communities?	Attitudes towards researchers accessing NSSI communities	110	3 Yes	56 49.6%	1 No	3 Yes
Q14: Do you think researchers can accurately convey the experiences of adolescents accessing these online communities?	Perceived abilities of researchers to convey experiences	110	2 Uncertain	40 35.4%	1 No	3 Yes
Q15. How comfortable are you with researchers studying your posts?	Comfort towards researchers	110	2 Somewhat uncomfortable	42 37.2%	1 Extremely uncomfortable	5 Extremely comfortable
Q16: Do you trust researchers to protect your privacy?	Trust towards researchers to safeguard privacy	112	2 Uncertain	46 40.7%	1 No	3 Yes

Table A3: Ranked Correlation Analysis: Kendall's tau_b between Responses to Digital Footprint Awareness, Hidden Communities, and Researcher Access

		Q11 Have you ever posted something online, that you believe would affect your future if it were discovered?	Q12 Have you ever posted content online in a hidden online community?	Q13 Do you think it is okay for researchers to access these online communities?	Q14 Do you think researchers can accurately convey the experiences of adolescents accessing these online communities?	Q15 How comfortable are you with researchers studying your posts?
Q12 Have you ever posted content online in a hidden online community?	Correlation Coefficient	.268**				
	Sig. (2-tailed)	.001				
	N	111				
Q13 Do you think it is okay for researchers to access these online communities?	Correlation Coefficient	.010	.018			
	Sig. (2-tailed)	.901	.836			
	N	111	110			
Q14 Do you think researchers can accurately convey the experiences of adolescents accessing these online communities?	Correlation Coefficient	.183*	.202*	.248**		
	Sig. (2-tailed)	.026	.021	.004		
	N	110	109	110		
Q15 How comfortable are you with researchers studying your posts?	Correlation Coefficient	-.071	-.023	.324**	.141	
	Sig. (2-tailed)	.366	.788	<.001	.089	
	N	110	108	109	108	
Q16 Do you trust researchers to protect your privacy?	Correlation Coefficient	.036	.193*	.372**	.363**	.341**
	Sig. (2-tailed)	.657	.027	<.001	<.001	<.001
	N	112	110	111	110	110

Table A4: Statistically Significant Ranked Correlation Analysis: Kendall's tau_b between Responses to Digital Footprint Awareness, Hidden Communities, and Researcher Access

	Correlation Coefficient	Significance (2-tailed)	n	95% CI
Q1 Age and Q16 Trust towards researchers to safeguard privacy	-0.190	0.036	98	-0.315, -0.059
Q2 Gender and Q14 Perceived abilities of researchers to convey experiences	-0.290	0.002	105	-0.403, -0.168
Q2 Gender and Q16 Trust towards researchers to safeguard privacy	-0.200	0.029	107	-0.319, -0.075
Q11 Existing digital footprints and Q12 Participation within hidden communities	0.268	0.01	111	0.148, 0.380
Q11 Existing digital footprints and Q14 Perceived abilities of researchers to convey experiences	0.183	0.026	110	0.059, 0.301
Q12 Participation within hidden communities and Q14 Perceived abilities of researchers to convey experiences	0.202	0.021	109	0.078, 0.319
Q12 Participation within hidden communities and Q16 Trust towards researchers to safeguard privacy	0.193	0.027	110	0.070, 0.311
Q13 Attitudes towards researchers accessing pro-NSSI communities and Q14 Perceived abilities of researchers to convey experiences	0.248	0.004	110	0.127, 0.362
Q13 Attitudes towards researchers accessing pro-NSSI communities and Q15 Comfort towards researchers	0.324*	<0.001	109	0.206, 0.432
Q13 Attitudes towards researchers accessing pro-NSSI communities and Q16 Trust towards researchers to safeguard privacy	0.372*	<0.001	109	0.259, 0.474
Q14 Perceived abilities of researchers to convey experiences and Q16 Trust towards researchers to safeguard privacy	0.363*	<0.001	110	0.249, 0.467
Q15 Comfort towards researchers and Q16 Trust towards researchers to safeguard privacy	0.341*	<0.001	110	0.225, 0.447

Appendix B: Western University Non-Medical Research Ethics Board NMREB Approval on January 26, 2023

Western Research

Date: 26 January 2023

To: Dr. Shannon Sibbald

Project ID: 121308

Study Title: Understanding the awareness and perspectives of older adolescents towards targeted online data collection practices

Short Title: Awareness and perspectives of older adolescents towards online data collection practices

Application Type: NMREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 03/Feb/2023

Date Approval Issued: 26/Jan/2023 09:49

REB Approval Expiry Date: 26/Jan/2024

_____

Dear Dr. Shannon Sibbald

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Focus Group Interview Guide	Focus Group(s) Guide	27/Oct/2022	1
Qualitative and Quantitative Survey	Online Survey	07/Dec/2022	2
List of Mental Health Support Services	Debriefing document	07/Dec/2022	1
Verbal debriefing script	Debriefing document	07/Dec/2022	2
Understanding the ethics of social media research v3 poster	Recruitment Materials	21/Dec/2022	3
Mass Recruitment Email_v2	Recruitment Materials	11/Jan/2023	2
Scheduling and response for focus group_V2	Recruitment Materials	11/Jan/2023	2
Focus group consent form	Written Consent/Assent	11/Jan/2023	3
Consent form Survey	Implied Consent/Assent	11/Jan/2023	3
Parental LOI focus groups	Implied Consent/Assent	11/Jan/2023	3
Email to Youth Groups	Recruitment Materials	25/Jan/2023	2

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
Volunteer hours document	Other Document	11/Jan/2023	2

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Ms. Katelyn Harris , Research Ethics Officer on behalf of Dr. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix C: Question Guide

Appendix C1: Survey Questions

Q1 Are you 16 to 19?

○ Yes (how old) (4) _____

○ No (5)

Q2 Please indicate your gender?

○ Male

○ Female

○ Non-binary / third gender

○ Prefer not to say

○ Option not listed _____

Q3 When did you start using social media?

○ Just this month

○ In the past year

○ Around 1 to 2 years ago

○ Around 3 to 5 years ago

○ More than 5 years ago

○ Prefer not to answer

Q4 Indicate how often you use social media.

○ Daily

○ More than once a day

○ A few time a week

○ A few times a month

○ A few times a year

○ Never

○ Prefer not to answer

Q5 Which social media communication platform do you engage with the most (select any/all that apply)?

☐ Instagram

☐ Youtube

☐ Facebook

☐ Discord

☐ Twitter

☐ Tumblr

☐ Tik Tok

☐ Snapchat

☐ Vsco

☐ Reddit

☐ Other (list as many as you'd like)

☐ Prefer not to answer

Q6 Do you have an anonymous account within any of the above social media platforms?

○ Yes (please explain why) _____

○ No

○ Prefer not to answer

Q7 Have you ever posted content online about a problem you were having in any of the following reasons?

	Yes	No	Uncertain	Prefer not to answer
School (1)	○	○	○	○
Family or Friends (2)	○	○	○	○
Money (3)	○	○	○	○
Body Image (4)	○	○	○	○
Romantic relationships (5)	○	○	○	○
Sexuality (6)	○	○	○	○
Bullying (7)	○	○	○	○
Local or world news (8)	○	○	○	○
Personal illness (9)	○	○	○	○

Q8 How did you feel after you posted online?

○ Much worse

○ Somewhat worse

○ About the same

○ Somewhat better

○ Much better

○ Prefer not to answer

Q9 Thinking about your answer to #7, where do you typically post?

☐ Instagram (1)

☐ Youtube (2)

☐ Facebook (3)

☐ Discord (4)

☐ Twitter (5)

☐ Tumblr (6)

☐ Tik Tok (7)

☐ Snapchat (8)

☐ Vsco (9)

☐ Reddit (12)

☐ Other (Please specify and list as many as you'd like) (10)
_____

☐ Prefer not to answer (11)

Page Break

Q10 How long do you think before you post?

○ Less than a minute

○ 1 to 10 minutes

○ 10 to 30 minutes

○ A couple of hours

○ More than 1 day

○ It depends on which social media platform

○ Prefer not to answer

Q11 Have you ever posted something online, that you believe would affect your future if it were discovered?

○ Definitely not

○ Probably not

○ Might or might not

○ Probably yes

○ Definitely yes

○ Prefer not to answer

Q12 A hidden online community is where people can meet to discuss topics, they may not feel comfortable sharing with their friends or families in real life. Have you ever posted content online in a hidden online community?

○ Yes

○ No

○ Uncertain

○ Prefer not to answer

Q13 A researcher is someone whose job it is to study a topic, to learn new facts or gain a deeper understanding of the subject.

Hidden communities can be viewed by researchers through hashtags and artificial intelligence (AI). Researchers are not marketers trying to sell products – instead, they are often trying to learn from and support the community.

Do you think it is okay for researchers to access these online communities?

○ Yes

○ No

○ Uncertain

○ Prefer not to answer

Q14 Do you think researchers can accurately convey the experiences of adolescents accessing these online communities?

○ Yes

○ No

○ Uncertain

○ Prefer not to answer

Q15 How comfortable are you with researchers studying your posts?

○ Extremely uncomfortable

○ Somewhat uncomfortable

○ Neither comfortable or uncomfortable

○ Somewhat comfortable

○ Extremely comfortable

○ Prefer not to answer

Q16 Do you trust researchers to protect your privacy?

○ Yes

○ No

○ Uncertain

○ Prefer not to answer

Q17 How likely are you to ask for assistance from each of the following people on a typical day if you were experiencing a personal issue? (with 1 being extremely unlikely and 5 being extremely likely).

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	Prefer not to answer (6)
Friend (1)	○	○	○	○	○	○
Parent (2)	○	○	○	○	○	○
Sibling (16)	○	○	○	○	○	○
Another family member (specify which) (3)	○	○	○	○	○	○
Intimate Partner (e.g. girlfriend, boyfriend etc) (4)	○	○	○	○	○	○
GP / family doctor (5)	○	○	○	○	○	○
Mental health professional (e.g. psychologist, social worker, counsellor) (6)	○	○	○	○	○	○
Teacher / school counsellor (7)	○	○	○	○	○	○

Religious leader (e.g. imam, priest, rabbi) (8)	○	○	○	○	○	○
Phone helpline (e.g. Kids Help Phone) (9)	○	○	○	○	○	○
Online counselling service (10)	○	○	○	○	○	○
A person I know that has had their own experiences of emotional/mental health difficulties (11)	○	○	○	○	○	○
Blogger/Influencer (15)	○	○	○	○	○	○
i would not ask for help from anyone (17)	○	○	○	○	○	○

Q18 If you wanted more information about a personal or emotional problem would you look online for help?

○ Yes

○ No

○ Uncertain

○ Prefer not to answer

Q19 if you answered Yes, where on the internet or social media would you find more information?

☐ Health website

☐ Mental health app

☐ Internet search

☐ Social media Blogger/ Influencer

☐ Forums / discussion boards

☐ Websites that you already use for other kinds of content (eg. Popsugar)

☐ Other _____

☐ Prefer not to answer

Q20 What aspect of this online source mentioned in the question before, did you find helpful, or unhelpful?

_____

Q21 How certain are you that you can find the assistance you need on the internet or social media?

○ 1 (not certain at all)

○ 2

○ 3

○ 4

○ 5 (very certain)

○ Prefer not to answer

Q22 We are conducting a focus group with adolescents in your age range on social media behaviours and interactions with risky online content. If you are interested, click here to provide your email in a seperate link from this survey.

◯ No, I am not interested

Appendix C2: FG Interview Guide

Welcome to our session. My name is Ahrrabie Thirunavukkarasu and assisting me is (RA student). I am a graduate student, and (name of undergraduate research student) is an undergraduate student from Western University. Thanks for taking the time to join us to discuss your perspectives towards researchers studying adolescent behaviours to advance the field of health promotion. Today we are going to discuss your perspectives on online research specifically around adolescent social media usage. We want your perspectives on how information is posted, used, and collected from online social media platforms. We are having this conversation with several different groups of teens; we are also doing surveys and other research on this topic.

You were invited to this study, because your opinions will help inform researchers on how to conduct ethical data collection. You can receive up to five volunteer hours for partaking in this study and completing the survey. You will also receive a $10 gift card upon completion of this study.

2. Provide an overview of consent forms
3. Key Points/Ground Rules

Before we start, I would like to go over some Ground Rules:

1. We want you, as the participants, to do all the talking, and we are hoping that all of you will be able to participate.
2. There are no incorrect answers. It is expected that there will be agreements and disagreements.
3. As a researcher, I may have to report on instances of self-harm. Please keep this in mind during our conversation. This is a safe space; please feel free to remove yourself if you need to during the discussion. (Breakout room, leave the room and RA will be there).

4. The focus group will be audio recorded in person/ during the zoom meeting. We are not video recording. Though we are using our first names in this conversation, a pseudonym will be used to identify each participant in the study results. Your personal information will be confidential.

D. FG Interview Question Guide

1. Icebreaker: How about we go around the table/on the zoom call, and you tell us what your favourite or most used social media platform is and why you are drawn to it.

For the next few questions, think about one or two apps, and let us know which app you are thinking about, when answering these questions. I would like for you to keep in mind this social media app that you now have in your mind.

2. How often do you post, and what do you think about before, or as, you are posting? What do you consider when posting online?

   a. Does the amount of time you think about what you are posting change based on the content, context, or topic of your post?
   b. How do you feel, or what do you think about, after you post?
   c. When you are posting personal information online, who do you think is viewing your content?
   d. "Nothing ever gets lost or forgotten on the internet" How does this statement make you feel?

Risky online content (like self-harm and violent content) and hidden online communities are frequent on social media.

3. What risky, self-harm or violent content have you been exposed to?

   a. What has your experience been with these sorts of anonymous social media pages? Do you know of any hidden online communities in particular? Have you ever interacted with these hidden online communities? For example, responding to a post.
   b. Is your experience with risk, self-harm, or violent content the same across all apps?

    c.   Has your experience with risky content changed the way you interact with apps or social media broadly?

    d.   How does it make you feel when you come across risky self-harm or violent content online?

    e.   Do you think it is problematic to engage with these sorts of anonymous and risky pages?

Probe: Do you think those around you engage with this content? Why might you ignore the risks of interacting with risky online content?

There are researchers online, like me, who are interested in studying online communities. Researchers are different from marketers as their goal is to learn and advance health in different populations through scientific investigation. To conduct research, researchers must undergo years of training and follow strict rules protecting participants in a study. Research is not for personal gain, but to make contributions to improve people's health. On the other hand, marketers tend to be interested in financial gain and encouraging people to interact with their products.

4. How do you feel about researchers going online to explore your social media use– around this topic of risky, self-harm or violent and often anonymous, behaviour?

a. Do you feel that researchers can understand your personal experiences, by studying your online behaviours?
b. How do you feel about researchers observing hidden communities when they themselves may not be a part of that community? Probe- (eg: trust, sceptic, confusion)

5. How would you want to be involved in the research? What would it look like? 6. Is there anything you would like to add? I really want to thank you for taking time to chat with me today - I appreciate some of these ideas may be difficult to think and talk about.

F. Wrap Up: TURN OFF THE RECORDER NOW.

    1.   Check-in: "That concludes our FG. Great job, thank you so much! How are you doing?"
    2.   Debriefing: Is there anything they would like to raise or discuss?

3. Insights into the FG:

    1. How did it go?

    2. Was it what you were expecting?

    3. Did anything unanticipated emerge for you? Was this a valuable exercise?

    4. We will thank them again for taking part.

Appendix D: Consent Forms

Appendix D1: Survey Consent Form

SURVEY LETTER OF INFORMATION AND CONSENT

Project Title: Understanding the awareness and perspectives of older adolescents towards targeted online data collection practices

Principal Investigator
Dr. Shannon Sibbald, PhD Associate Professor, School of Health Studies (Faculty of Health Sciences), Family Medicine and the Schulich Interfaculty Program in Public Health 1151 Richmond St, London, ON Canada N6A 3K7

Coinvestigator
Dr. Gerald McKinley, PhD Western Centre for Public Health and Family Medicine 1151 Richmond St, London, ON Canada N6A 3K7

Graduate Student Researcher
Ahrrabie Thirunavukkarasu, MSc Candidate Health and Rehabilitation Science Program at Western University

Conflict of Interest
No conflicts of interest identified

Introduction
You are being invited to participate in a research study on the perspectives of older adolescents towards researchers collecting their personal online information to advance the field of health promotion. We are hoping you will inform us on how we can consider the independent teenage perspective when conducting online research. This letter has been designed to provide you with the information necessary to make an informed decision about whether to participate in an online survey. If you have any questions, please do not hesitate to contact our research team.

Background/Purpose
There is a lack of regulatory oversight for online research, which is becoming more dependent on powerful algorithms to access vulnerable communities online that teenagers frequent. We are interested in understanding how aware adolescents are of the usage of their personal information to understand certain online behaviours. We are hoping to further the conversation on ethical data collection practises by researchers through asking questions about social media use, general trust in researchers, and mental health information seeking behaviours. In this study, we will be answering the following question: What are the attitudes of older adolescents towards researchers collecting personal information through social

media to support health promotion research? We are looking for volunteers who can consent to this study and participate in an online questionnaire about your attitudes towards researchers and behaviours on social media, which will be approximately 20 minutes.

 Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on you.

Confidentiality
 All data collected will remain confidential and accessible only to the study research team and will be stored on Western University servers. Your age and gender will be used to ensure you fit the study criteria and during analysis of the results. The information collected will be used for research purposes only, and no information which could identify you will be used in any publication or presentation of the study results. Information from the results will be shared through aggregated data, de-identified descriptors, and direct quotes. Any identifiable factors will be removed during sharing of results. No identifiable information will be retained for longer than 7 years. Our questionnaires will be collected anonymously through a third party, secure online survey platform called Qualtrics. Qualtrics uses encryption technology and restricted access authorizations to protect the privacy and security of all data collected and retained, including personal information. Western's Qualtrics server is in Ireland, where privacy standards are maintained under the European Union's General Data Protection Regulation, which is consistent with Canada's privacy legislation. Please refer to Qualtrics' Privacy Policy. The privacy statement for Qualtrics can be found (https://www.qualtrics.com/privacystatement/) At the end of the survey participants will be asked if they want to participate in the focus group and you will have the opportunity to provide your email address through a link that is independent to the survey. Please note the focus group is optional and will be audio recorded. While all personal information will be handled with the utmost privacy and care as outlined, one cannot guarantee that there will never be a privacy breach. If you decide to withdraw from the study, you may do so at any time by [e.g., exiting the survey window]. Due to the anonymous nature of your data, once your survey responses have been submitted, the researchers will be unable to withdraw your data. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research. Participants do not waive their legal rights by agreeing to participate in this study.

Benefits
You may not directly benefit from participating in this study, but information gathered may provide benefits to society which include informing future health promotion practices and encouraging more stringent regulations on the harmful online communities that youth frequent that encourage risky behaviours. It will also contribute to the way ethics is negotiated and obtained within online communities and on social media.

Risks
 There is minimal risk to partaking in the survey.

Questions
 If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844- 720-9816, email: ethics@uwo.ca. This office oversees the ethical conduct of research studies and is not part of the study team. Everything that you discuss will be kept confidential. Feel free to download this letter for your records.

 By giving us your consent, you acknowledge that you: Have been given a written explanation (letter of information) of the study. Have been given the contact information for the members of the research team

Understand that you can choose to take part or not to take part in the study and given the anonymous nature of data, we cannot delete it once the survey has been submitted. Have been given the chance to ask questions about the study and understand that you can ask more questions about the study at any time.

By checking this box on the survey, I am confirming that I have read the Letter of Information concerning the data collection for this study, I have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

◯ I consent to participating in the study (1)

◯ I do not consent to participating in the study (2)

Appendix D2: FG Consent Form

FOCUS GROUP LETTER OF INFORMATION AND CONSENT

Project Title: Understanding the awareness and perspectives of older adolescents towards targeted online data collection practices

Principal Investigator: Dr. Shannon Sibbald, PhD
Associate Professor, School of Health Studies (Faculty of Health Sciences), Family Medicine and the Schulich Interfaculty Program in Public Health

Coinvestigator: Dr. Gerald McKinley, PhD
Western Centre for Public Health and Family Medicine

Graduate Student Researcher: Ahrrabie Thirunavukkarasu, MSc Candidate
Health and Rehabilitation Science Program at Western University

Conflict of Interest: No conflicts of interest identified

Introduction

You are being invited to participate in a research study on the perspectives of older adolescents towards researchers collecting their personal online information to advance the field of health promotion. We are hoping you will inform us on how we can consider the independent older adolescent perspective when conducting online research. This letter has been designed to provide you with the information necessary to make an informed decision about whether to participate in a focus group. If you have any questions, please do not hesitate to contact our research team.

Background/Purpose

There is a lack of regulatory oversight for online research, which is becoming more dependent on powerful algorithms to access vulnerable communities online that teenagers frequent. We are interested in understanding how aware older adolescents are of the usage of their personal information to understand certain online behaviours. We are hoping to further the conversation on ethical data collection practises by researchers through speaking with teenagers about risky online behaviours, autonomy, and trust towards researchers.

In this study, we will be answering the following question:
What are the attitudes of older adolescents towards researchers collecting personal information through social media to support health promotion initiatives?

We are looking for volunteers who can consent to this study and participate in a 60-to-90-minute online or in person focus group interview with the researcher and other teenagers about your personal experiences engaging with social media and with risky online content. Through these means, we will be documenting diverse perspectives of older adolescents regarding the usage of their data and online social media practices. The focus group will either occur online through Zoom or in-person at a designated University of Western Ontario space or London, Ontario based Public Library. We anticipate a minimum of five and a maximum of six people will participate in each focus group.

Confidentiality

All data collected will remain confidential and accessible only to the study research team and will be stored on Western University servers. Your full name and email address will be used to schedule the

interview and your gender and age, will be used to ensure you fit the study criteria and to ensure diverse perspectives are being heard. Personal identifying information that will be linked to a unique ID code and pseudonym in a master list will be your first and last name, email, and phone number. The information collected will be used for research purposes only, and neither your full name nor information which could identify you will be used in any publication or presentation of the study results. Information from the results will be shared through aggregated data, de-identified descriptors, and direct quotes. Any identifiable factors will be removed during sharing of results.

The interviews will be audio recorded, transcribed, and permanently destroyed following transcription. Audio recordings are mandatory during focus group interviews. At the end of the interview, you will be asked to provide a pseudonym that will be used to describe yourself in place of your full name during the communication of the results. All identifiable information will be redacted in the study records and replaced with a pseudonym during the communication of the results.

Your informed consent will be gathered through a third party, secure online survey platform called Qualtrics. Qualtrics uses encryption technology and restricted access authorizations to protect the privacy and security of all data collected and retained, including personal information. In addition, Western's Qualtrics server is in Ireland, where privacy standards are maintained under the European Union's General Data Protection Regulation, which is consistent with Canada's privacy legislation. Please refer to Qualtrics' Privacy Policy (https://www.qualtrics.com/privacystatement/) for more details about Qualtrics' information management practices. The data will then be exported from Qualtrics and securely stored on Western University's server. The collected data will be stored electronically in password-protected, encrypted files for 7 years, per Western University guidelines. While we do our best to protect your information, there is no guarantee that we will be able to do so.

Please note the internet is an insecure public network which means there are risks that information may be intercepted by unauthorized people (hacked). Videoconferencing technology like Zoom has some privacy and security risks. Please refer to Zoom's Privacy Policy https://explore.zoom.us/en/privacy. We also use NVivo for data analysis after any personal information has been deidentified. All media files and transcripts uploaded to or produced by NVivo Transcription are encrypted while in storage and in transit. Data is securely stored in Canada. Please refer to the privacy statement for more information https://www.qsrinternational.com/privacy-policy.

Please note that researchers have an ethical obligation to report instances of self-harm or abuse to the authorities, despite potentially breaching confidentiality. Overall, we believe the incidence of this happening will be low as this is not the focal point of the focus group discussion. Should this happen, we will not deliberately seek evidence about this issue, as it is unrelated to the research objectives. Please be mindful of this during our discussion. Though the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others. Participants do not waive their legal rights by signing the consent form.

Delegated institutional representatives of Western University and its Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research in accordance with regulatory requirements.

Benefits

You may not benefit from participating in this study. The information gathered may provide benefits to society, which includes better preparing and educating youth about the risks of posting/engaging with risky online content. This research is well-equipped to inform future research practices and encourage more strict regulations on the harmful online communities that encourage certain behaviours (violent or self-harm actions). It will also contribute to the change in the way consent is negotiated and obtained within online communities and on social media.

Risks

The possible risks and harms to you include emotional upset or distress. Since Non-suicidal Self-Injury (self-harm) will be used as a case study for this project, it may come up during the interview. Though you will not be asked about any history of self-harm, you may be asked about your understanding of what it is, which is potentially distressing. We also ask participants how they feel being exposed to violent/risky content online; this may be upsetting to some. There are additional measures in place to support participants in the event of upset (e.g., breakout room/separate designated area with a research assistant and provision of mental health resources). However, the risk of participating in this research is no greater than what you may encounter in your everyday life.

While all personal information will be handled with the utmost privacy and care as outlined, one cannot guarantee that there will never be a privacy breach.

Compensation

All students working towards an Ontario Secondary School Diploma (OSSD) must complete at least 40 hours of Community Involvement. You can choose to receive up to two volunteer hours for partaking in the focus group OR receive a $10 'Everything' gift card, which can be used to select a gift card from a large selection of brands, including Tim Hortons, Amazon, Indigo, Uber, Cineplex, etc through email transmission.

Freedom to Withdraw or Refuse Participation

Participants are under no obligation to participate. Participants do not waive any legal right by consenting to the study. You have the right to stop partaking in the interview at any time, or to refuse to answer any of the interviewer's questions without prejudice from the investigator. You may withdraw from the study by emailing the graduate student [email redacted] or by contacting the PI (information attached above). If you choose to withdraw from this study prior to publication, all data associated with your code will be fully removed from any data sets and destroyed. Once the data are published, their data cannot be withdrawn.

Questions

If you have any questions about this study, please contact the Principal Investigator Dr. Shannon Sibbald (519) 661-2111 x86258, email: [email redacted] or the Graduate Student Ahrrabie Thirunavukkarasu, email: [email redacted].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844- 720-9816, email: ethics@uwo.ca. This office oversees the ethical conduct of research studies and is not part of the study team. Everything that you discuss will be kept confidential.

We will send you a copy of the Letter of Information and consent form through email to keep for your records.

PARTICIPANT FOCUS GROUP CONSENT FORM

Project Title: Understanding the awareness and perspectives of older adolescents towards targeted online data collection practices

All my questions have been answered to my satisfaction.
- ❑ Yes
- ❑ No

I consent to having de-identified direct quotes from my interview used in any publication of results.

- ❑ Yes
- ❑ No

Please print, date, and sign your full name below and return this form to the interviewer:

Full name of participant _____

Date of signature _____

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

Participant's signature _____

My signature means that I have explained the study to the participant named above. I have answered all questions.

Full name of person obtaining informed consent: Ahrrabie Thirunavukkarasu

Date of signature: _____

Signature of person obtaining consent: _____

Appendix E: Mass Recruitment Email

Dear Student,

We would like to invite you to participate in a research study investigating the perspectives and attitudes of teenagers towards online data collection practices by researchers. Individuals between the ages of 16 and 19 are eligible to participate in this study.

We are looking for volunteers who can consent to this study and participate in an online questionnaire about your attitudes towards researchers and behaviours on social media, which can take approximately 20 minutes to complete.

https://uwo.eu.qualtrics.com/jfe/form/SV_26lBQ8Q7Td5cxcW

You are also invited to participate in 60-to-90-minute online or in person focus group interview with the researcher and other individuals about your personal experiences engaging with social media and risky (ie. self-harm or violent) online content. Students will receive a $10 'Everything' gift card which can be used to select a gift card they would like from a large selection of brands including Tim Hortons, Amazon, Indigo, Uber, Cineplex, etc.

If you require any further information regarding this research project or your participation in the study, you may contact the principal investigator Dr. Shannon Sibbald [email redacted], or the graduate student Ahrrabie Thirunavukkarasu [email redacted].

If you have any questions about the conduct of this study or your rights as a research participant, you may contact the Office of Human Research Ethics at 519.661.3036 or ethics@uwo.ca.

Thank you for considering participating in this study.

Ahrrabie Thirunavukkarasu

Appendix F: Recruitment Poster

Are you between the ages of 16 and 19 and are an active poster or consumer of social media?

If so, consider participating in a research study on the attitudes of older adolescents towards the gathering of personal information by researchers. Complete an online survey for approximately 20 minutes If you participate, you will be asked questions about:

- Your perceptions and engagement with social media
- Attitudes towards health information being presented on social media
- Perceptions of risky behaviours on social media
- Your age and gender.

To participate, click the link to the survey below
Email ▮▮▮▮▮▮▮▮ca with questions. Thank you!

Appendix G: Survey Codebook

Q1: Gender
- Male (1)
- Female (2)
- Non-binary (3)

Q2: Age
- 16 (1)
- 17 (2)
- 18 (3)
- 19 (4)

Q8: Emotional resonance after posting content online
- Much worse (1)
- Somewhat worse (2)
- About the same (3)
- Somewhat better (4)
- Much better (5)

Q10: Time spent considering before posting

- Less than a minute (1)
- 1 to 10 minutes (2)
- 10 to 30 minutes (3)
- A couple of hours (4)
- More than one day (5)
- Depends on platform (8)

Q11: Whether posts will affect future
- Definitely not (1)
- Probably not (2)
- Might or might not (3)
- Probably yes (4)
- Definitely yes (5)

Q12: Having posted to hidden online communities
- No (1)
- Uncertain (2)
- Yes (3)

Q13: Okay for research access
- No (1)
- Uncertain (2)
- Yes (3)

Q14: Perceived accuracy of portrayal
- No (1)
- Uncertain (2)
- Yes (3)

Q15: Comfort towards researcher activities
- Extremely uncomfortable (1)
- Somewhat uncomfortable (2)
- Neither comfortable nor uncomfortable (3)
- Somewhat comfortable (4)
- Extremely comfortable (5)

Q16: Trust towards researchers to safeguard privacy
- No (1)
- Uncertain (2)
- Yes (3)