INVESTIGATING PRIVACY PERCEPTIONS, ATTITUDES AND BEHAVIOURS OF THE INFLAMMATORY BOWEL DISEASE ONLINE HEALTH COMMUNITIES

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Abstract

During their lifetime, people living with Inflammatory Bowel Disease (IBD) may require social support. Over the past 3 decades the internet has provided new opportunities for people living with chronic health conditions to meet virtually to both seek and receive empathetic support from the comfort of their own homes. Furthermore, the prevalence of smart mobile devices and social media platforms has provided individuals with easy to reach, on the go social support to meet their needs. Online support has been recognised as having additional benefits to face-to-face support, such as how the asynchronous nature of online communications affords individuals to browse a rich history of previous posts. However, self-disclosed information on the internet is subject to privacy risks. In Law and Sociology, health information is considered to be 'sensitive' data; however, there are thousands of individuals living with IBD sharing intimate health information on social media platforms.

This thesis explores how people living with IBD perceive their privacy on social media through a dual lens of social privacy and information privacy. A mixed-methods approach was adopted across 3 empirical studies to examine the perceptions, attitudes, and behaviours of people living with IBD and using social media to participate in online health communities. The first study explored how people living with IBD use Facebook, Twitter, and Instagram to engage with online health communities through 38 semi-structured interviews. The findings indicate that each of the platforms shared similar functionality which in turn

generally afforded similar therapeutic outcomes. The analysis found evidence to suggest that people's experiences of each platform was not exclusively as a result of the technical functions of each platform but were combined with their motivations and their previous social interactions. Significantly, this study also drew a distinction in the ways in which people perceive privacy on social media; demonstrating clear understandings of their social privacy boundaries and the actions they take to reduce privacy violations. Conversely, participants demonstrated a low awareness of how their data is collected and used by social media platforms, thus making it difficult for individuals to identify information privacy risks. The second study involved community leaders participating in focus groups to discuss the privacy challenges as well as identifying possible prototypes to support the digital well-being of potentially vulnerable people. Finding that an education-driven approach would be a suitable short-term option to improve people's understanding, an intervention was developed through Patient and Public Involvement for the third study. The final study involved pre and post web-surveys to digital interventions to assess people's attitudes towards learning more about online privacy, as well as its impacts on the IBD community.

Taken together, this thesis presents new evidence to suggest how individuals use different social media platforms. It also demonstrates how social privacy and information privacy are thought and acted upon in different ways. However, there is some evidence to suggest that over the course of data collection for this PhD

(2017-2020) there are changing attitudes towards information privacy and the ways in which people’s health information is used by social media platforms.

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Glossary of Terms

- **Traditional social networking –** refers to social networking taking place on Web 1.0 technologies included web-based forums and bulletin boards.
- **Contemporary social networking** – observes social networking on social media platforms associated with 2.0 ideologies.
- **Bonding Social Capital –** the potential to secure benefits from close/strong relationships in social networks
- **Bridging Social Capital -** the potential to secure benefits from weak relationships (e.g. acquaintances) in social networks
- **Crohn's Disease –** a form of Inflammatory Bowel Disease that can affect any part of the digestive tract.
- **Ulcerative Colitis –** a form of Inflammatory Bowel Disease that exclusively affects the colon/large bowel.
- **Indeterminate Colitis** – a diagnosis given to patients where it is unclear whether they have Crohn's disease or Ulcerative Colitis.
- **Lurking** – also known as legitimate peripheral participation refers to people who do not actively post in online communities but instead observe.
- **Trolling** – a term that refers to those who deliberately intend to upset others online.

Abbreviations

- **IBD** – Inflammatory Bowel Disease
- **UC** – Ulcerative Colitis
- **OHC** – Online Health Community
- **GDPR** – General Data Protection Regulation
- **RRI** – Responsible Research and Innovation

- **VoIP** – Voice over Internet Protocol (e.g. Skype)

INTRODUCTION

CHAPTER 1: INTRODUCTION

1.0 Background

It is widely accepted that social media platforms, such as Facebook, Twitter, and Instagram play an important role in people's lives. These contemporary social networking technologies are used on a day-to-day basis for people to connect with friends, read the news, and join communities of shared interest. Not only is half the world's population connected through social media (Internet World Stats, 2020), but on average people use 8 social media accounts (Chaffey, 2020) illustrating the pervasiveness and prominence of this phenomenon.

In the context of healthcare, social media platforms are used by people seeking social support and exchanging knowledge about health conditions (Merolli et al, 2014). While health information websites are accessed on a regular basis (Fox, 2014), social media turns people from exclusively consuming information, to also producing content (Gillmor, 2010).

One such illness, that is the focus of this thesis, is Inflammatory Bowel Disease (IBD). Non-visible to others, people living with this life-long auto-immune condition have complex needs and a lower quality of life. Feelings of stigma has been reported by young people living with IBD (Daniel, 2001; Saunders, 2014), where individuals may experience both felt stigma (shame and fear of being stigmatised) and enacted stigma (actual experience of being stigmatised). Despite over 300,000 people in the UK and 1.5 million in the USA living with IBD (Crohn's and Colitis UK, n.d; Crohn's and Colitis Foundation of

America, 2014), scholarship on how people use contemporary social media platforms is scarce.

The social interactions that take place on these social media platforms are often text-based and asynchronous, which consequently means that self-disclosed health information stays online indefinitely, unless the user actively deletes posts. The persistent nature of information on social media, as social media scholar danah boyd[1] (2014) notes, has associated advantages and risks. For people who want to learn more about other people's experiences, the accumulation of historical posts offers a rich repository of information (Coulson, 2007; Tanner, 2017)). However, the accessible, searchable and persistent nature of information sharing on social media can pose privacy challenges, particularly with more sensitive subject matters.

Historically, there have been reported misuses of health data on the internet. In 2010 it was reported that health support forum, Patients Like Me, suffered a loss of over 200 users after they learned how the company sells data to third parties (Angwin & Stecklow, 2010). Two years later, Facebook conducted psychological tests to assess people's moods and how they could even change their emotional state through emotional contagion (Kramer, 2012). As recent as 2019, it was found that more than 19 self-reporting and tracking health apps were

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[1] Please note in this thesis, boyd will be referred to in her preferred lower-case form

sharing data with companies like Facebook and Google (Huckvale et al, 2019; Grundy et al, 2019).

While the landscape of data protection and privacy has seen significant changes over the past 5 years, it is believed that “users still have little understanding of how the data they entrust to these apps is being shared” (Woodward, 2019: para 8). With health information regarded as particularly sensitive by current European Union (EU) regulation (EU, 2016), it is important that the privacy perspectives of people living with chronic health conditions is understood.

Following previous research by Gürses & Diaz (2013) and Lutz & Strathoff (2011) that strongly suggests two distinct factions of privacy should be considered in the examination of online social networks, this thesis explores privacy through a dual lens of *social privacy* and *information privacy.* For immediate clarification: social privacy is defined as “the concerns that users raise and to the harms that they experience when technologically mediated communications disrupt social boundaries” (Gürses & Diaz, 2013: p.3). Meanwhile, information privacy “concerns describe people’s uneasiness and fear that their data is used for unwanted purposes,” (Lutz & Strathoff, 2011: p.85).

As such, this PhD focuses on the privacy attitudes, beliefs and behaviours of people using social media to engage with the IBD online health communities. In order to understand the context of health information disclosures on social media, this thesis also examines how people living with IBD use Facebook, Twitter and Instagram to engage with the online health communities.

1.1 Research Objectives

A small number of qualitative studies have indicated how people living with chronic health conditions manage their health information disclosures on traditional and contemporary social networking platforms[2] (Brady et al, 2016; Patterson, 2013). However, the emphasis is placed on how people manage their identity to other people. Current online privacy literature also remarks on how institutions, such as corporations and governments, use people's personal information, which poses additional and obfuscated privacy risks (Patterson, 2013; O'Hara, 2016). Yet, there is no evidence to indicate how people living with IBD approach either social privacy or information privacy when engaging with health communities on contemporary social media platforms. Seeking to understand how privacy plays a role amongst chronic health communities was the core objective in this thesis:

Research Objective 1: To understand the privacy beliefs, attitudes, and behaviours demonstrated by people using social media platforms to engage with IBD online communities.

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[2] See Glossary of Terms

Taking the position that privacy is contextually constructed (Nissembaum, 2004), it was critical that a fuller understanding of how contemporary social media platforms are used and experienced by people living with IBD. With little rigorous research exploring the IBD online health communities' experiences using social media platforms such as Facebook, Twitter, and Instagram, Study 1 of this thesis (Chapter 4) was designed to address the second, but related, research objective:

Research Objective 2: To understand how contemporary social media platforms used by people with Inflammatory Bowel Disease, who are engaged in online health communities.

The three studies in this thesis adopted different but complimentary methodological approaches and stakeholders to explore the overarching research objectives. Study 1 provides a detailed analysis of semi-structured interviews with people living with IBD using contemporary social media platforms and offers findings of how social and information privacy are understood and responded to. Study 2 provides a view of online privacy from a multi-stakeholder perspective, with the inclusion of community leaders and a national UK-based charity. In the recognition of how there were misunderstandings of information privacy, Study 3 further explored people's attitudes towards social and information privacy, inclusive of their willingness to learn more about how their information is used by institutions on the internet.

Each study focused on different research questions that pertained to each of the overarching research objectives. This can be viewed in Table 1.

Research Objectives	Research Questions	Study no.
RO1: To understand the privacy beliefs, attitudes, and behaviours demonstrated by people using social media platforms to engage with IBD online communities.	RQ1b: What are the online privacy perceptions of individuals living with Inflammatory Bowel Disease?	1
	RQ2b: What are the privacy challenges perceived by community leaders?	2
	RQ2c: What types of interventions do community leaders believe would benefit the IBD online communities?	2
	RQ3a: Do people with IBD report to have a disposition to social and information privacy concerns?	3
	RQ3b: To what extent does (1) disposition to privacy concern, (2) time, (3) perceived technical knowledge, and (4) access to learning materials impact on barriers to learning?	3
	RQ3c: Is there an appetite amongst individuals with IBD to learn more about data collection and processing practices by social media platforms?	3
	RQ3d: How are information privacy concerns, perceived control and, likelihood to act on their privacy preferences impacted by awareness interventions?	3
	RQ3e: What are people's experiences of the Health Privacy Toolkit, and how can it be improved for public release?	3
RO2: To understand how contemporary social media platforms used by people with Inflammatory Bowel Disease who are engaged in online health communities.	RQ1a: How are social media platforms used by people with Inflammatory Bowel Disease who engage with online health communities?	1
	RQ2a: According to community leaders, what are the affordances of social media-based online health communities?	2

Table 1 Research objectives and study research questions

1.2 Research Position

It should be made aware that one motivation for this research enquiry stems from the researcher's lived experience with IBD. Having lived with the condition from a young age, her observation of health disclosures on social media platforms encouraged her to examine the role of privacy with academic rigour.

This thesis adopts a critical realism approach to addressing the privacy beliefs, attitudes, and behaviours of people living with IBD using social media for support. Building on opposing ontologies of realism[3] and interpretivism[4], critical realism defends that there is a reality independent of our knowledge, but accepts that knowledge is historically, socially and culturally situated. It acknowledges that there are different phenomena that have different ontological, epistemological and methodological characteristics: for instance, social studies are typically more interpretive and qualitatively explored, while biology seeks objective realities in the relationships between organisms. Also referred to as the *third research paradigm* (Johnson, Onwuegbuzie, & Turner, 2007), critical realism accepts that different research methodologies and methods may be applied in order to access an independent reality.

Triangulation, or mixed-methods research, refers to the use of two or more methods to explore a particular research enquiry (Campbell & Fisk, 1959;

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[3] Realism posits that there is an independent reality whereby the "*the investigator and investigated are independent entities*" (Sale, Lohfeld, & Brazil, 2002, p. 44)

[4] Interpretivism in the social sciences seeks relationships that are not as "ahistorical, invariant, or generalizable" (Ashley & Orenstein, 2005: p.241) as what are found in realist enquiries.

Denzin, 1978). By using different methods to answer a research question, researchers can benefit from the strengths of different approaches which increases validity and rigor (Johnson, Onwuegbuzie, & Turner, 2007). The application of mixed methods presents researchers with a diverse perspective of the same issue, that might not be possible by using one method. In this thesis, mixed methods have been adopted by the researcher to explore and interpret privacy perceptions, attitudes and behaviours, in the context of IBD online health communities.

Finally, this thesis is aligned with the principles of Responsible Research and Innovation (RRI) set out by the Engineering and Physical Sciences Research Council (EPSRC). It is expected that the researchers "anticipate, reflect and engage on the wider ethical and societal impacts, implications and value of their work, entering into dialogue with the public and other stakeholders where appropriate, and respecting the views of others" (EPSRC, n.d: para 2).

Considerations of how RRI was integrated into the research design will be described in each study chapter. It was anticipated at an early stage that the research should be designed to mitigate participants becoming worried about their information privacy. Ultimately, it was recognised that given the therapeutic benefits of online support, this research should not prevent participants from feeling comfortable to engage in online health communities. Secondly, given the sensitive nature of what is shared in online health communities, combined with the primary motivations for accessing these spaces, it was considered unethical to adopt methods that would undermine informed consent, such as digital ethnography and data mining techniques. This research therefore takes an active approach in engaging with participants to understand their perceptions, attitudes, and behaviours using social media for health-related support.

In light of the considerations for critical realism as well as the requirement for researchers to engage ethically by considering the wider societal impacts of their work, this thesis adopted a pragmatic approach to data collection. The research design of each study, with consideration of RRI, will be presented in their respective chapters.

1.3 Research Areas

With this thesis' core aim to provide new knowledge of how people living with IBD perceive and approach privacy through a dual lens, this research draws on intersecting themes and methodologies from different disciplines.

1. This thesis draws inspiration from *health psychology* research that has explored the health benefits of online health communities (See Chapter 2).
2. This thesis builds on *Social Psychology* theories of self-presentation and impression management to understand social privacy behaviours. Secondly, this thesis recognises how social interactions shape people's imagined affordances of different social media platforms. Methodologically, the studies in this research reflect qualitative and quantitative methods to understand the roles of social privacy.

3. To understand how people with a chronic condition perceived and managed their privacy on social media, *Human Computer Interaction* (HCI) has a significant presence in this thesis. This thesis draws on literature that explores privacy concern, behaviours, the privacy paradox, and contextual integrity to understand how privacy is managed on the internet. The underpinnings of affordance theory used in HCI research, inspired the methodological approach in understanding the relationship between social media platform features and therapeutic affordances in Study 1.
4. Finally, this thesis draws on *Media Education Research* to understand the role of digital literacy in social and information privacy management on social media. Using internet-based privacy literacy resources for inspiration, this thesis presents the development of a resource for lifelong learning. Methodologically, as seen in previous privacy literacy works (Sideri et al, 2019; Vanderhoven et al, 2014), pre- and post-intervention surveys were employed in Study 3 to understand the impacts of the resource.

1.4 Publications from the Thesis

Two publications have been peer reviewed and published in one journal and one conference proceedings. These publications are outputs from Study 1 (See Chapter 4).

Journals:

O'Leary, K., Coulson, N., Perez-Vallejos, E., & McAuley, D. (2020). Towards understanding how individuals with inflammatory bowel disease use contemporary social media platforms for health-related discourse. *Computers in Human Behavior*, *112*, 106463. https://doi.org/https://doi.org/10.1016/j.chb.2020.106463

Conference Presentations:

O'Leary, K. (2020). Understanding privacy for patients with a chronic illness using social media platforms for support. Paper presented at: *International Conference on Medical and Health Sciences*. Rome. Italy.

1.5 Structure of Thesis

Following the current introductory chapter that aims to provide context to the research area and the researcher's position, Chapters 2 and 3 focus on the literature underpinning this thesis. Chapter 2 examines Inflammatory Bowel Disease; what it is and how it impacts on people's lives, giving additional context to why people require social support. This chapter also serves as an opportunity to critically discuss how IBD online health communities have been historically examined.

In Chapter 3 the literature review continues with a critical discussion of privacy on the internet. It reviews the current literature around conceptualisations of privacy, the privacy paradox, information privacy, social privacy, privacy antecedents, and behaviours. An exploration of how privacy has been studied in the context of online health communities was also undertaken to provide clarity over the research gaps.

The collection of empirical work follows the literature review; the methods for each study are found in their respective chapters. Study 1 in Chapter 4 is a semi-structured interview study that explores how social media platforms are used by the IBD online communities and begins to understand how individuals perceive privacy through a dual lens of social and information privacy. This study outlines how platforms and features are used to achieve *self-presentation*, *connection*, *exploration*, *narration* and *adaptation.* It continues to describe participant experiences that are based on a combination of platform features, social interaction, and personal preferences. The second part of the analysis outlines how participants perceive and manage social privacy and information privacy on social media.

Study 2 is described in Chapter 5. Building on the uncertainty of information collection and uses by social media platforms identified by people living with IBD from Study 1, this Focus Group study further explores the privacy challenges with online support. Two focus groups, one with a UK national charity and another with a group of community leaders, were formed to provide a different perspective on the privacy challenges in online health communities. Findings from this study indicated a need for increased awareness of the digital economy landscape to provide individuals with more information about how data about them is collected. Focus groups offered intervention recommendations that were both informative yet would not cause panic or fear that might cause individuals to withdraw from the online communities.

Chapter 6 is home to the final empirical study that introduces an online learning resource to individuals. Online surveys were used to understand privacy perceptions of people with IBD on a larger scale and assess their attitudes towards information privacy. The findings suggest that people living with IBD may have less privacy concerns than healthy participants but are equally as likely to want to learn more about their online privacy. Further analysis explores the factors relating to concerns, privacy control, and activity to learn

This thesis concludes with a comprehensive discussion that draws on the empirical findings and the current literature. Chapter 7 includes key discussion points such as the observation that attitudes towards information privacy are changing, with evidence to suggest that over the past two years people are becoming more engaged in their information privacy. It also discusses the implications of the findings on future work as well as the practical application of the Health Privacy Toolkit. Finally, the methodology and limitations of the research are critically evaluated. Following Chapter 7 is the bibliography and appendices.

LITERATURE REVIEW

CHAPTER 2: INFLAMMATORY BOWEL DISEASE AND ONLINE SUPPORT

2.0 Introduction

This chapter is positioned to provide an understanding of Inflammatory Bowel Disease, how it impacts an individual’s life, and how they benefit from social support. It will do so firstly by describing the condition, its prevalence and how IBD can impact people’s lives. With complex and changing support requirements, this chapter then explores the role of online support, paying particular attention to the significance of experience sharing.

2.1 Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a lifelong, incurable autoimmune illness that causes unpredictable inflammation of the digestive tract (Hanauer, 2006). The two main constituents of IBD are Crohn’s disease and Ulcerative Colitis (UC). Crohn’s disease can be identified through patchy inflammation throughout the digestive tract from mouth to rectum; while UC is recognised by its continuous inflammation localised to the large bowel (Head & Jurenka, 2003). A person living with IBD will experience symptoms which may be stigmatising and/or embarrassing (Daniel, 2001; Saunders, 2014) such as abdominal pain and diarrhoea, sometimes with mucus, pus, or blood (Crohn’s and Colitis UK, 2017). In turn blood loss, interrupted sleep, dehydration, and poor digestion can cause fatigue, anaemia, and weight loss (Hall et al., 2005; Crohn's and Colitis UK, 2017b). Further complications that can lead to surgical intervention include bowel narrowing, fistulas[5], and bowel ruptures (Crohn's and Colitis UK, 2017b).

IBD affects over 300,000 people in the UK (Crohn's and Colitis UK, n.d.) and a further 1,500,000 in the United States (Crohn's Colitis Foundation of America, 2014). There are more reported cases of patients with IBD in the USA and in Europe comparative to developing countries (Baumgart & Carding, 2007); however there are reports of increasing cases of UC across Asia (Loftus, 2004). Loftus (2004) observed a low incidence rate in developing countries, though it is unclear "whether this is due to low diagnostic awareness, confusion with infectious causes of diarrhea, or a truly low incidence rate" (p.1507).

People living with IBD will experience a lifetime of care from gastroenterologists, with routine appointments and tests to monitor illness activity and drug responsiveness (Hanauer, 2006). There are currently 5 main medicinal types that are used to treat the illness with varying levels of success between patients (Pithadia & Jain, 2011). Indeed, people may also experience side effects from the medications which can have a negative impact on people's lives, such as sleeplessness, mood changes, skin irritation, and hair loss (Shah et al, 2015). Surgical intervention such as resections and stoma[6] formations may also be required (Larson & Pemberton, 2004). Although it should be noted that recent

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[5] An abnormal passageway connecting one organ to another.

[6] A stoma is an opening to the body; for patient with IBD they can be created to bring part of the intestine to the surface. Faeces will then be collected through a bag fitted around the stoma. (Recalla et al., 2012)

research has shown that there is a significant decrease in Crohn's disease patients requiring surgical intervention in the ten years following their diagnosis (Burr et al, 2019).

Finally, previous studies have reported how IBD has psychological impacts including feeling hopeless (Matini & Ogden, 2015), stigmatised (Daniel, 2001; Saunders, 2014), embarrassed (Hall et al, 2005; Lönnfors, 2014; Matini & Ogden, 2015), and alone (Britt, 2017). These psychological impacts are closely connected with how the illness affects people's lifestyles and so will be discussed in the next section.

2.1.1 The Lifestyle Impacts of IBD

Living with IBD is known to have an impact on different aspects of people's lives. The literature concerning the lifestyle impacts of IBD agrees that the illness can cause disruptions to people's work life (Ito et al, 2008; Lönnfors et al, 2014; Bernklev et al, 2006). It is reported that people take time off work for their symptoms as well as hospital visits (Lönnfors et al., 2014; Crohn's and Colitis UK, 2017b). Bernklev et al (2006) observed that a lower quality of life is associated with increased illness-related absence from work. Secondly, the physical impact of the illness, such as fatigue, has been shown to negatively impact on people's participation in work-related social activities (Ito et al, 2008).

Living with IBD has been observed to have an impact on people's personal relationships. Lönnfors et al (2014) reported that two thirds of their participants did not report to have any difficulties regarding friendships. Furthermore, individuals with close friends and family who are more understanding of the impact of their illness (Matini & Ogden, 2015) have been shown to provide sympathy and tangible support (Otley et al, 2007; Schneider & Fletcher, 2008). Meanwhile, some people living with IBD may believe that their friends and family members do not have a true understanding of their illness (Hall et al, 2005; Otley et al., 2007; Rogala et al, 2008) and can even downplay its seriousness (Matini & Ogden, 2015). There are several studies that indicate the challenges associated with maintaining relationships with IBD. Symptoms associated with IBD and dietary restrictions have been known to disrupt people's social plans (Cheung et al, 2000; Rogala et al, 2008; Schneider and Fletcher, 2008) which in turn can cause people to experience feelings of guilt (Schneider & Fletcher, 2008; Hughes et al, 2013). Close friends and partners who demonstrate acceptance and understanding of the illness can have a positive impact on people's quality of life by providing social support (Lahat et al, 2014; Matini & Ogden, 2015). However, a third of participants in a survey study perceived that their illness had prevented them from pursuing intimate relationships (Lönnfors et al, 2014).

IBD has had a reported impact on family planning and voluntary childlessness (Tavernier et al, 2013). Although research indicates that for most women, the ability to conceive and start a family is no different for people living with IBD than for those who are healthy (Tavernier et al, 2013), nearly half of the participants in a 2009 study were concerned about infertility as a result of their Crohn's disease (Mountfield et al, 2009).

Overall, scholars have reported that people living with Crohn's disease and UC have a lower quality of life than healthy individuals (Guthrie et al, 2002; Oliveira et al, 2006). Academics have highlighted the importance of both disease management and positive coping mechanisms to improve people's long-term quality of life (Greenley et al, 2010; Kilroy et al, 2011). One particular method, that sits outside of clinical practice, to help people's quality of life, is having access to social support which has had reported positive outcomes on people's well-being and quality of life in the IBD community (Moody et al, 1993; Oliveria et al, 2006; Szigethy et al, 2009; Coulson, 2013; Coulson, 2015; Summers, 2018).

2.1.2 Social support

Social support is the "existence or availability of people on whom one can rely and from whom one can experience care, value, and love," (Liu et al, 2014: p.751). There is a body of research that indicates how social support, both experienced in person and online, can benefit mental health and coping mechanisms for people living with IBD (Moody et al, 1993; Oliveria et al, 2006; Szigethy et al, 2009; Coulson, 2013; Coulson, 2015; Summers, 2018). As previously discussed, the literature reports that while some patients experience adequate social support in their close circles with family and friends, others may feel the need to seek support from others with shared experiences.

The nature of social support has been observed through different categories by previous research. The Social Support Behaviour Code by Cutrona and Suhr (1992) has provided the basis for five types of social support that have been adopted in studies to organise social interactions. These types include information support, which offers the sharing of factual information and personal experiences; emotional support, that is the expression of concern, sympathy and empathy; esteem support which can be identified by reassuring comments; network support, that provides people a sense of community and belonging; and, tangible aid which offers the practical assistance to support another (Cutrona and Suhr, 1992). The ways in which these facets of support have been observed in online communities can be found in Section 2.2; however, the following paragraphs will describe how social support has been witnessed in face-to-face groups.

Local support groups are synchronous, local face-to-face meetings for patients and carers (Moody et al, 1993). The meetings provide individuals with the opportunity to meet others with similar experiences who can provide empathetic support, encouragement and share their stories (Moody et al, 1993; Oliveria et al, 2007; Szigethy et al, 2009). These groups may be self-organised by patients, charities, or medical institutions (Davidson et al, 2000). In a study that employed a questionnaire to assess the effectiveness of a support group for teenagers with IBD and their parents found that local support groups enabled stronger ties between teenagers, their parents, staff and other members (Takac & Kollman, 1994). The support group enabled young people to feel more comfortable sharing their anxieties and concerns around their illness (emotional support); sharing knowledge of coping mechanisms (information support); as well as decreased isolation (network support).

Although there are reported benefits of face-to-face social support groups two studies focused on the associated challenges. Joachim (1998) reported on the reasons why a local IBD support group closed through an interview study. Participants who had been diagnosed for longer periods of time did not feel as though educational sessions by the facilitator were useful, compared with those who have more recently been diagnosed. Instead individuals who had been living with IBD for several years were motivated to share their experiences. However, because they felt they didn’t feel benefitted by attending the support group, their attendance was inconsistent. Other reasons for group absence included work commitments, busy lifestyle and a lack of connection between group members. This study raises how support needs change over time, depending on factors including health status; whether a person is in relapse or remission. In another study, Moody et al (1993) reported similar findings answering why retention is difficult in face-to-face support groups. 40% survey respondents who hadn’t joined a local support group declared that the reason for not joining was they were too busy. Meanwhile, 23% responded that they lived too far away, indicating a lack of convenience.

The internet provides people living with chronic illnesses with opportunities to seek support. In the most recent Pew Research Centre’s survey of online health searching, it was estimated that 7 in 10 adults in the United States have searched for health-related information on the internet (Fox, 2014). The literature also demonstrates how people living with chronic illnesses have been using online services, such as web-based forums, to mediate virtual support groups since the 1990s (Ferguson, 1997; Nonnecke & Preece, 1999). In 2014, reports from the United States of America indicate that nearly a third of Americans living with a chronic illness have used the internet to read or watch other people's health-related experience (Fox, 2014). Meanwhile, 19% reported to network with others who have shared experiences in the previous 12 months (Fox, 2014).

While social networking and online support has been observed over the past three decades, social media platforms and the rapid technological developments in smart devices has afforded more opportunities for social support online (Naslund et al, 2016; Merolli et al, 2014). Social media scholar boyd (2014) distinguished that "online communities were organized by topic, with separate spaces" (p.6); however, social media platforms reconfigured the way that people network and instead communities organised around individuals.

2.2 Online Health Communities

Support groups that gather virtually on social networking platforms are referred to as Online Health Communities (OHCs) (Zhang et al, 2018). With the rapid development and adoption of digital technologies, social support for health conditions is frequently accessed on the internet; a fifth of Americans with a chronic illness using the internet to connect with others who have shared experiences (Fox, 2014). Similar to face-to-face support groups, people living with IBD are motivated by their need to learn more about their condition, seek empathetic support and mitigate feelings of loneliness (Merolli et al, 2014), when engaging in OHCs. This section will explore motivations, engagement, topics discussed online, as well as the psychosocial impacts of participation.

In the case of the IBD OHCs, previous research has focused predominantly on asynchronous web-based forums (Malik & Coulson, 2011; Loane & D'Alessandro, 2013;2014; Coulson, 2013;2015; Loane & Webster, 2017; Britt, 2017), YouTube (Frohlich & Zmyslinski-Seelig, 2012), and Facebook (Fortinsky, 2012; Coulson, 2015; Roccetti et al, 2015;2016a;2016b; Guo et al, 2016; Frohlich, 2016; Szeto et al, 2018).

Basaraova & Choi (2014) introduced the functional model of self-disclosure from the analysis of Facebook posts. Their findings conclude that there is a causal link between people's goals and the ways in which they behave on Facebook. For instance, people seeking who post on their profile to all their friends (or publicly, depending on their settings) demonstrate validation and self-expression motivations. Meanwhile, rational development and the disclosure of "more intimate information" (p.650) was observed in private message and groups. In the IBD online health communities context, motivations have been identified through content analysis of publicly available information. Beyond previously reported motivations, such as mitigating feelings of loneliness, IBD OHCs research has shown that people were accessing social support around illness-related events, including diagnosis (Matini & Ogden, 2015; Coulson, 2013); starting new treatments (Loane & D'Alessandro, 2014); experiencing new symptoms; and, preparing for surgery (Summers, 2018; Frohlich & Zmyslinksi-Seelig, 2012; Loane & D'Alessandro, 2014).

Online research methods have presented new opportunities to researchers to understand different aspects of OHCs (Coulson, 2007), including what topics are discussed. Social media mining, derived from data mining techniques, pertains to the collection and analysis of large data sets from social networking sites (Zafarini et al, 2014). Using content analysis and social network analysis, researchers can understand the architecture of networks as well as what communities discuss (Zafarini et al, 2014). For instance, Roccetti et al (2015; 2016a; 2016b) used social media mining to identify discussion themes and sentiments around IBD medical treatments on Facebook and Twitter. Meanwhile, Britt (2017) similarly collected a large data set (through string sampling[7]) of over 50 topics and 2000 posts in an online forum and identified additional topics of symptoms and side-effects.

Themes of social support have been adopted to understand what kind of support is exchanged online in web-based forums and to understand the psychosocial outcomes of connecting with others (Coulson, 2013, Britt, 2017).

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[7] Britt used a generator to select 50 unique numbers, which corresponded with topic numbers within the forum.

Information support, emotional support and network support have been frequently identified across the IBD literature (Wang et al, 2017; Coulson, 2013, Britt, 2017; Choi et al, 2017).

In social support theory ‘information support’ refers to the seeking and sharing of directive information, or facts and advice (Newman et al, 2011), and non-directive information, otherwise known as personal experiences (Prescott et al, 2017). It is routinely remarked as one of the most frequent support types in OHCs (Wang et al, 2017). IBD OHC literature agrees that information sharing is the most frequently observed social support type on web-based forums (Malik & Coulson, 2011; Britt, 2017) and YouTube (Frohlich & Zmyslinski-Seelig, 2012), followed by emotional support and network support.

Social support theory studies typically amalgamate directive and non-directive information support (Wang et al, 2017). In the SCENA Model of Therapeutic Affordances (SCENA) (Merolli et al, 2014), information support is divided between two affordances. Seeking and sharing directive information is consistent with the affordance of *exploration* while experiential information refers to the affordance of *narration*. The following sections will explore directive and non-directive information support separately. It is important to focus on these two areas independently because self-disclosure of personal experiences plays a significant role in understanding privacy.

2.2.1 Directive Information Support

Also understood in the SCENA Model (a fuller explanation of this model can be found on page 56) as *exploration* (Merolli et al, 2014), directive information support describes the seeking and sharing of factual information and advice (Newman et al, 2011). Directive information represents a significant part of what is sought and shared in online health communities because patients may need new information throughout their lives with a chronic illness (Malik & Coulson, 2011; Wang et al, 2017; Merolli et al, 2014). In a study of an IBD web-based forum, nearly 90% forum threads were initiated by members seeking advice from the community (Malik & Coulson, 2011). Seeking directive information is commonly observed among patients who have recently received diagnosis (Newman et al, 2011; Moore et al, 2016) and for those experiencing new symptoms or considering new treatment options (Coulson, 2013).

With the increased use of the internet and social media platforms, a study on an IBD forum (Coulson, 2013) found that the internet is a likely place where people will discover new treatments and research for a cure. One participant said "if a cure for Crohn's was found tomorrow, I bet social networking sites are where I would hear about it first, because information like that just flies through the internet, especially when you have groups dedicated to sending that information to people who need it," (Coulson, 2013: p.4).

One way in which patients give information support is by signposting others to websites outside the community forum, such as e-commerce sites and charity pages (Huesch et al., 2017) as well as encouraging others to seek support from a GP or school nurse (Prescott et al, 2017). Prescott et al refer to this signposting as directional support that “[have] no personal story to support why they are suggesting the advice,” (2017: p.8).

2.2.2 Non-Directive Information Support

Non-directive support is the sharing of personal experiences and does not contain advice or factual information. Experiential information may include sharing of symptoms (Malik & Coulson, 2011), coping tactics (Prescott et al., 2017), treatments (Malik & Coulson, 2011; Sillence, 2016), side effects (Wang et al, 2012), and personal issues related to the illness e.g. sex. The sharing of personal stories is categorised as *narration* in the SCENA model (Merolli et al, 2014).

In a study observing communications on a young person’s IBD forum, experience sharing represented two thirds of the messages posted (Malik & Coulson, 2011). Sillence (2016) similarly reported that nearly half of the posts in a breast cancer forum were categorised as personal experience disclosure. However, in an ethnographic study of another online community by Prescott et al (2017), directional information was more frequently observed than non-directional information in a mental-health forum for young people. This indicates that there may be discrepancies in support types depending on illness types, age and platforms.

2.2.3 Information Support Behaviours

Patients motivations concerning information support have been shown to have an impact on the ways in which they behave in online health communities. Previous studies have shown that people who are solely seeking information, typically do not post (Nonnecke et al, 2006; Welbourne et al, 2012; Choi et al, 2017). Posts requesting information support are also less common than sharing information and providing emotional support (Maloney-Krichmar & Preece, 2003; Wang et al, 2017; Frost & Massagli, 2008).

While some report non-posting as passive engagement (Edelmann, 2013) and *lurking*, Lave and Wenger (1991) described "peripherality [as] an empowering position" (p.36) which has encouraged scholars to reconsider the role of non-posters as people who 'legitimately peripherally participate' (Jenkins et al, 2013). Nonnecke and Preece (2003) suggests that lurking is a "complex set of actions, rationales and contexts" (p.116) which includes the editing and organizing of messages in bulletin boards. This kind of participation in social media platforms may be inclusive of post 'reactions' and 'likes' (Fernandes, 2020).

Legitimate peripheral participation offers researchers the opportunity to think about why people do not post. Lave and Wenger (1991) proposed that it allows people to understand the community norms and culture, while indeed OHCs research indicates support motivations impacts on people's propensity to post (Nonnecke et al, 2006; Welbourne et al, 2013; Choi et al, 2017). Joinson et al (2006) and Taddicken (2014) have also suggested that heightened privacy concern may also contribute towards non-disclosure, which shall be discussed further in Chapter 3. Methodologically, the significant number of non-posters in online communities highlights a limitation of data mining techniques: that the data collected is limited to active contributors, which raises questions around community representation (Bone et al, 2016). Broadly, online lurking has been associated with the 90-9-1 rule (Nielsen, 2006) whereby 1% contribute frequently, 9% sometimes, leaving 90% as lurkers. By comparison, research has estimated that lurkers represent 45% - 52% in OHCs (Nonnecke & Preece, 2000; Setoyama et al, 2011), which suggests that people with health conditions may be more likely to contribute to online discussions and ask for support.

Media scholars also note how lurking is key for people to understand the community norms (Jenkins et al., 2013) prior to future active participation (Coulson, 2015). However, should a patient not wish to participate by sharing their own experiences, advice, or providing socio-emotional support, then patients may not ever move beyond a state of lurking. Research conducted by Coulson (2015) that compares posting and lurking in an IBD forum, found that lurkers do not visit forums as frequently and will spend less time on them. However, there was not a significant difference between posters’ and lurkers’ involvement with the community over time. A longitudinal study of a cancer support group observed the behaviour of its members over an 11-year period

(Wang et al, 2017). The enquiry into the relationship between posting behaviours and longitudinal participation (both active and peripheral) found that patients who solely seek information typically do not stay in the group, unless they decide to actively participate (Wang et al, 2017).

2.2.4 Therapeutic Outcomes of Information Support

The literature has shown how information support can help people feel more in control and make informed decisions about their illness (Roter & Hall 1992; Coulson, 2013). In a study observing stigma-related posts in a perinatal depression forum, women "often sought advice on diagnosis, whether or not they should contact a health care provider, healthcare providers' attitudes to illness and treatment. Nearly all the replying posts urged women to contact their healthcare providers," (Moore et al, 2016: p.3). While this study does not indicate the rate in which women then sought professional support, it implies that there is a strong community spirit towards encouraging others to seek medical attention from experts.

Some illnesses may require a person to take a more active role in their disease management, such as diabetes (Lewinski et al., 2017; Newman et al., 2011) and seeking information may be beneficial for a patient's well-being (Coulson, 2013). Coulson describes the feelings of control felt by members of an IBD forum, he quotes two participants: "I am more in control than I would be otherwise. I am learning about how to eat and how my body works," and "I feel

I am able to take some control over my health," (2013: p.6). Feelings of control demonstrate an improvement in a patients' well-being, thus highlighting the importance of peer-to-peer support.

Being able to read the experiences of others enables patients "to re-evaluate their situation through lateral and downward social comparison. Being able to see how others coped with their condition reassured members that they could manage their condition through education, adjustment, adaptation, and acceptance," (Allen et al, 2016: p.8). In the IBD online community literature, Coulson (2013) refers to this self-comparison as illness reappraisal. Patients can posit the severity of their illness with others; identifying that others are worse off than them (downward comparison) and others that are better, who act as inspiration (upward comparison). One patient remarked on how reading other people's success stories with medication "makes me calmer" (2013: p.4) while another said "although I have really suffered with this disease, there are plenty of people who have made a good recovery from flare up and it gives me hope," (2013: p.5). Conversely, patients seeing others struggling with their illness may lend itself to feelings of anxiety over their future. Studies have also shown that sharing of information, particularly experiences, can be therapeutic for patients (Malik & Coulson, 2011).

2.2.5 Limitations of Information Support

While the ability to access and share information online yields therapeutic benefits, there are notable limitations. The volume of information, particularly in long-standing and large communities can become overwhelming, making it difficult to retrieve specific information (Allen et al, 2016; van Uden-Kraan et al, 2008; Coulson, 2013). Furthermore, in IBD communities with high activity, Malik and Coulson (2011) found that 19 of 310 initiated threads in an IBD forum were not responded to at all (Malik & Coulson, 2011). This indicates how although larger communities can benefit individuals with lots of information, it is possible that posts are missed.

While factual information may be shared, including links to other sources, there are legitimate concerns over the circulation of misinformation in online health communities (Ruckenstuhl et al, 2016; Coulson, 2013). When patients use information that they have read online to inform clinical decisions around their care, it is critically important that they are exposed to correct information to mitigate harm. While some community members feel comfortable giving directional advice, Coulson found that some information needs to be taken with a “large grain of salt,” (2013: p.6) as patients are not all medical professionals and some community posters may have ulterior motives, such as selling alternative treatments. In a study on a bone cancer community, only around half of the participants reported that they trust the information shared in the community is correct (Ruckenstuhl et al, 2016).

2.2.6 Socio-Emotional Support

The literature refers to this support as either social support, emotional support or as socio-emotional support (Welbourne et al, 2012). Social support "refers to contact between two or more people with the same illness and giving each other emotional or instrumental support," (Welbourne et al, 2012: p.130). Meanwhile emotional support is the "ability to convey an understanding for what another person is feeling, is particularly valuable to people who feel that they cannot change their situation, but who must adapt to it," (Wright, 2011: p.197). Given the interoperability, socio-emotional support best encompasses all the terminology.

Chronic illnesses such as Inflammatory Bowel Disease that have stigmatised symptoms such as diarrhoea and fatigue may impose social barriers for people to disclose the nature of their condition to their current friends "for fear of discrimination or rejection," (Carter et al, 2015: p.421). Across chronic illnesses, patients seek empathetic support from others to help them cope with their condition and feel less lonely (Leung, 2007).

Feeling isolated is a frequently reported emotional concern among people with chronic illnesses, including IBD patients (Schneider & Fletcher, 2008; Hughes et al, 2013). Notions of *connectivity,* a therapeutic affordance recognised by Merolli et al (2014) underpin definitions of emotional and social support. The connection between two or more people who find themselves in a similar situation (such as sharing the same illness) mitigates feelings of isolation (Merolli et al, 2014; Coulson, 2013) because they can offer empathetic understanding.

2.2.7 Emotional Support Behaviours

With patients having shared lived experiences of their illnesses, there is often a sense of mutual understanding and empathy within these communities that may be absent from offline support (Allen et al, 2016; Newman et al, 2011; Tannis, 2008). Empathetic support is communicated through comforting, encouragement, and affirmation (Tannis, 2008). It is described as socio-emotional support for it requires others to offer this understanding. The perception of similarity and shared understanding is "part of a basic need to belong which can reduce feelings of isolation," (Tanis, 2008: p.700; Coulson, 2013; Brewer, 1991; McKenna & Bargh, 1998; King & Moreggi, 1998).

In an IBD forum, 11.3% messages exchanged from 1505 messages in the data set, were identified as being replies empathetic in nature (Malik & Coulson, 2011). Giving encouragement is another reported behaviour of emotional support when patients motivate others to think more positively about a situation (Prescott et al, 2017) or to perform a particular action such as seeking medical advice (Moore et al, 2015). Meanwhile, one study describes how patients motivate themselves by encouraging others (Newman et al, 2011). Finally, companionship, which is also known as network support, is the general chatting about other non-health related topics and humour (Wang et al, 2012). Companionship, often in the form of seemingly off-topic discussions, can help patients get to know each other personally as they discuss topics beyond their health; some patients may continue to bond in other online spaces (Newman et al, 2011).

2.2.8 Outcomes of Emotional Support

Previous research has recognised the benefits of receiving health-related emotional support on the internet. In Coulson's paper on an IBD forum, participants remarked that "knowing you are not alone in your suffering and symptoms. There is always someone to talk to and communicate with," and "you do not feel alone, you realise how many people are going through the same emotional distress etc as you," (2013: p.5). Beyond reduced feelings of isolation (Malik & Coulson, 2011; Coulson, 2013), there have been reports that feeling part of a community helps patients to cope with their condition and its impact (Tanis, 2008; Allen et al, 2016; Ruckenstuhl, 2016), as well as a reduction in stress (Welbourne et al, 2012).

2.2.9 Limitations of Emotional Support

As a result of the geographical distribution of patients who use online health communities, instrumental support, the ability to run errands and give a hug, is extremely low and often not experienced from using the internet to seek support.

Reading the experiences of others enables patients to compare their illness to others. In some cases this may be demoralising to patients because they might become anxious about their future with the illness (Coulson, 2013; Allen et al, 2016). Finally, not all the comments shared on the internet are useful or supportive; Malik and Coulson (2011) identified one thread that sparked 7 negative comments following a patient sharing their experience of cannabis use for their IBD. While negative comments are infrequent, they may have a negative effect on patients' well-being. It should be pointed out that a moderator of the forum did intervene on this thread, thus highlighting the role of admins and moderators to foster a safe environment.

2.2.10 Affordances of using Social Media Platforms for Online Health Communities

The literature that focuses on social support agrees that information support and emotional support are the most frequently observed interactions in online health communities. Researchers have focused their attention towards understanding how the therapeutic outcomes of using digital technologies can be understood through an affordance theory perspective (Merolli et al, 2014; Coulson, 2017).

Stemming from perceptual and cognitive psychology, Affordance Theory is based on how individuals perceive their environment, identifying objects within it and the potential actions the objects can afford (Gibson, 1977). In *The Design of Everyday Things,* Norman (2016) emphasised the importance of object design so that individuals can perceive their affordance before taking action. This design approach positions technologies as objects with functional, cognitive and sensory affordances and has been significantly referenced in human computer interaction (HCI) research (Pozzi et al, 2014).

Hutchby (2001) argued however, that while functional affordances are designed and built into objects, the experienced affordances are open to interpretation. Individuals bring their own preferences, beliefs, motivations, and, experiences to an object; these converge to allow imagined affordances to be realised (Zhao et al, 2013; Nagy & Neff, 2015). Nagy and Neff (2015) contend that imagined affordances emerge between users' perceptions, attitudes, and expectations in addition to the functionality of the online service. Butcher and Helmond (2017) are critical that this theory of imagined affordance neglects the emotional aspects of human computer interaction. When considering an individual's expectations and experiences of an online platform through a cognitive and emotional lens, imagined affordances supports Norman's belief that everyone's experience of objects is unique (Norman, 2016).

To understand the role of social media in OHCs, Merolli et al (2014) established a model through an affordance theory approach. Through the analysis of a survey responded to by people living with chronic pain who use OHCs, the SCENA Model of Therapeutic Affordances of Social Media (SCENA) was created. The affordances identified included self-presentation, connectivity, exploration, narrative and adaptation.

Drawing on sociology scholarship, *Self-Presentation* offers the notion that people choose how they present themselves in different scenarios (Leary & Kowalski, 1990). Social media enables people living with an illness a platform for how they wish to present themselves on the internet. For some, they might publicly associate themselves with a health condition, which can help attract new members to online communities and raise awareness (Bernardi, 2016). Others may feel uncomfortable with being personally associated with a condition and choose to disclose under a pseudonym or in private groups (Shoebotham et al, 2016). Ways in which people manage their self-presentation is further discussed in Chapter 3 (See: 3.3).

Connection, which offers "the ability to connect with others, and participants used this connection to support each other, exchange advice, and to try to overcome feelings of loneliness" (Shoebotham et al, 2016: p.8). Connection has been reported to be the most frequently discussed affordance of social media-based online health communities (Merolli et al, 2014; Shoebotham et al, 2016; Bernardi, 2014). Merolli et al (2014) emphasised how a key objective of accessing OHCs is to mitigate feelings of isolation through connection. Bernardi (2016) observed that social media platforms afford people with chronic illnesses to build a support network, through leveraging features such as hashtags on Twitter. Secondly, having access to a global network of people means that people are responded to quickly, providing them with timely support when it is needed (Bernardi, 2016).

As previously explained, *Exploration* and *Narration* refer to the seeking and sharing of information. *Exploration* refers to "learning by searching and sharing practical information" (Bernardi, 2016: p.8). Meanwhile, *Narration* allows individuals to not only tell their own story, but to read about other people's experiences. Through self-disclosure and interaction with other community members, the literature indicates that patients receive emotional support and develop a stronger sense of empathy and community cohesiveness (Merolli et al, 2014; Bernardi, 2016).

Finally, *Adaptation* refers to the ability to use social media platforms, and their features, in response to their motivations and requirements. Merolli et al (2014) most prominently observed this affordance through social media's utility "in allowing participants to alter their self-management when pain flared or health deteriorated" (p.10).

2.3 Summary

To summarise, people living with IBD face a lifetime of care and illness management and it can have an impact on different areas of people's lives from their work, personal relationships and mental health. Online health communities, like face-to-face support, has been shown to help improve people's perceived quality of life and coping mechanisms living with their illness, learning to accept their new normal. A significant benefit of using asynchronous networked technologies means that people can benefit from the posts that have accumulated over time, providing them with access to experiential information. The nature of people’s self-disclosed experiences varies from symptoms and medications through to surgery. Previous studies indicate that people living with IBD may feel embarrassed and stigmatised by their illness, yet there is also a significant amount of personal experiences shared in a public setting (accessible by researchers). Indeed, this evokes questions around the role of privacy in online health communities, which shall be explored further in the next chapter.

CHAPTER 3: PRIVACY ON THE INTERNET

3.0 Introduction

This chapter seeks to explore the concept of privacy and how it is imagined and negotiated on the internet through OHCs. Drawing on literature from different disciplines including law, philosophy, computer science and psychology, this chapter outlines the importance of privacy in society and how it translates in the social media context. Specifically, it distinguishes two privacy categories: social privacy and information privacy. The chapter explores both of these categories, outlining their meaning, and how they are experienced and negotiated by people using online health communities. It concludes by positioning the focus of this thesis according to the gaps in the literature that have been identified through this review.

3.1 Contextualising Privacy in Society

The notion of privacy has deep philosophical roots that stem back to Aristotle, who conceptualised 'the private' as a sphere protected from the public gaze (Swanson, 1994). Public baths and shared living quarters were commonplace until the Renaissance period (Ferenstein, 2015), yet in ancient Greece some buildings were designed with windows to maximise available sunlight while reducing the view from others (Burke, 2000). Though increasing privacy behaviours were demonstrated throughout the Industrial Revolution, it wasn't until 1890 that privacy was acknowledged as a political right. Building on

Aristotle's philosophy of the private sphere 'The Right to be Let Alone' (Warren & Brandeis, 1890) demanded that people should have the choice to seclude themselves from observation and judgement of others.

The 20th Century was witness to systemic political surveillance in Nazi Germany and Soviet Russia, inspiring George Orwell's fictional totalitarian 'Big Brother' state in his novel *Nineteen Eighty-Four: A Novel* (1949), which popularised semantic terminology for oppression and surveillance culture. Laws that followed this period limited surveillance powers of the state and large institutions and strengthened privacy for individuals (Nissembaum, 2004). However, contemporary privacy scholars, whose work focusses on privacy with digital technology, describe the 11th September 2001 terrorist attacks on North America as a turning point for current privacy debates, when the prioritisation of national security gave way to mass data collection of citizens across the globe (Solove, 2007; Greenwald, 2014; Angwin, 2014; Schneier, 2015).

State surveillance has been regarded by privacy scholars as a threat to individual privacy (Solove, 2007; Greenwald, 2014; Schneier, 2015) and can inhibit people from engaging in certain activities, fearful of the potential consequences (Solove, 2007). However, government agencies are not the only threat, with commercial entities employing mass data collection and processing systems through internet services (Zuboff, 2015; Cinnamon, 2017). Many scholars employ the term *dataveillance* (Clarke, 2003; Ashworth & Free, 2006; Solove, 2007; van Djick, 2014; Cinnamon, 2017), which refers to the "systemic use of personal data systems in the investigation or monitoring of the actions or communications of one or more persons," (Clarke, 1988: p.31). Though drawing on similar concepts, "surveillance presumes monitoring for specific purposes, dataveillance entails the continuous tracking of (meta)data for unstated preset purposes," (Dijck, 2014: p.205). Finally, the notion of *surveillance capitalism* refers to the commodification of personal data through dataveillance (Zuboff, 2015). While some refer to privacy and personal data as a commodity which follows the idea that "is it's free, then you are the product" (Lewis, 2010: p.1), Zuboff (2019) argues that the very services and products that collect, process, and monetise personal data, are so deeply woven into the fabric of normal life that dataveillance is unavoidable.

3.2 Conceptualisations of Privacy

Despite having a long history, through politics, architecture and everyday activities, privacy is both widely understood yet challenging to define. Legal scholar Solove (2007) writes "privacy is not reducible to a singular essence; it is a plurality of different things that do not share one element in common but that nevertheless bear a resemblance to each other," (p. 756) and therefore shall never be universally defined. Many definitions share similar properties including control, ownership and the flow of information (O'Hara, 2016). One of the most popular definitions has been put forward by Public Law scholar Westin (1967):

> *"the claim of individuals, groups, or institutions to determine for themselves, when, how and to what extent information about them is communicated to others,"* (Westin, 1967: p.7)

This definition positions autonomy and control of information as a core feature of privacy. However, the claim that an individual can control information about them, and therefore their privacy, has been contested by others. Legal scholar Gavison (1980) maintained that individuals cannot personally control the flow of information between other parties once it has been disclosed. She also highlighted that information can be obtained through means other than intentional disclosure (Gavison, 1980), such as through surveillance or dataveillance techniques (Solove, 2007).

Solove (2011) presented a taxonomy of privacy that mapped four stages of how information flows from an individual to second and third parties. The first stage is *information collection* which refers to both voluntary disclosure and unsolicited dataveillance (Gavison, 1980). Indeed at this stage individuals will have a certain degree of agency over what they self-disclose on social media platforms (Joinson et al, 2006; Taddicken, 2014), including the choice of whether they use truthful information when signing up to a platform, such as date of birth (Angwin, 2014; Kosyfaki, 2017). The extent to which a person can control themselves as subjects of dataveillance is called into question with pervasive tracking technologies and social pressures to use particular services (Zuboff, 2019).

Information processing describes the analysis of collected information for secondary use (Solove, 2011). In the context of social media platforms, their business models centre around serving targeted ads to individuals based on their inferred interests and demographics (Dewey, 2016). The algorithms developed to process this information are not public knowledge and are constantly changing; however, the literature observes how individuals try to make sense of why they have been served particular adverts based on their perceived habits (Ruckenstein & Granroth, 2019).

The third stage, *information dissemination*, pertains to the sharing of personal information, or algorithmic decision making with third parties (Solove, 2011). It was at this stage that Angwin and Stecklow (2010) reported people's discomfort with Patients Like Me, an online health support forum, admitting that they share information with third parties including pharmaceutical companies.

Finally the fourth stage, *invasions*, refers to how information can be used to interfere with an individual's personal affairs (Solove, 2011). Contemporary privacy scholars are concerned with algorithmic decision making that can have a significant impact on someone's life, such as their ability to get a loan, or insurance (Crawford and Schultz, 2014; Scism, 2019).

Information science scholar Nissembaum (2004) proposed the concept of *contextual integrity* that suggests privacy is defined by the socially constructed norms that frame a given situation. The appropriate flow of information in a given context is defined by who is sending the information, who is receiving it, what are their roles, how it is being transmitted and the information itself. In some contexts, how information is transmitted and processed is governed by law, such as in the healthcare sector. A patient will disclose information about their health concerns in a private room to a medical professional, who is bound by law to keep this information confidential from others who do not have a legitimate interest in the patient's health. It is acceptable for information to be shared with another medical professional, but it is inappropriate and unlawful to share it with someone else outside the medical setting, such as a friend. It is when the context is compromised that privacy is violated. In keeping with the notion that privacy is contextually constructed, Marwick and boyd (2010) describe a privacy violation as a *context collapse*.

Though contexts can be created through mutually understood social and lawful norms (such as data protection laws), they are also supported by architecturally defined boundaries such as walls, windows, curtains and locks (boyd, 2008). boyd argued that physical features "help people have a sense of just how public their actions are," (2009: p.14). However, with an increasing amount of people connected online and social convergence becoming the norm (boyd, 2008), it is suggested that the line between private and public spheres on the internet is blurred (Papathanassopoulos, 2015).

To further the complexity of private and public, there are two distinct contexts in which people's information flows through social media platforms.

Privacy can be categorised into *social privacy* and *information privacy*[8]. The following sections will explore both of these concepts and how they relate to online health communities. As the IBD online community has not previously been subject to privacy-related research, the following discussion draws on literature from other conditions.

3.3 Social Privacy

The concept of social privacy describes the flow of information from an individual to other people using the internet (Lutz & Strathoff, 2011). With social media platforms working as a central environment for individuals to manage communications with different networks, social privacy is an important part of people's online experiences (Marwick & boyd, 2010). Lutz and Strathoff (2011) suggest that social privacy is "accessible and easy to understand," (p.85) as people can imagine their audiences, evaluate the privacy risks[9], and can manage their information disclosure through different means (Raynes-Goldie, 2012).

From a social psychology perspective, the social privacy risks that have been identified for individuals engaged in online health communities include employability, discrimination, fear of stigma and being judged, impact on personal relationships and fear of being hurt by others (Naslund & Aschbrenner, 2019; Moore et al, 2016; Patterson, 2013; Zhang et al, 2018). While people living

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[8] 'Organisational' and 'institutional' privacy have also been used in the literature to describe this.

[9] Privacy risks are the perceived negative outcomes if a context collapse occurs and the likelihood that it will happen.

with chronic conditions have a wide range of social privacy concerns, previous IBD-related research has mined significant amounts of publicly available data that pertains to people’s health, including symptoms and medication side effects (Roccetti et al, 2015; Britt, 2017) and surgery experiences (Frohlich and Zmyslinksi-Seelig, 2012).

While previous research on online health communities have focused on social support, Merolli et al (2014) proposed a framework that indicates the therapeutic affordances of social media in the context of OHCs. While the SCENA model proposes five affordances, the theme of *self-presentation* bears similarities with social privacy controls. Self-presentation describes how individuals attempt to manage other people’s impressions of them (Leary & Kowalski, 1990). Sociologist Goffman (1959) proposed that in social settings and circumstances, self-presentation is controlled differently depending on the context and their role within it. In the context of health communities, individuals may choose different ways they want to talk about their health depending on the context (O’Hara, 2016). Social media platforms offer different technical features that provide individuals with agency over these contexts and what they share within them (Merolli et al, 2014).

When we consider privacy to be the maintenance of information flows in a context (Nissembaum, 2004), disclosure alone does not demonstrate a sacrifice of privacy (O’Hara, 2016). Disclosure to whom, in what setting and under what conditions must also be considered to understand the full context in which information is shared (Nissembaum, 2004). To preserve the contextual integrity of their information, individuals in OHCs have been reported to mitigate social privacy risks through their online behaviours: self-censorship, audience management and disclosing anonymously.

3.3.1 Self-Censorship

An individual can exercise self-censorship controls over what and how frequently they self-disclose on social media platforms. Most individuals who have a health condition, such as IBD, choose not to self-disclose at all (Kosyfaki et al, 2017). As discussed in the previous chapter, *lurking* behaviours are associated with information seeking motivations in IBD online health communities (Coulson, 2015). However, in privacy studies, non-disclosure is also correlated with increased social privacy concern (Joinson et al, 2006; Taddicken, 2014). Liao's (2019) survey study about privacy concern, health disclosure, and gratifications on social media observed that non-disclosers have a higher privacy concern than those who post. In a study exploring Facebook support groups for new mothers, Chalklen and Anderson (2017) reported that lurking offers a "risk-free way of accessing the extra social insight afforded by Facebook without being subject to the judgment," (p.4). Though limited, the literature that observes the relationship between privacy concern and health disclosure supports the privacy calculus, which broadly suggests a bidirectional relationship between privacy concern and self-disclosure: with increased concern, non-disclosure increases (Li, 2012). A fuller review of the privacy calculus is found in Section 3.4.3.

A qualitative study by Brady et al (2016) offers some insights into how social privacy is managed through self-censorship in an OHC context. One participant reported blogging about their personal health experiences with their known identity. She described how decisions over what to share were made carefully, with consideration of potential context collapse; she disclosed only what she felt confident about explaining in a different context, such as in a job interview. The same participant further described how her fertility complications and subsequent treatments were “too personal, too vulnerable [to blog about], especially when we are right in the middle of it” (participant quote from p.5, 2016); however, after successfully becoming pregnant she chose to write about her experience. The cause for privacy concern and self-censorship was not regarding the information itself, rather it was “shaped by the need to control the context in which the information was,” (p.5).

Frost et al (2014) whose research focused on cancer OHCs demonstrates that although there is high self-disclosure of health information, individuals often do not share any other personally identifying information, such as what occurs in their personal life, in these community spaces. It suggests that participation is specific to health support gratifications and sharing other aspects of life is not necessary. This idea that self-censorship differs depending on who might receive information offers the idea that audiences are managed.

3.3.2 Audience Management

O’Hara (2016) illustrates how audience management online is a core part of maintaining contextual integrity as “a person may be private as part of a group, but not be private within that group,” (p.87). With reference to the limited previous research that indicates individuals with a health condition are more likely to self-disclose personal information on the internet, it is important to recognise privacy management techniques such as audience segmentation.

In social networking studies, Granovetter (1973) proposed that the combination of frequent interactions, the mutual disclosure of ‘intimate’ topics, and emotional intensity, demonstrates the strength of an interpersonal tie between individuals. In studies of healthy participants Bazarova et al (2012), Litt and Harggitai (2016), and Zhang et al (2018) concluded that higher disclosure occurs more frequently with strong network ties (such as family and close friends) than with weak network ties (friends of friends or acquaintances). However, a study of OHCs (Liao, 2019) indicated that only 9.5% of people who self-disclosed health information, which is considered to be sensitive, did so with their family and friends. Furthermore, 50% of self-disclosure occurred on platforms with weak ties, such as social media subgroups, online forums and blogs (Liao, 2019). This supports O’Hara’s claim that individuals may be private as part of a group but may not be private within that group (2016). It is surprising that health information, which is legally (General Data Protection Regulation, 2016) and sociologically (Bansal et al, 2010) considered to be sensitive, is shared frequently with weak ties, particularly as weak ties are also considered to be less trusted to respect privacy (Jung & Rader, 2016).

An explanation for why health information is more freely self-disclosed amongst OHCs is the trade-off for perceived information and emotional support (Zhang et al 2018). Zhang et al (2018) observed that individuals with poorer health perceive more effects of information benefits on their disclosure behaviours than healthy people. Meanwhile, Liao (2019) concluded that gratification positively correlated with higher reports of health disclosure, suggesting that positive experiences from sharing information, such as receiving support, will encourage disclosure in the future.

However, individuals who self-disclose health information on the internet recognise that there are some privacy risks (Patterson, 2013). There is evidence indicating that they understand that when data is permanent (until deletion) and available for the public to read (Brady et al, 2016), the author loses control of its audience and the context by which it might be received (Gavison, 1980). People living with a chronic illness have been reported to negotiate the technologies available to them to manage their audiences. In Brady et al's interview study (2016) with 20 individuals who live with myalgic encephalomyelitis and chronic fatigue syndrome, participants described using "other methods of communication, such as live chat, instant messaging, emails, or private messages," (Brady et al, 2016: p.6) to increase control over the intended audiences.

Audiences may also be managed across different social media platforms (Patterson, 2013). In a study that focuses on sharing of health data created through wearable devices, Patterson (2013) found that "most [participants] were vehemently opposed to sharing health information across [social media] services," (p.37) for fear of being negatively judged by unintended audiences. Patterson (2013) discussed how social media platforms are used for different contexts: "as a general rule of thumb, people I interviewed used Facebook for communicating casually with family and friends, Twitter for sharing and receiving information about work, Fitbit for sharing information about light-natured health and wellness issues, and health support groups for discussing more specific and intimate health issues," (p.39).

It appears that individuals with long-term conditions or poorer health disclose more sensitive information about themselves with weaker ties online; however, the literature also indicates that individuals negotiate the available technologies to segment their audiences to control their self-presentation and reduce risks of context collapse (Brady et al, 2016; Patterson, 2013).

3.3.3 Anonymity

Being able to participate in OHCs anonymously is another explanation for increased health disclosure online (Braithwaite et al, 1999). In Coulson (2013), participants described how being anonymous in IBD forums enabled them to feel comfortable with speaking openly about their symptoms and experiences.

Being able to disassociate from one's real identity and participate anonymously on the Internet has been found to positively influence self-disclosure of health information (Braithwaite et al, 1999; Frost et al, 2014; Brady et al, 2016; Kosyfaki et al, 2017; Liao, 2019). In a study by Kosyfaki et al (2017) that explores the privacy paradox and health disclosure behaviours online, it was found that 70% participants prefer anonymous and pseudonymous posting. This finding however is not supported by Liao's (2019) research that concluded that compared to healthy individuals, people with a severe health condition are more like to disclose their real identity on social media. The reasons why individuals in this study prefer to remain identifiable is unclear; it might be from personal choice, or whether the social media platform they used did not enable anonymity.

In an interview study focusing on privacy concerns expressed by members of diabetes and chronic fatigue syndrome (CFS) web-based forums, Brady et al (2016) described the different techniques employed by individuals based on their personal preferences and concerns. Though some discussion threads may have restricted access to members, the posts in web-based forums are accessible to non-members. Participants in Brady et al's study (2016) reported that they employed pseudonyms to increase their privacy. For one participant, her condition was reported as "an intensely personal experience," (p.5) with only two people in her life knowing about her diagnosis. It was important for her not to be identifiable to people that personally know her. Despite already engaging in a web-based forum, separate from her social media-based networks, using a pseudonym added an additional layer of control, providing enough comfort to self-disclose about her health.

Anonymity on contemporary social media platforms can be difficult when the user agreement requires people to use their real name. Facebook employs a known name policy whereby “the name on your profile should be the name that your friends call you in everyday life. This name should also appear on an ID,” (Facebook, 2020: para 10). This means that individuals who use Facebook to access IBD support communities will be identifiable and anonymous self-disclosure is impossible. Other platforms, such as Twitter and Instagram however do not enforce ‘known name’ policies, giving individuals the choice to employ a pseudonym.

Through quantitative (Kosyfaki, 2017; Zhang et al, 2018; Liao, 2019) and qualitative methods (Patterson, 2013; Brady et al, 2016), research exploring privacy and online health disclosures, there is evidence to suggest that individuals pay attention to their online identity and the management of information flows (Patterson, 2013; Brady et al, 2016; Liao, 2019). They make careful decisions around what they choose to disclose, with whom, and through which technologies as a means to maintain contextual integrity. Some might participate in public forums but adopt pseudonyms to protect their real identity (Patterson, 2013; Brady et al, 2016). Others may choose to use their real identity (chosen or as a consequence of the platform they use, such as Facebook) but share in controlled environments such as specialist groups (Liao, 2019) and direct messaging (Brady et al, 2016).

3.4 Information Privacy

The other context of online privacy is how information flows between users, the platforms providers, and third parties. Information privacy[10] refers to how information flows from people using the Internet, platform providers and other companies or organisations (Lutz & Strathoff, 2011). O'Hara (2016) contends that while individuals may have controls over their social privacy, their data "may be given away freely or sold," (p.87) in exchange for a service, such as a social media platform. In 2017, privacy and identity specialist Wilton described how our online interactions are mediated through a service provided by a company; we send emails through a client (like Outlook and Google), browse the internet through a browser (like Google Chrome and Safari), and connect with friends and communities through social media platforms (like Facebook, Twitter and Instagram). The business models of these platforms rely on collected user data to target advertising; therefore, often personal data and indeed privacy is often perceived as a kind of currency or asset (such as oil) to be traded (Patil & Shyamasundar, 2017).

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[10] Information privacy is often interchanged with organisational, institutional or data privacy.

Online information collection usually happens at scale and through big data computing (Crawford & Schultz, 2014). Individuals disclose information to social media platforms on sign up and through day-to-day use, such as uploading pictures and sharing status updates. People’s data is also subject to dataveillance whereby behavioural information, or metadata, such as location, time accessed, devices, likes, groups joined and so on, is also collected (Angwin, 2014). Together these data sets can be used to create a detailed picture of individuals (Crawford & Schultz, 2014), employing algorithms to make inferences about people and their interests. In 2016, it was reported that there were nearly 100 data points that could be inferred about Facebook users for advert targeting (Dewey, 2016). One example given was the identification of users who buy over the counter medications, indicating that Facebook has an algorithm that monitors health in some way (Dewey, 2016). It is this mass surveillance, or ‘dataveillance’ (Clarke, 1988) that has brought concern amongst journalists, policymakers and academics, who argue that personal freedoms are under threat and online companies have an unreasonable amount of information about their users (Curran, 2018).

The dilemma that researchers and privacy advocates face is that the data collection and algorithmic processes that social media platforms employ are not transparent to their users. Firstly, the documents that outline how social media platforms use people’s personal data (privacy policies) are verbose (Wang, 2017). And secondly, the algorithms that process personal data to make inferences about individuals are hidden from public knowledge (Cinnamon, 2017). As a result, there is an asymmetry of knowledge between the companies that create the platforms and the rest of the world (Lanier, 2014), with experts and everyday users alike not having a clear understanding of the context in which personal information flows.

Instead of having agency over how their information is collected and processed by online services, individuals are presented with privacy agreements that stipulate the terms of how user data is used. The minority of internet users admit to having read these documents (Debatin et al, 2009; Patterson, 2013; Rao et al, 2016; Obar & Oeldorf-Hirsch, 2020), including individuals participating in online health communities (Patterson, 2013). As a result, Rao et al (2016) warn that online service users are unaware of the context that their information will be used and ultimately exposes them to “unanticipated privacy risks,” (p.77).

It has been routinely noted that while the verbosity of privacy policies may serve a legal requirement, they require a high level of language proficiency (Patterson, 2013; Wang, 2017) and a lot of time to read them (Rao et al, 2016). A study that explored the interpretations of privacy policies by the general population, knowledgeable users, and privacy policy experts suggested that the policies are “too ambiguous to be meaningful,” (Reidenberg et al, 2014: p.83). When individuals do not read or understand the policies, but still want to use free online services, it “introduces a pervasive requirement for [individuals to] trust,” (Wilton, 2017: p.2) companies to use the information appropriately.

Furthermore, while companies like Facebook aim to have “1 billion people join meaningful communities” (Facebook, 2017: para 9), social media platforms have been under increasing pressure to be more transparent about their commitments to information privacy (Lomas, 2018). In 2011 Facebook settled an eight-count privacy complaint to the Federal Trade Commission over its “deceptive” (p.4) privacy practices (Leibowitz et al, 2011). By 2017, Facebook was receiving multiple complaints from European Watchdogs (Data Protection Authority, 2015) and a €110 million fine from the European Commission (Cardosa & Tsoni, 2017).

Indeed, the machine learning algorithms under which user data is processed are considered to be ‘black box’, which suggests that the algorithms become so complex they’re only understood by the inputs and outputs (Montgomery, 2019). According to their privacy policies, social media algorithms are used to infer people’s interests and demographics to deliver targeted advertising (Ruckenstein and Granroth, 2019). Privacy scholars are concerned about when personal information is used to make life-changing decisions about individuals through algorithms. A recent example of this is when the UK Government made a U-turn on its algorithmic model to predict A-Level students’ grades, which had an impact on young people’s ability to get into their chosen universities (Carroll-Meehan, 2020). There are challenges for individuals to understand how a decision is made; Crawford and Schultz (2014) and Cinnamon (2017) described how when a claimant cannot see evidence as to why a decision is made through an algorithm it "renders people voiceless to challenge any misuse of their personal data,” (Cinammon, 2017: p. 612). Finally, it should be noted that algorithms are written by humans and therefore subject to all manners of bias, such as racial discrimination (Angwin et al, 2016), which can influence its outcome. As a result, individuals have little way of knowing how their information is used, whether it benefits them or not.

3.4.1 Information Privacy and Trust

Trust is a multi-faceted concept that is often underpinned by notions of risk and vulnerability. Mayer et al (1995) suggest that trust is the “willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party” (Mayer et al, 1995: p.712). There is also a relationship between trust and risk insofar as “one must take a risk in order to engage in trusting action,” (Mayer et al, 1995: p.724) which indicates that whenever a service provider is trusted, risk is assumed. These risks might be known, such as the risk of data theft in a cyberattack, or they might be unknown because privacy policies have not been read, are misunderstood or aren’t explicit.

The literature often explores trust through three themes of ability, benevolence and integrity (Mayer et al, 1995). Ability refers to the skills, competencies and experiences held by the trustee to perform in a specific context. Benevolence is the belief a trustee wishes to support others for reasons beyond their own merit and cares about the outcomes. Finally, integrity is the perception that the trustee adheres to a set of principles that the trustor finds acceptable.

In the context of online health communities, trust can be considered through an interpersonal as well as an institutional lens. When considering technological trust, ability is replaced with ‘functionality’ of the service; benevolence becomes ‘helpfulness’; while integrity becomes ‘reliability’ (Bhattacherjee, 2002; Lankton & McKnight, 2011).

Bhattacherjee (2002) explored the relationship between ability, benevolence and integrity on people’s behaviours, finding that each of the characteristics of trust have a positive correlation with a willingness to transact with an online firm. In addition, the notion of familiarity with a service or firm positively correlated with trust and a willingness to transact and share personal information.

In a study by Lankton & McKnight (2011), that explored how individuals trust Facebook, individuals assigned both interpersonal and technological trusting characteristics on the platform. Lankton and McKnight concluded that individuals perceived and trusted Facebook as a “quasi-person” (p.49) whereby both interpersonal and technological attributes are attributed to the platform, suggesting that users are aware that Facebook as an organisation, not simply a technology, makes conscious decisions in the way they use personal data.

Previous research has examined the role of trust in online behaviours. In a study on healthy participants, Mesch (2012) found that trust in online services was positively correlated with disclosure intentions. Secondly, trust is also associated with continuance intention of using an online platform (Pentina et al, 2013; Taşkın & Taşkın, 2019). However, recent reports indicate that trust in social media platforms is lower than ever before (Arnold, 2018; Rad Campaign, 2018). Despite this supposed crisis in trust, social media platforms such as Facebook, Instagram and Twitter continue to grow their active monthly user base (Facebook, 2019; Twitter, 2019).

While there have been previous studies to explore interpersonal trust within online health communities (Fan et al, 2010;2014;2018; Sillence, 2010), there is a lack of scientific evidence over how far individuals trust social media platforms with their health information.

3.4.2 Information Privacy Risks

When the context of information flows is not understood, articulating actual risks is problematic (Patterson, 2013), particularly when privacy violations are often anecdotal and the resultant harms are unclear. For individual users, perceived information privacy risks include unwanted, targeted advertising (Lutz & Strathoff, 2011). Platforms use the inferences made about users to create audiences for advertisers, purportedly enabling them to market more directly to their potential client base. Third-party cookies that are downloaded into the browser are also used to show adverts to users of products that they might have recently viewed online (Tsuei, 2010). These practices can result in a sense of being followed around the internet, which feels “creepy” to some people (Thode et al, 2015; Ur et al, 2012; Ruckenstein & Granroth, 2019).

Patterson (2013) discusses the privacy risks of quantified health apps, which is where a lot of personal health information is also disclosed and shared with internet-based companies that have opaque privacy policies. She describes the granular and ubiquitous information collection which “results in corporations holding vast treasure troves of highly personal health data about tens of thousands of users—health and wellness libraries with unprecedented and complete entries of incalculable value to business associates, employers, and insurance companies” (p.9). And once information has been shared with third parties, often without the user’s knowledge, understanding how it is used and whether it is combined with another data set becomes an impossible task (Patterson, 2013). In her study, participants described commercial researchers, such as pharmaceutical companies as “greedy and horrible” (p.43) and believed that “very few people are benefitting” (p.43) from their research.

When individuals do not have knowledge on how social media platforms collect and process their data, the information privacy risks become perceptions over informed judgements. Rao et al (2016)[11] found that in a comparison between user expectations and the stipulations in privacy policies, people with lower understanding of information privacy are more likely to have a mismatch in their

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[11] It should be made clear that this study is not based specifically on people’s risk perceptions of health collection on social media platforms.

expectations of how personal data is used by online platforms, insofar as they believe that more information is collected by websites than is described in the privacy policy. In online health community research, it has been routinely reported that individuals with a lower level of education are also more likely to have increased privacy concerns (Kosyfaki et al, 2017).

O'Hara (2016) refers to how individuals misperceive the privacy risks because of their non-visible and unnoticeable nature[12] (Lutz & Strathoff, 2011) as phenomenology*:*

> *"social networkers feel private as they share information and chit-chat with their small group of friends. It feels warm and social, not like the chit-chat is owned by the network. Even if a social network is open about its use of information, via its privacy policy, and its users cognizant of the widespread exploitation of their personal data in the advertising business, that doesn't mean that social networking will feel as if it is exploited by advertisers and site owners," (p.87).*

Empirical research by Kehr et al (2015) supports this notion, finding that individuals underestimate privacy risks when they are confronted with an interface that "elicits positive affect," (p.2).

An article by Angwin and Stecklow (2010) revealed the distressing impact of information privacy violations on individuals who feel safe to disclose health information in an online environment. In this news article, the investigative journalists report on how media-research firm Nielson scraped data from the

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[12] Phenomenology is bidirectional as individuals may also perceive an unnecessarily high risk to their information privacy (O'Hara, 2016).

health forum Patients Like Me, monitoring consumer insights about products for companies including pharmaceutical companies. To the users this was unknown until Patients Like Me issued a notice explaining what had happened. Within this notice, they brought to their users' attention their own privacy policy which explicates that they also analyse and sell user data. A forum that once felt like a safe haven for users to share their stories and speak about their illnesses, left those who used the forum to share their health experiences feeling "totally violated," (Angwin, 2015: p.2). Wilton suggests that "we should ask whether there has been an ethical shortfall in the service provider's behaviour concerning collection, use, sharing, safe custody or disposal of the data," (2017: p.2) if a service provider's use of personal data comes as an unfavourable surprise.

Researchers also indicate that an absence or unawareness of previous negative experiences play a role in why privacy risks are underestimated (Song & Zahedi, 2007; Frost et al, 2014; Bansal et al, 2016). Bansal et al (2010) observed that previous positive experiences of a website reduce privacy concern and increase trust; this supports the notion of anchoring bias which is "the disproportionate reliance on the information first available when we make decisions," (Waldman, 2020: p. 106).

Meanwhile, previous negative encounters, such as experiencing a privacy violation, increases privacy concern and reduces self-disclosure motivations in online health community settings (Angwin & Stecklow, 2010; Frost et al, 2014; Bansal et al, 2016). However, negative impacts, such as privacy risks, are also expected as part of the online experience, particularly when services are available for free (Blank & Dutton, 2012).

Hallam and Zanella (2017) found that individuals who had not experienced a context collapse (privacy violation), or perceived risks to be temporally and psychologically distant, were more likely to favour the short-term gratifications. This means that longer term potential risks such as impacts on health insurance may be weighted less than the present importance of receiving support (Acquisti, 2004). However, this is not supported by Frost et al (2014) who found that younger people with higher digital literacy present higher privacy concerns because they are unsure about how it might impact their future. There is not enough evidence in the OHC field to conclusively support or discredit the psychological distancing of risk.

3.4.3 Privacy Paradox

The privacy paradox pertains to the gap between perceived privacy risks and privacy behaviours, arguing that individuals often behave in ways that contradict their concerns (Acquisti, 2004; Barth & Jong, 2017). In a systematic review of the privacy paradox literature that covers e-commerce websites, social networks and apps, Barth & Jong (2017) observed that the majority of the papers reviewed discerned a risk-benefit calculation in users' privacy-related decision making.

This rational calculation of risks and benefits is known as the *privacy calculus* (Culnan & Armstrong, 1997; Li, 2012). Intended and actual behaviour are influenced by the expected positive outcomes of self-disclosure; if the perceived positive outcomes outweigh the identified risks then the risks are discounted in favour of the benefits (Culnan & Armstrong, 1997; Acquisti, 2004; Barth & Jong, 2017). Since 1997, there has been a growing body of research around the privacy calculus, challenging how rational decision making is limited by factors including: bounded rationality, convenience, temporal discounting, and a lack of knowledge to rationally consider the risks.

One frequently reported explanation for people's inability to make rational decisions, is having limited knowledge in what the risks are (Acquisti, 2004; Lutz & Strathoff, 2011; Brady et al, 2016). The afore discussed asymmetries in knowledge between platforms and their users, such as with verbose and unread privacy policies, offers significant evidence to explain how challenging it is for individuals to understand information privacy risks. With an asymmetry in knowledge and difficulties in understanding the link between specific behaviours and negative outcomes (Brady et al, 2016), previous research has been sensitive to people's inability to process large amounts of information to make informed decisions (Acquisti, 2004; Acquisti & Grossklags, 2005; Jia et al, 2015). Bounded rationality refers to limitations in people's ability to acquire, memorise and process relevant information which means that individuals subsequently rely on simplified mental models and heuristics to support their decision making (Acquisti & Grossklags, 2005).

Indeed, psychological distortions have been the focus of several studies exploring the privacy paradox and calculus. The notion of immediate gratification (Acquisti, 2004) and the discounting of long-term risks (Hallam and Zanella, 2017) offers insights into people's preference for convenience and short-term benefits over taking more consideration over the future implications of their actions. Optimism bias and comparative bias, which is the belief that they are unlikely to be negatively affected compared with others, has also been considered (Acquisti, 2004; Debatin et al, 2009; Cho et al, 2010; Min Baek et al, 2013; Kokolakis, 2015). As such, when benefits seem to outweigh the risks, and no mitigating action is taken, people are left in the position where they trust the service providers to "act in [their] interests, even if [the providers] have the opportunity and motivation to do otherwise," (Wilton, 2017) with regard to their information privacy.

On the other end of the privacy calculus is the perceived benefits. As discussed in the previous chapter there are personal benefits to participating in OHCs, as well as supporting others and contributing to research knowledge[13] (Brady et al, 2016; Kordzadeh and Warren, 2017). These might be perceived as more important, particularly in the short term, than individual privacy concerns. It should be remembered that Zhang et al (2018) and Bansal et al (2010) both reported that non-disclosure was more likely amongst individuals with high

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[13] Participants in Patterson (2013) also indicates a strong discomfort with commercial research, such as pharmaceutical companies, accessing and using OHC data for their own benefits.

privacy concerns, indicating that the perceived benefits were not deemed worth the privacy risk. For individuals self-disclosing in OHCs, 65% of those who had left a comment and exchanged opinions had said it was “definitely worth the price,” (Kosyfaki et al, 2017: p.5) of the privacy risk.

Li (2012) proposed a model where the privacy calculus precedes the *risk calculus.* The risk calculus “is derived from the protection motivation theory, which refers to the trade-off between perceived risks and the efficacy of coping with the risks,” (Li, 2012: p.472). As such, the risk calculus recognises people’s mitigating actions which contribute towards a net privacy concern (Li 2012; Zhang et al, 2017; Lee et al, 2017).

While perceived privacy risks might be identified and weighed against the perceived benefits, Lutz and Strathoff (2011) suggest that the privacy calculus, and indeed the risk calculus “neglects the emotional and incorporated aspects of behaviour. Many actions – also online – are routinely performed or driven by irrational affective factors." (p85-86). In the health context, motivations to participate online are centred around seeking information and emotional support; individuals may have personal worries about their symptoms, medication side effects or how their illness might impact on them in the future. Kosyfaki et al (2017) supports this, stating that 65% of respondents who participate in online health communities reported that their reasons for participation were emotionally driven. This suggests that people may not think about the risks in a rational way when they are emotionally motivated to seek support.

3.4.4 Information Privacy Behaviours

Lutz and Strathoff (2011) assert that “most forms of privacy protection behaviour, such as privacy settings on SNS, can help users alleviate concerns about social privacy, but [they] do not solve information privacy concerns,” (p.94). It is possible that individuals are able to mitigate social privacy risks; however, without enough knowledge of the information privacy context, individuals may be unaware of or downplay the information privacy risks and misunderstand how to mitigate them.

Given that people with chronic conditions are “uncertain about back-end information flows because they do not have a clear, accessible, and understandable source of information,” (Patterson, 2014: p.3), it’s unsurprising that there is little evidence to suggest how people within online health communities try to protect their information privacy. While some users of online health communities mask their real names with pseudonyms primarily for social privacy concerns, one study remarked on how many still used their real email address and personal information to sign up to a service (Kosyfaki et al, 2017). To provide an example of how such users might increase their information privacy in practice, in her quest for online privacy, Angwin (2015) used an email masking service which generated unique forwarding email addresses for every online account, to prevent her data being collected and merged by third parties.

Drawing on the behaviour of self-censorship, Patterson's (2013) qualitative study focusing on FitBit (and sharing information on social media) found that one individual reported to "use the service to track her exercise and her food intake, but not her mood or personal reflections because she envisioned Fitbit employees reading her diary entries, or selling her information to third parties," (p.32). This demonstrates how participants had identified boundaries of what they felt comfortable sharing with online platforms, with the knowledge that it could be processed, shared, or sold. Kosyfaki et al (2017) and Patterson (2013) report that companies need to communicate their information flows clearly, such as in a visual manner, to better inform individuals of the context in which they are sharing health information.

Outside of the OHCs literature, research undertaken by digital risk solutions firm RSA indicates that 41% of consumers falsify personal information, such as email address and age (Ismail, 2018). Other tools are available to internet users to further control what information is collected about them, including Virtual Private Networks (VPN) and plug-ins to prevent third-party tracking cookies from being downloaded into the browser (Reidenberg et al, 2014). Scholars suggests that the use of these tools requires individuals to understand complex privacy concerns as well as having the technical proficiency to employ such privacy protections (Leon et al, 2012; Reidenberg et al, 2014). Using such tools is often perceived as an inconvenience (Angwin, 2014; Bai et al, 2016), or even "painful" (Angwin, 2014: p.197). To date, there is no empirical evidence that demonstrates whether individuals using the internet to access online health communities employ any of these strategies.

3.5 Self-efficacy and Privacy Literacy

Self-efficacy is the personal belief that an individual has the ability to influence events that shape their life and others'. Bandura (2008) contends that there are 4 aspects of self-efficacy: mastery, social modelling, social persuasion, and physical and emotional states.

Mastery, which is considered the most influential factor, demonstrates how successes build efficacy and failures limit it. However, persistence and resilience to overcome failures will overall have a positive influence on self-efficacy and an individual's belief in their abilities. Social modelling refers to "seeing people similar to oneself succeed by perseverant effort, raises observers' beliefs in their own abilities" (Bandura, 2008: p.2) while social persuasion observes the encouragement by others to persevere and believe in themselves. Finally, "positive mood enhances a sense of efficacy, depressed mood diminishes it. Efficacy beliefs are strengthened by reducing anxiety and depression, building physical strength and stamina, and changing negative misinterpretations of physical and affective states," (p.3).

The notion of self-efficacy and perceived behaviour control is a significant factor in the Theory of Planned Behaviour (TPB) (Ajzen, 1991). An extension of the Theory of Reasoned Action (TPA) by social psychologists Fishbein and

Ajzen (1975), TPA considers people's attitudes, subjective norms, intentions and self-efficacy in a behaviour change context. Both TPA and TPB are underpinned by the notion that people make rational decisions, particularly around behavioural change. Indeed, previous literature has explored the privacy paradox through a TPA lens (Roberts, 2012; Lutz & Tamò-Larrieux, 2020), finding that attitudes, social norms and self-efficacy contribute towards privacy behaviours.

With a lack of education contributing to the privacy paradox, interventions have been created to support people's awareness and privacy literacy (Sideri et al, 2019) to improve mastery (Bandura, 2008). Coming under the broader umbrella of digital literacy, privacy literacy specifically refers to the acquisition of both knowledge and skills in order for people "to be able to assess risks resulting from information disclosure, adopt technical mechanisms and strategies for combating cyber threats and, consequently, protect themselves efficiently," (Sideri et al, 2019: p.336).

Firstly, it should be noted that a significant number of the privacy literacy interventions being empirically evaluated have been in the context of formal learning environments (Vanderhoven et al, 2016; Sideri et al, 2019). Though there are many offerings on the internet that provide readers with information and activities to learn about online privacy, they have not been empirically studied for their impacts on understanding, attitudes, and behaviour (D'Ignazio & Bhargava, 2015). Examples of these resources include *Me and My Shadow*

(Tactical Tech, 2012), *Lightbeam* (Mozilla, 2019), *Do Not Track Documentary* (Gaylor, 2015), and *Immersion* (Jagdish, 2014).

In digital literacy literature, the control of personal information is generally positioned in the context of safety and security from other people on the internet, such as predators, paedophiles, and cyber criminals (Rodríguez-de-Dios & Igartua, 2016). Yet, as previously discussed in this literature review, controlling information from other people is only one strand of privacy on the internet. Indeed, the notion of 'Big Data literacy' has been used to describe the need for awareness around understanding how information is collected and processed at scale, and its impacts on individuals and society (D'Ignazio & Bhargava, 2015). The combination of understanding both social and information privacy supports a person's privacy literacy.

Privacy literacy interventions have been shown to increase privacy awareness and behaviours, and change attitudes (Vanderhoven et al, 2016). Though the scholars do not explicitly make the distinction between social and information privacy, Sideri et al (2019) remarked on how both identity management and awareness of how institutions use information should be understood in order to reduce what are considered 'risky' behaviours, such as not adjusting privacy settings.

A study set in a University context observed significant changes to attitudes and behaviours through a 13-week course entitled *Social Media: Identity, Communities and Application Environments* (Sideri et al, 2019). There were significant self-reported reductions in advertising interactions and location check-in, with an increased number of students changing their privacy settings on Facebook from open account to limited audiences, such as friends only.

In a secondary school study, Vanderhoven et al (2016) discussed that while they observed some changes, that they would expect more if the interventions ran over a longer period to give time for attitudes and behaviours to change more significantly. With scholars seeking to improve their interventions to see "stronger" (Vanderhoven et al, 2014: p.130) impacts on attitudes and behaviour, it is assumed that there are preconceived desirable privacy attitudes and behaviours, which neglects the notion that one size does *not* fit all (Toch et al, 2018; Walker et al, 2019) and individuals have their own personal preferences and privacy boundaries (O'Hara, 2016).

Furthermore, other scholars remark on how privacy preferences and attitudes may change over time (O'Kane et al., 2013; Lutz & Strathoff, 2011), suggesting that while education is important, there are other antecedents that explain people's concerns and behaviours online (Acquisti et al, 2015).

3.6 Research Gap

Through this literature review of IBD, OHCs, and privacy on the internet, research gaps were identified that formed the research objectives for this thesis' empirical enquiries.

The previous two literature review chapters have evidenced the requirements for, and benefits of, online support for people living with IBD. Having a lower quality of life as a result of the lifelong illness that impacts on different areas of a person's life, social support has been shown to improve well-being and coping mechanisms. Throughout their lifetime, people living with IBD may encounter illness-related events that motivate them to learn about other people's experiences of medications, procedures and surgeries.

Currently in the literature around IBD, there is little evidence of people's experiences using contemporary social media platforms. Guo et al (2016) and Szeto et al (2018) observed that people with IBD have reported using platforms such as Facebook, Twitter, Instagram, YouTube and Snapchat, yet their enquiries did not examine how these platforms are used or people's experiences of them. Current reports indicate that the average social media user has 8 accounts (Chaffey, 2020) therefore, it has been recognised that there is a need to understand whether online support should be observed more holistically across different platforms. Secondly, while Coulson (2015) observed marginal differences in the reported outcomes of using web-based forums and Facebook for online support, there is currently no evidence to suggest how people's experiences differ between platforms or whether the architecture of each platform lends itself to different experiences. Taken together, these research gaps led to **RO1**:

RO1: *How are contemporary social media platforms used by people with Inflammatory Bowel Disease engaging in online health communities?*

Next, the complexities of online privacy were established. From an analysis of the limited literature that specifically explore online health communities, there is some evidence to indicate that people with long-term conditions pay attention to the contextual integrity of their personal information in social contexts. In essence, research by Brady et al (2016) indicated how people with long-term conditions actively demonstrated social privacy enhancing behaviours, such as through audience management and anonymity.

While there is evidence indicating that people may recognise social privacy online, there are research gaps in people's perceptions, attitudes and behaviours towards information privacy in the context of online health communities. People's unawareness of how information is collected and processed has been recognised as an antecedent contributing to the privacy paradox. However, the invisible nature of these processes and the stochastic outcomes make it difficult for people to make connections between their online behaviours and unintended privacy outcomes. Privacy literacy, which refers to the acquisition of knowledge and skills pertaining to both social and information privacy, impacts on people's attitudes and behaviours on social media (Vanderhoven, 2014).

With inconclusive results pertaining to the relationship between self-disclosure and health status, coupled with the lack of research demonstrating how people with IBD think about and negotiate online privacy through a dual lens of social and information privacy, the second research objective was identified:

RO2: What are the privacy perceptions, attitudes and behaviours of people living with IBD using contemporary social media platforms for health-related support?

3.7 Summary

This chapter has outlined the theoretical foundations which this PhD thesis is based on. A health psychology perspective has been presented to identify the support requirements of people living with IBD, and how social support has been observed on traditional and contemporary social networks. This literature review identified different social media platforms that are used by IBD OHCs, however, few studies have explored people's experiences of them.

The chapter identifies how despite feelings of stigma and shame being associated with Crohn's and UC, there is not currently any empirical work that examines self-presentation and privacy management online. This chapter reflects on the complexities of privacy on the internet and identifies how there are two prominent constituents: social and information privacy.

With a lack of evidence from the IBD literature, this chapter described ways in which people living with long-term health conditions perceive and manage their social privacy online. These included the use of pseudonyms and heightened privacy settings. However, there is little evidence of how information privacy plays a specific role, in how people use social media platforms for health-related support. With mixed results in whether health-status plays a role in people's self-disclosure behaviours, broader literature proposed that people behave in ways that conflict with their privacy preferences. This privacy paradox is discussed as an information privacy challenge; data collection practices are invisible, obfuscated, and difficult to understand, particularly when privacy policies are unclear and not read by the majority. Privacy literacy interventions however have been shown to have an impact on awareness and behaviours amongst students in secondary and higher education.

This chapter identified the research gaps and the subsequent research objectives. The following chapters seek to address the gaps in the literature around privacy in the Inflammatory Bowel Disease online health communities on social media. The following three studies unpack people's experiences of using different contemporary social media platforms, their privacy awareness and attitudes, and their behaviours, through multiple perspectives.

EMPIRICAL RESEARCH

CHAPTER 4: STUDY 1 – Interviews with IBD Patients

4.0 Introduction

The outcomes of the literature review demonstrated that understanding privacy in social networks should be considered in a more holistic manner that considers social privacy and information privacy as separate concepts (Gürses & Diaz, 2013). Secondly, Nissembaum (2004) proposed that privacy is constructed contextually, by understanding who is sending and receiving information, the sensitivity of the information, the roles of each stakeholder(s), and how it is transmitted. While some online health community research has explored how social privacy is managed (Patterson, 2013; Brady et al, 2016); there is limited evidence to suggest how people with health conditions manage their information privacy. Furthermore, notions of online privacy have not been previously examined in the context of IBD OHCs using social media.

Taking the position that privacy is contextually constructed, there is a requirement to better understand the IBD OHC landscape. To date, literature that focuses on the experiences of people living with IBD and using contemporary social media platforms is sparse. Yet there is evidence indicating that Facebook, Twitter, and Instagram, among others, are used by people living with IBD (Szeto et al, 2018). As previously discussed in Chapter 2, research specifically exploring the outcomes of online support amongst people living with IBD, has been investigated through a social support theory lens (Coulson, 2013; Britt, 2017). While these findings offer important insights for health psychologists, this approach neglects how the platforms and features influence these outcomes. As such, this study examines the IBD OHC landscape through an affordance theory perspective (Merolli et al, 2014; Hayes et al, 2016) to yield a comprehensive picture of the relationships between social interaction, human-computer interaction and therapeutic affordances.

Taking these requirements together, this Chapter is guided by two lines of research enquiry. The research procedures and findings are presented in the following sections.

RQ1a	*How are social media platforms used by people with Inflammatory Bowel Disease who engage with online health communities?*
RQ1b	*What are the online privacy perceptions of individuals living with Inflammatory Bowel Disease?*

4.1 Study Design

4.1.1 Participants

Participants were recruited from three different contemporary social media platforms: Facebook (n=9), Twitter (n=16) and Instagram (n=13). Calls for participation were advertised through the researcher's social media accounts, on Instagram and Twitter, and were shared organically by community members. Two Facebook Groups were approached and authorised the call for participation in their support groups (IBD Superheroes; #getyourbellyout). These groups, that originate in the UK but have a global presence, yielded a high response.

Research candidates expressed their interest in the research either through replying to the study advert or by directly emailing the researcher. Through direct messaging facilities on each platform, the researcher sent an information sheet and consent form, or requested an email address to send these documents. During this time, participants were given the opportunity to ask questions about the study prior to providing consent to have their interviews recorded, transcribed and analysed. Participants returned the consent forms digitally signed through email before interview dates and times were scheduled. As part of the consent process, participants were asked to self-declare that they felt well enough to participate in the research, to reduce any burden on patients who felt particularly unwell with their IBD.

In the study, 26 participants in this study were aged between 21 and 40 years in age; 11 were older than 41 years; and 1 younger than 20 years old (Figure 1). Figure 2 visualises the platforms that participants self-reported to use for IBD-related communications according to their age. Of the 14 participants who represented the 21-30 age bracket, 12 self-reported to use Instagram for IBD-related communications, and 7 using Facebook and/or Twitter. This finding coincides with findings from the 2018 Ofcom report indicating that Facebook is being used less by younger audiences (Ofcom, 2018). The majority of the participants (n=31) were based in the UK, while 6 were from the USA and 1 from South Africa. The countries represented indicate the globality of social media

OHCs; however, the location of the participants did not appear to have a significant effect on their social media use, nor their privacy perceptions.

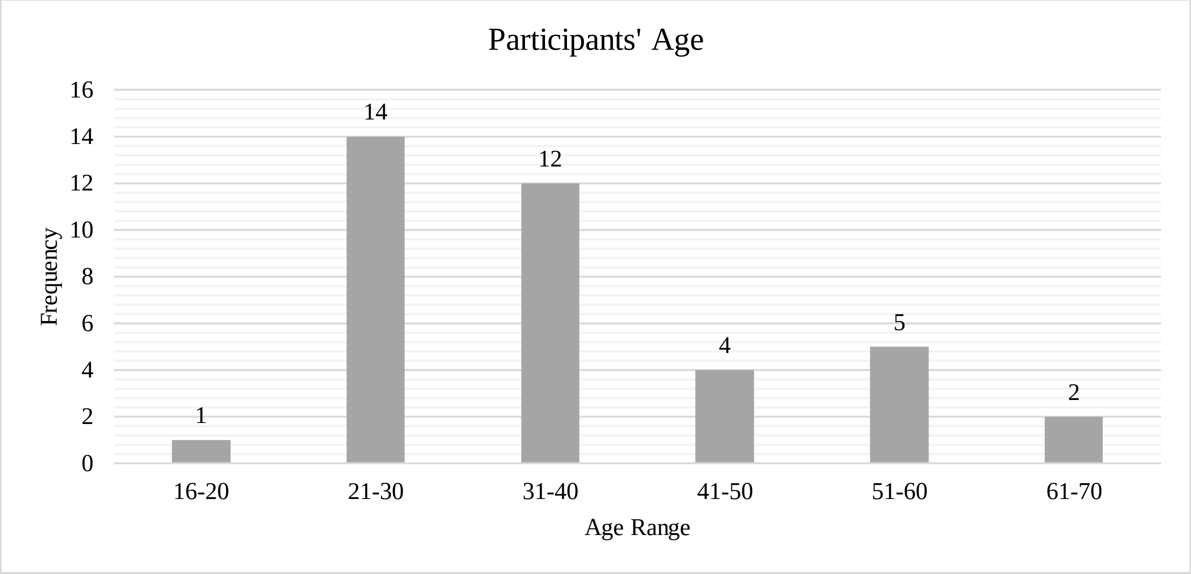

Figure 1 Bar Chart visualising age demographics of Study 1 participants

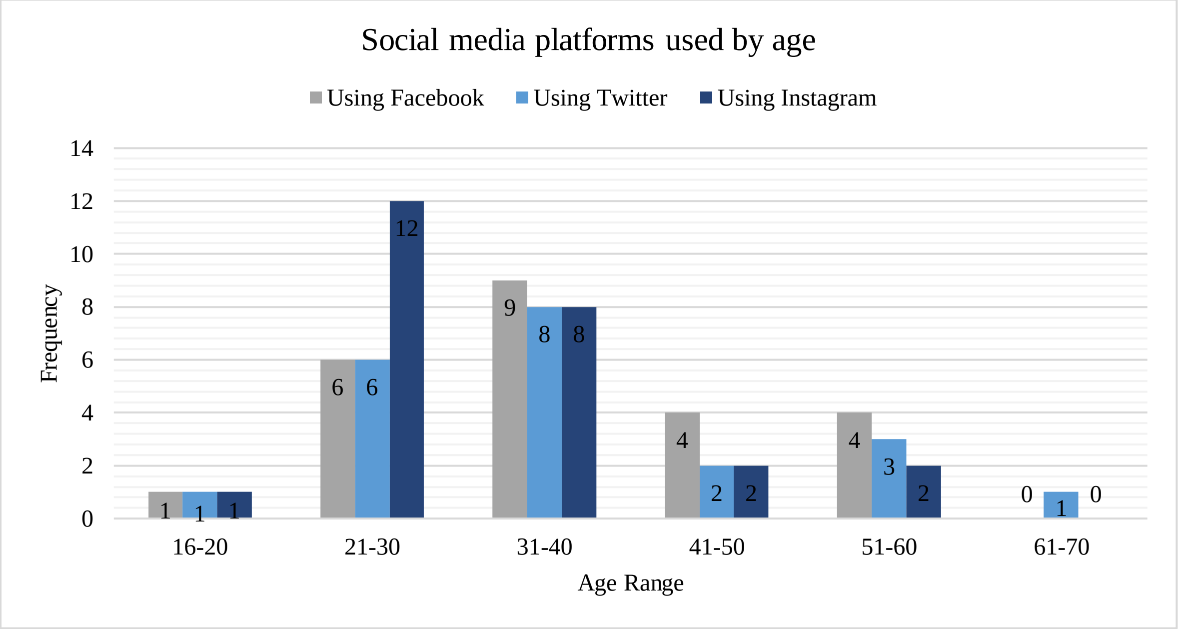

Figure 2 Chart visualising distribution of social media platform use by age

The recruitment yielded an evenly distributed data set according to gender with 53% female (n=20) and 47% male (n=18). Across this data set, it was apparent that more females used Instagram and Facebook for IBD-related communications than males (Figure 3). Females on average used one more platform than men, with 3.15 and 2.3 platforms used for IBD respectively. This result supports the findings from a recent UK national report that stipulates how women typically spend more time on social media platforms than men (Ofcom, 2018). Furthermore, participants of this study commented on the uneven distribution of males to females posting about IBD, with perceptions of men adopting more observational roles than contributors.

> *"I've noticed there are few male accounts compared to female accounts. I think it would be nice to have a more male presence."* (P/20)

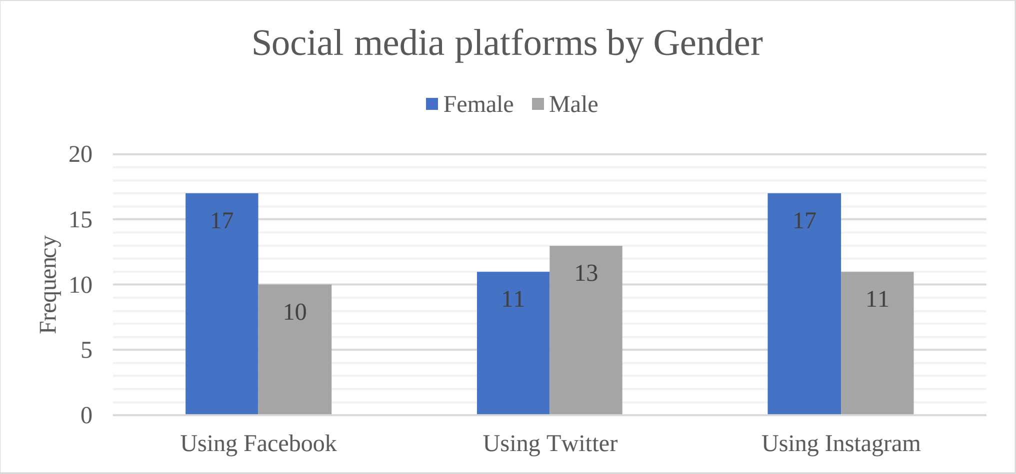

Figure 3 Chart visualising distribution of social media platform use by gender

Through content analysis, the transcripts indicated that all 38 participants have been diagnosed with IBD (Table 2). 25 reported to have Crohn's disease, 12 with Ulcerative Colitis (UC) and 1 with indeterminate colitis[14]. This result is not representative of the distribution of patients living with IBD, with the estimation that there are more people living with UC than Crohn's disease (Crohn's and Colitis UK, nd; Loftus, 2004). It should be made clear however that the purpose of the data collection was not for statistical analysis; a larger quantifiable data set would be more appropriate for establishing more representative trends across the IBD community.

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[14] Indeterminate colitis is a diagnosis given if it is unclear whether a person has Crohn's disease of UC (IBD Relief, n.d)

P	Gender	Age Bracket	IBD	Recruited	Location
1	F	21-30	Crohn's disease	Twitter	UK
2	F	51-60	Ulcerative Colitis	Twitter	USA
3	F	31-40	Crohn's disease	Twitter	UK
4	F	31-40	Crohn's disease	Twitter	UK
5	M	61-70	Crohn's disease	Twitter	UK
6	M	31-40	Crohn's disease	Twitter	USA
7	M	31-40	Ulcerative Colitis	Twitter	UK
8	F	31-40	Ulcerative Colitis	Twitter	UK
9	M	51-60	Crohn's disease	Twitter	UK
10	F	31-40	Crohn's disease	Twitter	USA
11	F	41-50	Crohn's disease	Twitter	UK
12	M	51-60	Crohn's disease	Twitter	UK
13	F	51-60	Indeterminate Colitis	Twitter	UK
14	M	31-40	Crohn's disease	Instagram	UK
15	M	61-70	Crohn's disease	Twitter	UK
16	F	21-30	Ulcerative Colitis	Instagram	USA
17	M	21-30	Crohn's disease	Twitter	UK
18	F	21-30	Ulcerative Colitis	Instagram	UK
19	F	21-30	Crohn's disease	Instagram	UK
20	M	21-30	Crohn's disease	Instagram	UK
21	M	21-30	Ulcerative Colitis	Instagram	UK
22	M	51-60	Crohn's disease	Facebook	UK
23	F	41-50	Crohn's disease	Facebook	UK
24	F	41-50	Crohn's disease	Facebook	UK
25	M	31-40	Ulcerative Colitis	Facebook	UK
26	F	21-30	Crohn's disease	Instagram	UK
27	F	21-30	Ulcerative Colitis	Instagram	UK
28	M	31-40	Ulcerative Colitis	Facebook	UK
29	M	21-30	Crohn's disease	Instagram	UK
30	M	21-30	Crohn's disease	Instagram	USA
31	F	41-50	Crohn's disease	Facebook	UK
32	F	21-30	Crohn's disease	Facebook	UK
33	F	31-40	Crohn's disease	Instagram	South Africa
34	M	31-40	Ulcerative Colitis	Instagram	UK
35	M	21-30	Crohn's disease	Instagram	UK
36	F	21-30	Ulcerative Colitis	Facebook	UK
37	F	31-40	Crohn's disease	Facebook	UK
38	M	16-20	Ulcerative Colitis	Twitter	UK

Table 2 Demographics of participants

4.1.2 Data Collection Procedure

This study employed a semi-structured interview method to understand how people with IBD seek support using either Facebook, Instagram, or Twitter, and their social and information privacy concerns. The following section will explain the justifications behind this methodological approach.

Previous studies have invited people living with IBD to complete surveys on their use of web-based forums (Choi et al, 2017) or Facebook (Coulson, 2015; Ruckenstuhl et al., 2016). Others have taken a data mining approach, collecting and analysing accessible user-generated data through YouTube (Frohlich & Zmyslinski-Seelig, 2012) web-based forums (Britt, 2017), and, Twitter (Roccetti et al, 2015;2016). Social media data mining however faces particular ethical dilemmas as data is used without informed consent. While researchers make the case that publicly available data "is technically published, and subject to criticism and quotation with citation," (Kozinets, 2014: p.268), taking the contextual integrity (Nissembaum, 2004) position towards privacy, health information is disclosed online in the context of seeking and giving support, and not for research enquiry. Furthermore, there are dozens of IBD OHCs that are not publicly available in closed Facebook Groups that were of particular interest in Study 1.

To gain a rich understanding of how social media platforms were used for health-related communications, with a particular focus on the topic of privacy, semi-structured interviews were identified as an appropriate and ethical method to get an insight into the phenomena studied (Polit & Beck 2010). Semi-structured interviews are characterised by their flexibility and fluidity (Mason, 2004). A key benefit of this qualitative method is that it enables the interviewer to improvise follow-up questions (Hardon et al, 2004), which is not possible in surveys. A limitation of semi-structured interviews however is that participants may deliberately or not-deliberately distort and even exclude experiences and perceptions, if they interpret them to be socially undesirable (Farrall, 2009).

Though semi-structured interviews are often conducted face-to-face, IBD OHCs are distributed all over the world. It was imperative that to improve the study's accessibility that interviews could be conducted over the phone or Voice over Internet Protocol (VoIP), to overcome geographical dispersion and mobility boundaries (Janghorban et al, 2014). For some IBD patients, leaving the house for a long period of time may be problematic due to symptoms; such as bowel incontinence and fatigue (Johnson, 2017).

It has been suggested that interviewees may feel more comfortable and open in Skype interviews because they are in a chosen environment (Hanna, 2012; Seitz, 2015) such as in their own home. However, distributed interviews that are conducted through such technologies, also have some limitations such as sustaining a suitable connection; technical interruptions may create a loss of intimacy (Seitz, 2015). Another significant limitation is the ability to build a rapport with an unfamiliar interviewee (Cater, 2011), establishing a trusting relationship to enable open dialogue; this is much less of a factor should there be a pre-existing relationship between interviewer and interviewee (Lo lacono et al, 2016).

To overcome such limitations, at the beginning of each interview the researcher shared a short overview of her experience living with Crohn's disease and how she had noticed how online support had changed over the past two decades. The aim of this self-disclosure was to build rapport and foster a safe, empathetic environment. While this method was not empirically examined for its effectiveness for creating a safe environment for participants, they appeared interested in hearing the researcher's study; some asked questions and made comments.

The semi-structured interview was designed in December 2017 and it was reviewed and approved by the supervision team in January 2018. A participant information sheet, consent form and the interview questions were submitted to and approved by the Computer Science Ethics Committee[15] at the University of Nottingham in January 2018 giving permission to begin recruitment in January 2018. These materials can be found in Appendix 1 (Page 363).

Each interview covered three areas; the interview schedule can be found in Appendix 1 (Page 363). The first part invited participants to talk about their experiences with IBD. Though this was not a core area of the study's investigation, this open-ended question was used to give participants the

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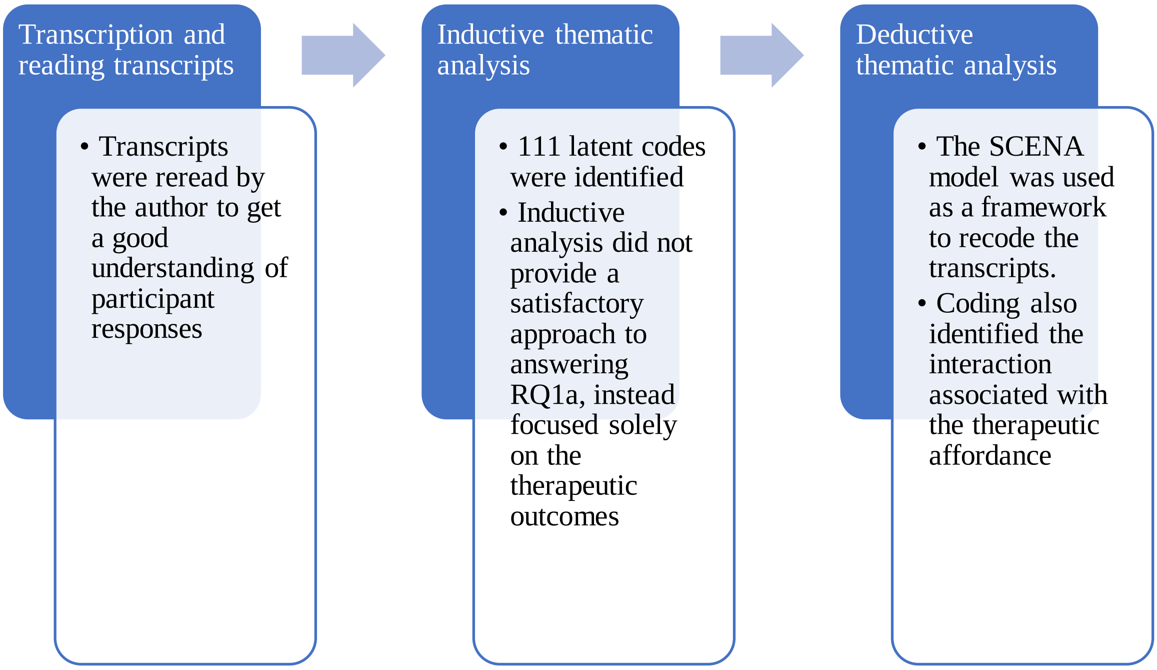
[15] Ethics reference number: (CS-2017-R5)

opportunity to provide context to their involvement in OHCs as well as to help participants relax into the interview before further questioning. The second area explored how individuals currently used social media platforms in relation to their condition to understand: what platforms were used; how many; what they self-disclose about their health; and, their general experiences of using social media platforms. The third area focused on their perceived privacy concerns; their privacy-related experiences and what actions they take (if any) to maintain contextual integrity.

The 38 interviews took place over Skype (n=15), the telephone (n=22), and face to face (n=1) between February and May 2018. Each interview was recorded on a Dictaphone. There was a combined total of 30 hours and 43 minutes with interviews ranging between 27 and 97 minutes in length ($\mathrm{mean} = 49\ minutes$). The researcher transcribed 33 interviews and the remaining 5 were transcribed by *Way with Words*, a transcription consultancy service to expedite the transcription process. Each transcription was read and reread in full by the researcher. With the breadth of topics covered in the interviews, a combination of analysis methods was applied to the dataset.

4.1.2 Analysis Procedure



Transcription and reading transcripts

- Transcripts were reread by the author to get a good understanding of participant responses

Inductive thematic analysis

- 111 latent codes were identified
- Inductive analysis did not provide a satisfactory approach to answering RQ1a, instead focused solely on the therapeutic outcomes

Deductive thematic analysis

- The SCENA model was used as a framework to recode the transcripts.
- Coding also identified the interaction associated with the therapeutic affordance

Figure 4 Flow diagram of the analysis approach

In order to “see and make sense of collective or shared meanings and experiences,” (Braun & Clark, 2012: p.57), thematic analysis was conducted. Thematic analysis is considered to be the “foundational method for qualitative analysis” (Braun & Clark, 2006: p.4) that flexibly and minimally organises data in rich detail. Researchers are given choice in so far as how themes are identified according to the prevalence across data sets, as “the ‘keyness’ of a theme is not necessarily dependent on quantifiable measures –but in terms of whether it captures something important in relation to the overall research question,” (p.10). An inductive or deductive approach can be taken. An inductive approach, a bottom-up approach, the themes are strongly related to the data; whereas in a deductive approach, themes are guided by the researcher’s theoretical interests.

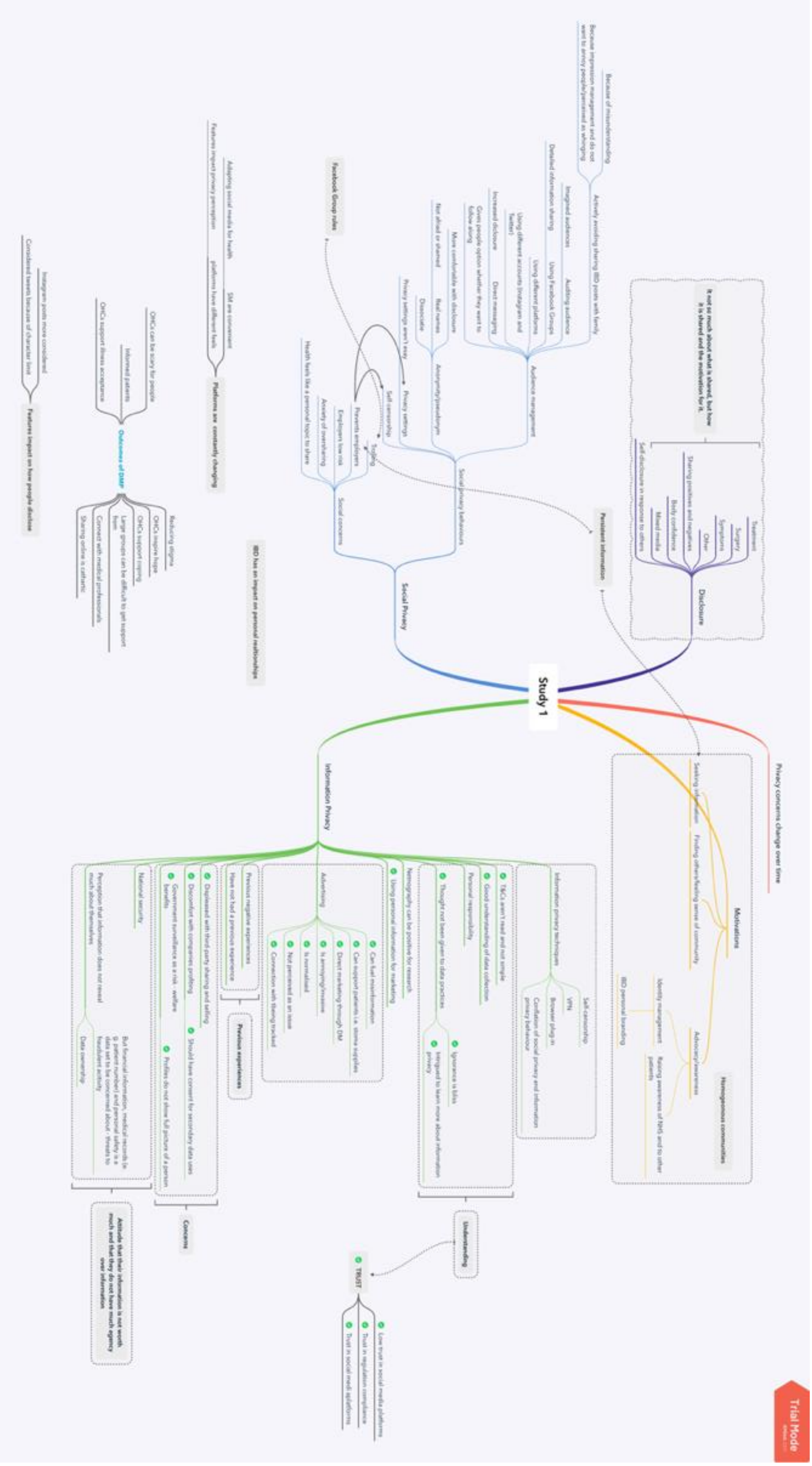


Figure 5 Thematic map (larger version available in Appendix 1e and online)

Following Braun and Clarke's (2006; 2012) approach to thematic analysis, using NVivo 12.0 qualitative analysis software, 111 latent codes were inductively identified. Through an iterative approach, the codes were organised into themes that interpreted their broader meanings (Patton, 1990). As evidenced in Figure 5, not all the codes comfortably sat within themes that were of particular interest to the research questions and were less prioritised for further analysis. The codes and themes that were identified in the data set were reminiscent of social support theory themes, such as information support, and did not provide the author with enough nuance in understanding how people realise those support outcomes through interacting with social media interfaces. Two supervisors who had independently coded a small subset of transcripts (n=4) to make sure the coding was robust agreed that a different analysis method may help to answer the research question.

In order to understand whether patients had different experiences using the three platforms, the coding framework used by Merolli et al (2014) to create the SCENA Model of Therapeutic Affordances of Social Media (SCENA Model), was adapted and employed. Compared with other theories used for social media research, such as Uses and Gratification theory (Whiting and Williams, 2013), the SCENA model originates in health-related online communications research (Merolli et al, 2014). The SCENA model introduces 5 therapeutic affordances: *Self-presentation, Connection, Exploration, Narrative, and Adaptation*.

Self-presentation is identified as a ‘control’ affordance where individuals can control their identity and self-disclosure online. People do this through impression management by curating how they present themselves to different audience (Leary & Kowalski, 1990; Goffman, 1959; Merolli et al, 2014). It has been remarked that the ability to control what a person self-presents online supports the notion that identity on social media is performative (Mendelson & Papacharissi, 2010; Spratt, 2019; Ellison et al, 2006; Orsatti et al, 2012). While Merolli et al (2014) found that self-presentation and the ability to perform different identities is afforded by social media platforms, this study specifically explores how people with IBD use these technologies to achieve identity management.

An “activity particularly suited to social media” (Merolli et al, 2014: p.8) *Connection* refers to social interactions between individuals online. Merolli et al (2014) regard the *connection* as an affordance that identifies how speaking with other people mitigates feelings of isolation. A sense of belonging and community has been shown to have a positive influence on well-being (Zhao et al, 2012). However, a sense of belonging is more frequently associated with weak ties (Sandstrom & Dunn, 2014; Granovetter, 2012). Ellison et al (2010) observed similarities between strength of weak ties theory and social capital theory; weak network ties correspond with bridging social capital, while strong network ties relate to bonding social capital. Bonding social capital benefits from the forming of close relationships (Putnam, 2000), while bridging social capital is “derived from casual acquaintances and connections, can also lead to tangible outcomes such as novel information from distant connections and broader world-views," (Ellison et al, 2010: p.875). With the knowledge that social networks are made up of strong and weak ties where bridging and bonding social capital is observed; the coding structure for *connection* was adapted to identify how platform features are used to support both types of social capital.

Exploration and *Narration* speaks to discourse around sharing of information and experiences respectively (Merolli et al, 2014). Prescott et al (2017) categorised these interactions as non-directive and directive support whereby non-directive refers to the sharing of personal experiences and directive support suggests factual information and advice provision.

Finally, *adaptation* "afforded by social media to allow users to evolve their self-management behaviors based on disease-specific needs at different points in time highlights how use changes depending on motivations" (Merolli et al, 2014: p.284). In the computer science field, this adaptation is also referred to as *appropriation* which is "a subjective process, where the meaning and use of technology is dependent on context and technology is transformed through the utilization process" (Isika et al, 2015: p.2; Mackay & Gillespie, 1992).

While Merolli et al created the model (2014) from broad use of social media, in this study it was used to identify which therapeutic affordances different platform features yielded. Table 3 tabulates both the original and adapted coded schema for the SCENA model. The author discussed this coding model with the PhD supervisors who were satisfied with this approach.

Language (merolli et al, 2014)	**Theme (merolli et al, 2014)**	**Language (adapted)**	**Theme (adapted)**	**Affordance/theme**
Disclosure, control, private, anonymity, masquerade	Disclosure, control, identification	Privacy, control, audience, disclosure, safety	Disclosure Control Identity	Self-presentation
Communicate, exchange, share, discuss, advice, support, isolation, alone, worldwide	Interaction, exchanging information, support, mitigating isolation, geographic freedom	Finding others, discoverability, speaking to others, commenting, chat, isolation, community	Inclusion Interaction Networking Mitigating isolation Empathy	Connection
Look, research, find, learn, monitor, moderate	Information seeking, learning, reputability	Information about disease, treatments and surgeries, research	Directive information seeking (prescott et al., 2017) Directive information sharing (prescott et al., 2017)	Exploration
Share, stories, experiences, journey, distress	Imparting knowledge, understanding, emotional catharsis	Stories, journey, personal experiences (symptoms, treatments, surgeries)	Non-directive information seeking (prescott et al., 2017) Non-directive information sharing	Narration
Flared-up, affected, bad, sick, hospital	Variation in use.	Unwell, having a flare, fatigue, remission, hospital	Variation in use	Adaptation

Table 3 Coding schema: SCENA Framework

Quote	Code	Theme
"I like the fact that you've got closed groups. I think that is one of my biggest things. I love that bit mostly because I'm not ashamed of what I talk about I don't want my replies to certain people to end up on my feed." (P1)	Control; audience (Facebook Groups)	Self-presentation
"I really like the like obviously hashtags was the way that I found out that there are like other people out there in the world that have IBD" (P16)	Finding others; discoverability (Hashtags)	Connection (bridging social capital)
"More for the Instagram private messages I've had people ask me about the real ins and outs of the surgery and I think the with the direct messaging, I think you can give someone a much more detailed answer." (P18)	Speaking to others (Direct Message)	Connection (bonding social capital)
"Facebook, in the group some of the features are really nice, they ask for recommendations for a dietician for example that's really good with Crohn's. You can actually link it to Facebook page and that person already has that dietician's phone number, Facebook page, email address, website, whatever so it's nice and quite easy to recommend or send links, even website links" (P33)	Information about treatments (Facebook Groups)	Exploration
"I think the stories is really good because it feels a lot more immediate and personal. I can share just thoughts and feelings with people who are following me" (P26")	Personal experiences (Instagram stories)	Narrative
"*if you're not feeling too well you just really haven't got the energy or my brain kind of goes to mush when I'm not feeling too great. It could be one or two lines or I might not answer someone at all and think I will go back to that later when I am feeling a bit better and try and answer or reply or whatever then. So yeah if I'm not feeling too great then yeah it does change." (P3)*	Unwell (posting)	Adaptation

Table 4 Examples of SCENA framework adapted coding

4.2 Findings

The following section presents the findings from Study 1. Given the qualitative nature of semi-structured interviews, direct quotes from participants will be used throughout this section. They are identifiable by their italicised formatting style: short quotes are embedded inline and longer quotes stand-alone in separate paragraphs.

The first part of the findings will explore the therapeutic outcomes of the social media platforms' technical features, through the data set's analysis through an adapted SCENA model. Findings pertaining to social and information privacy follow. The following sections then present the findings of inductive themes pertaining to social and information privacy.

4.2.2 Feature-Orientated Affordances

	Self-presentation	Connection	Exploration and Narrative	Adaptation
Twitter	Tweets Name and handle Direct message Privacy settings (binary)	Search* Mention* follow* reply-to** direct message**	Tweet search function hashtags hyperlinks	Tweet (character limit)
Facebook	Posts Profile picture Messenger Privacy settings Facebook Groups	Search* tag* comment** react** direct message** Facebook Groups***	Posts search function Facebook Groups hyperlinks	
Instagram	Posts Instagram Stories Direct message Privacy settings (binary)	Search* tag* follow* comment** direct message**	Posts search function hashtags	

*** Bridging social capital**
**** Bonding social capital**
***** Bridging and bonding social capital**

Table 5: Platforms, features and identified affordances

Participants were recruited from three different contemporary social media platforms and 79% (n=30) used more than one platform to engage with the IBD OHCs, with 3 platforms representing the mode. In this particular study there was not any demographic factors that explained multiple platform use. To analyse whether there were differences reported in the functionality of the platforms, the transcripts were first analysed through an adapted SCENA model coding schema (Table 3). Table 5 presents the platforms’ technical features and the therapeutic affordances discussed by participants using Facebook, Twitter, and Instagram. During this first phase the transcripts were analysed through a feature-oriented lens, it was clear that the platforms shared several homogenous features that yielded the same affordances. Furthermore, through the observation between specific platform features and the affordance described by participants, it was clear that the notion of ‘adaptation’ was not associated with any particular function, but instead was realised through the general access to support through social media platforms.

While Table 5 organises the discussed platform features by the therapeutic affordances outlined by the SCENA model, this approach alone did not sufficiently evidence how people’s experiences differ between platforms. Throughout the thematic analysis it was evident that some functionality was more commonly associated with particular platforms. The following sections provide a more in-depth view of how these platform features were described by participants.

4.2.2.1 Self-Presentation

Self-presentation refers to how social media platforms afford “chronic disease sufferers more choice and control over how they present and assert themselves, as well as how much about their condition they disclose and share” (Merolli et al, 2013: p.965). In this study, self-presentation was associated with posting functionality, usernames, and privacy settings.

Firstly, to approach posting types; all of the platforms provide users with a profile where they can create posts to construct an identity to others. Notably, the posting limitations on both Instagram and Twitter were described as having an impact on how people could share their experiences. Firstly, Twitter imposes a strict 240-character limit on tweets which forces people to reduce what they wanted to say to fit, as Participant 15 reported: *"the problem with Twitter is you're restricted by words so you try to make it as quick as relevant as you can"*. While the reduction of detail on Twitter can add a level of frustration for people with complex problems and experiences, some participants described having seen others thread[16] tweets to share their experience more fully: *"But I also like the fact that you can thread it, so I can have a whole conversation with myself and it be four or five different tweets,"* (P/1). For some participants, they said that if they felt they needed to go into more detail about something, they would use another platform, as Participant 19 described: *"when I'm using Twitter like that it's never for anything detailed. Like I leave that for Instagram really"* (P/19).

Instagram does not enforce a stringent limit on the amount a person can write in a post's caption, but these posts must include a media file upload of a picture or a video. For some, sharing visual imagery of their illness is difficult to do because of the non-visible nature of IBD: *"the problem with it being an invisible condition it's quite hard to portray via pictures"* (P/20). However, others described how they shared pictures of themselves in hospital, or of their surgery scars and stoma bags. The ability to share videos as well allows people to present

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[16] "A thread on Twitter is a series of connected Tweets from one person. With a thread you can provide additional context, an update, or an extended point by connecting multiple Tweets together." (Twitter, n.d)

themselves in a way that they feel helps others to understand the impacts on their condition more, as Participant 35 explained:

> *"one of the posts I did about myself on my personal one and it was a video one of using the Humira[17]. And I think I did that because sort of, it's easier to tell people what you're going through but unless they see exactly what you're doing they understand more,"* (P/35)

For individuals who might have difficulties in visually presenting their illness, felt uncomfortable with sharing pictures, or had a particular style of the kinds of pictures they shared, Instagram posts allow people to write captions to share their experiences through text.

> *"I keep my like actual page full of posts are mostly just food posts because that was the whole initial impetus for starting this account. So my main posts are usually more neutral kind of general stuff about diet and then I will use the captions to maybe talk about what's going on with my life."* (P/16)

Although the technical limitations were identified to impact on people's self-disclosure behaviours, the privacy settings available on each platform also factored into people's comfort with self-disclosure. Firstly, in addition to the limit on characters, participants on Twitter described an awareness of the publicness of the platform.

> *"You won't go graphic on Twitter whereas in the [Facebook] forums you will. You might have a picture or you might say what a family member has been like but obviously you won't put it on Twitter in case someone else sees it.*

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[17] Humira is a biologic treatment that patients have to self-administer through an epi-pen

> *[Facebook] Forums are so closed you can put whatever you need on there without the worry of anyone else seeing it that shouldn't be seeing it."* (P/13)

On Facebook, the majority of participants who had reported to use it for IBD-related discussion described their use of Facebook Groups as the primary environment for accessing social support. The functionality available within Facebook Groups does not differ from what is used on people's profiles, such as posting, reacting, and commenting. However, the privacy-preserving nature of Facebook Groups, providing a space to share experiences, separate from their friends list, meant that participants frequently described how they used this functionality on Facebook to talk about their illness. In the analysis, all the groups that were referred to were described as being 'closed' which means that the groups are discoverable in a search, but the posts are only accessible to members. The private aspect of the Facebook Groups was frequently discussed by participants, indicating that they afford a space for members to feel "*safe*" (P/36) to speak "openly" (P/9,23,32) and intimately (P/2,13,31) about their illness, away from other audiences such as family, friends and colleagues (P/1/23/32). Twitter and Instagram, however, were not identified as having a similar feature where groups of people can congregate in private virtual spaces.

Instagram offers two modes of self-disclosure on their profiles: posts and Stories. Unlike posts that are *"memorialised"* (P/16) on people's profiles, Instagram Stories offer users the opportunity to share pictures and videos that are viewable for 24 hours by others. One participant described the difference in posting types as *"two entirely different content streams"* with *"an inherent brand to what you're posting on your timeline versus what you post as your Story,"* (P/30). Participants (P/16,27,30) described how more consideration is given on what they decide to self-disclose through an Instagram post because of its persistent nature (boyd, 2008) and in shaping their identity on their profile. The expiration of Stories after 24 hours was described by participants to afford greater disclosure:

> *"I share more on my Stories because you know they're temporary I don't have to really think that hard about what I share because I feel like you know not that many people might see it, it will disappear in 24 hours and I can delete it earlier if I decide"* (P/16)

Enabling people to have one-to-one conversations, direct messaging is available on Facebook, Twitter, and Instagram. Participants reported how having an intimate environment between individuals gives people a sense of comfort in sharing more as Participant 27 described:

> *"People are generally a lot more open in the direct messages than they are on a comment. Purely because comments can be viewed by hundreds of thousands of people whereas a direct message can really be viewed by one or just a few. And that's it, so definitely it's a lot more yeah, a lot more personal in a direct message."* (P/27)

However, during analysis, direct messaging was more prominently reported to be used on Instagram than on Facebook and Twitter.

A final noteworthy function of Instagram with regards to self-presentation is the ability to create multiple accounts, allowing users to portray different identities through each profile *"because I wanted a line between my personal life and my professional [IBD] blogging account"* (P/26). Given the proximity between self-presentation and social privacy, a more in-depth view of how people negotiate their online identity through platform functionality can be found in Section 4.2.5.

4.2.2.2 Connecting to and with Others

The ability to *connect* with other people with shared experiences, to mitigate feelings of isolation (Merolli et al, 2014) was the most frequently identified affordance across the platforms. The original coding structure for *connection* by Merolli et al (2014) embodied the concept of 'social capital', which refers to the "the benefits individuals derive from their social relationships and interactions: resources such as emotional support, exposure to diverse ideas, and access to non-redundant information," (Ellison et al, 2010: p.873). As such, the coding structure was adapted to delineate between bonding and bridging social capital, as proposed by Putnam (2000). To reclarify, bonding social capital refers to the benefits of close relationships, while bridging social capital describes the benefits of acquaintances (Ellison et al, 2010).

Instagram and Twitter share similar functionality for bridging social capital connectivity, whereby they can increase their network size and learn from other people's experiences without having to actively build a relationship with them. On Twitter and Instagram, people in the community organise through the use of hashtags. Individuals can assign hashtags to tweets, Instagram posts and Stories which means that others who search those hashtags will be able to see what they have shared. Participants in this study described how hashtags are used as a means to find information about other people's experiences.

> *"Oh #ostomy, #IBD you know what I mean, whatever. It helps me connect with other people too. I have been able to connect with a lot of people on Twitter that I may not have met otherwise." (P/2)*

Some participants may decide, after having discovered an account through searching hashtags, whether they want to 'follow' them and see their posts in their feed. Participants in this study remarked on how the 'follow' function on Instagram enables a more tailored experience of whose story and experiences they wish to regularly view (Participants 21 & 26).

It should be noted however that not all of the affordances were considered to be positive. The algorithms that order posts on users' feeds on Instagram were negatively associated with the affordance of *connection*. Participants described the algorithm as something which may limit the audiences who might see their posts (P/18, 21, 26 & 33) which ultimately limits their ability to raise awareness or seek support from others.

Connection through hashtags on Twitter was synonymous with Instagram, however a key difference was how synchronous discussions on particular topics were organised (P/1,5,12,13,29,38). Twitter chats were described to occur monthly in the UK and the USA, however, due to the time-zones Participant 1 described the difficulty in "*staying awake long enough*" to participate in the American chats. Different topics are chosen for people to share their experiences using a specific hashtag; participants described how they have "*learnt quite a lot about different aspects of things that I didn't think I would be interested in*" (P/1). Participants reported on how medical professionals also engage with the IBD community on Twitter and through the Twitter chats. Access to doctors means that patients can keep up to date with new research as well as receive factual information (P/1,4).

Unlike Twitter and Instagram, Facebook enables people to congregate in centralised spaces. Instead of individuals building a network around themselves and their interests, they join an established network in Facebook Groups.

Across all three platforms, the features that afford bonding social capital were synonymous. Participants reported on replying to others Facebook posts, tweets, Instagram posts, and Instagram Stories. On Facebook Groups, Participant 4 described how they *"can give my advice on it or how I'd been through it. I just like to read other people's experiences and stuff like that"*. Participant 6 echoed interacting with others to provide experiential advice and support through Twitter: *"I am much more apt to comment on someone else who's going for some sort of test, like a colonoscopy or a problem I am more likely to respond,"* (P/6).

Direct message, however, was described as an avenue where relationships can be built, as Participant 29 described: *"So there's more support I guess in direct messages because you build up a friendship or a support mechanism with that person"*. On Instagram, direct message is integrated with the Story feature, which explains why it was more frequently talked about for that platform; Participant 16 said: *"private messages has also been my main way of communicating with people,* (P/16). Furthermore, Stories are used to *"share immediately that you're in the hospital, like a selfie of how you're feeling, or an outside picture of the hospital or whatever it is,"* (P/26). Participant 26 described how the integrated direct messaging function allows people to also provide *"more immediate support in terms of people replying to that like 'good luck, well done'"*.

Overall, participants frequently reported how interacting with OHCs on social media, mitigated isolation and increased a sense of belonging: *"it's just that group factor if you like, you're not alone, there are other people out there who have been through the same thing as what you have been through,"* (P/22).

4.2.2.3 Narration and Exploration

Narration and Exploration typify the kinds of information that is shared on social media platforms; factual information and personal experiences, respectively.

With respect to the affordance of *narration* on Instagram, or experience seeking and sharing, indeed primarily people described the use of posts and

Stories. Sharing experiences is reported to take place on a regular basis through Stories *"I feel like with the Stories it's more like vlogging and it's continuous,"* (P/20). Posts, specifically the captions, are also a feature that enables patients to share their experiences: *"in my caption maybe explain that I've had a bad day or what symptoms I've experienced and try and use that as a call to action or a positive message for other people who might be feeling the same,"* (P/26). Not all experience sharing is broadcast on profiles through posts and Stories, as participants also described using more private spaces, such as direct message to exchange personal experiences (P/16,21,26,27). Participants in this study did not describe using Instagram to find factual information about their illness, but did report on its usefulness in sourcing dietary tips:

> *"from the Instagram side of it it's good to see people's food diaries, people putting on ideas, meals you can make cos I've been on a low residue diet, it's like anything cream and brown and that's it." (P/23)*

Sharing factual information (*exploration*) was more frequently associated with Twitter, which is where participants also reported to connect with medical professionals. However, as previously described, the character limits and publicity of Twitter can make experience sharing difficult. Yet, some participants described how, similar to Instagram Stories, that experiences can be shared in the moment:

> *"It's very in the moment so somebody could be waiting in their doctor's office, waiting to go in for a scope or blood work or something like that. maybe they*

> *just got denied coverage of a certain drug by their insurance company. It's very real and in that moment and it's very easy to empathise or sympathise depending on your situation with what they're saying. Whereas I don't see that personal touch on Facebook"* (P/6)

While Twitter does not embrace and encourage rich detailed experiences, participants remarked on how being able to quickly share their experiences and emotions in real time felt cathartic, as Participant 1 described *"when I first diagnosed I needed to sort of vent and say these are the things that are going on, I need to get these thoughts in here sort of out, so that they didn't overwhelm me"*.

4.2.2.4 Adapting Social Media use around Health Status

Building on the concept proposed by Morelli et al (2014), social media platforms allow individuals to *adapt* (or appropriate) how they use the services to meet their support needs. In this interview study, the researcher identified that people with IBD adapt their regular social media use to accommodate for health-related support, and it was not specifically associated with any particular functionality on any of the platforms. This section also discusses how health-status impacts on how participants reported using social media platforms.

Most interview participants reported that they were already social media users prior to joining and participating in health-related communities. Individuals who had been living with IBD for more than 15 years described their early adoption of online forums and transitioned to using social media to access support. Now that mobile technologies and social media platforms are much more accessible and a normative part of daily life, it will be more likely that people are social media users prior to diagnosis and may adapt their use should they wish to seek social support.

IBD status, i.e. if a person is newly diagnosed, in a period of relapse or remission, was perceived to have an impact on their behaviours in OHCs. Previously a Facebook user for day-to-day activities, Participant 23 spoke about their adapted use of social media to meet their needs as a newly diagnosed patient, seeking information and emotional support. She described how she *"just felt lost"* after her diagnosis and joined several Facebook Groups to:

> *"try and find out a bit more about the disease and do you know just finding out is there other people out there, has anyone had this happen to them, and in a about a week I think there was about four or five people that were newly diagnosed the same time as me and all had the same experience".* (P/23)

A significant proportion reported that when they were going through a difficult period with their illness, they participated more actively in OHCs in order to seek support. For instance, Participant 16 said *"I find that I use [Instagram] more often when I'm down and I need to like find encouragement and support".*

On the other hand, Participant 26 talked how when they were experiencing a Crohn's flare up that they were "a lot quieter [because it] is just really personal" and that "I'm much better at talking about the bad patch on social media after it's finished”. Similar to a participant in Brady et al’s study (2016) who described that sharing in the moment was “too personal” (p.5), non-disclosure because the privacy concern is perceived to be higher when they are feeling more vulnerable is indicative of the privacy calculus (Li, 2012). Furthermore, because the experience is still self-disclosed, it is not the information itself that is private, but the context in which the discloser finds themselves in and who they would be sharing with. Another participant (P/22) who had lived with Crohn’s disease for most of their life said that they don’t post any differently because they felt like they do not need social support to get through a flare up. Finally, during periods of remission, people with IBD may not actively participate in the online communities because they are busy living their life and “like many invisible illnesses you even sometimes forget yourself that you’re suffering from anything” (P/35).

Although poorer IBD health indicates an increased use of social media platforms with individuals seeking new information, encouragement and emotional support, it appears as though some patients feel that their experiences are too personal to share in the moment. This non-disclosure as a result of increased privacy concerns is indicative of the privacy calculus whereby if the benefits outweigh the privacy risks, disclosure occurs and vice versa.

4.2.3 Sequential Affordances

Though deductive analysis through the SCENA model was instrumental in organising and understanding the connection between particular platform features and the therapeutic affordances; it was recognised that features had multiple affordances, and that taken together people described having different experiences of each platform.

Facebook was considered by some to be *"personal"* (P/9) with P/33 describing that *"it feels more like you're connecting with friends"* through the Groups. The groups are considered as *"more user-friendly"* and a *"safe"* (P36) space away from other imagined audiences such as family, friends and colleagues. However, it was reported that some groups with lots of members can negatively support individuals with exposure to *"argumentative"* (P/17), *"negative"* and *"misleading"* (P/12) discussions.

The *"more public"* (P/29) nature of Twitter was reported to be *"a platform just to raise awareness"* (P/36) and for *"being an advocate"* (P/13). However, there were mixed views on the community cohesion on the platform with P/6 perceiving Twitter *"to be much more personal; it's person to person", "friendly"* (P/17) and a place for *"comedy"* (P/9). Conversely, it was also regarded as *"a more serious forum"* (P/12) with *"less [...] sense of community"* (P/17), *"less of a safe space"* (P4), *"political"* (P/8) and *"not as personal"* (P/26).

Despite Instagram following the same binary public/private accounts, it was considered to be a more *"personal"* (P/20 & P/26) platform. An explanation for this was that people visually share their personal experiences on their profile and through their Stories, enabling people to follow along with their journey as it happens.

Overall, while on one end of the spectrum Twitter was more frequently associated with being a public platform and Facebook, specifically the Groups, being a more private space, it was evident that additional factors of social interactions and motivations also shaped people's perceived affordances of the platforms.

4.2.4 What is Self-Disclosed on Social Media

> *"[On Instagram] There might be some posts about like me training or how I deal with training while having a long-term illness. It might be something to do with my medical appointments so it might be like, I think there is photos of me in a hospital gown waiting for my colonoscopy to be done, in a waiting room, or like a blood test form or like when I'm having my infusions, like I would normally always take a photo of me having my infusion and then upload it to be like 'oh look here I am having yet another infusion' sort of thing."* (P/27)

The text and image-based sharing functionality on Facebook, Instagram and Twitter enables individuals to share their experiences of living with IBD. This experiential information sharing aligns with the SCENA affordance of *narration.* Participants in this study have described self-disclosing experiences of their symptoms, hospital visits, medications, procedures, surgeries, diet, body image and mental health.

Symptoms that were shared included pictures of blood in the toilet, bathroom frequency, fatigue, weight-loss, pain and stoma blockages. It was reported that when people post about their symptoms *"they're looking for a response"* (P/38) that can advise them on how to cope or whether they *"should go in to A&E now?"* (P/8).

With regards to sharing of medications, participants discussed the frequency of information requests of medication side effects. Participant 37 described how people in Facebook Groups ask about a medication's side effects often before asking whether the treatment helped achieve remission: *"so they'll say, is anybody having side effects? That's always the first thing. Have you had any side effects? Not, has it worked for you?"*. The asynchronicity and perseverance of posts on social media platforms afford patients like Participant 19 to search other people's side-effect experiences:

> *"I always end up looking up the different side effects and symptoms that Crohn's has to offer. And you know as I said the reasoning for it is so that I'm aware so obviously it is like what's to come, what's in store for later on"*.

Participants described how they have seen or have themselves posted pictures and videos on Instagram to document their experiences with treatments. Participant 19, a Crohn's disease patient, described how they share the process of their infliximab biologic infusion through Instagram Stories to show that "*some* *people have to go through all of this"*. Meanwhile other patients reported having shared videos self-injecting biologic treatments as well as performing bag changes, as Participant 35 described:

> *"she was one of the first people I knew anyway, that did a video on Instagram of a full bag change, and it just sort of took off like crazy, there were a few comments of people in there saying 'that's not right, you shouldn't be posting it' but the majority was sort of saying 'I can't believe you've posted this because it's boosted my confidence' it's something that you can hide fairly easily, so for somebody to go and do that on social media is quite big."*

Sharing treatment and stoma management can feel uncomfortable to some, yet the ability for people to share their experience also means that others, both patients and non-patients, can learn about the realities of living with IBD.

Although participants described how a lot of experience sharing was illness and management specific, some community members also show *"what I'm doing in spite of my IBD"* (P/1) so that others can feel encouraged that *"it's not all doom and gloom"* (P/1). For instance, some community members share their fitness journeys through weight lifting (P/21), cross fit (P/33) marathon running (P/29) and skydiving (P30), while others focus on gut friendly diets (P/16; P/26), travelling (P30), and their daily life (P/18). Participant 20 described how some people on Instagram use it as a platform to share *"their day to day battles with the condition. Either trying to promote happiness and strength to others. I know there is one girl I follow and she has recently just had surgery so a lot of her* *activity has been all like pre-op, how the op went and then post op and how she's recovering from the op."*

The findings indicate how individuals will share many different aspects of their life with IBD from symptoms to medications, and from surgery to how they adjust their daily life around their condition. It was reported that posting about their experiences opens up a conversation to receive advice and support from others, while simultaneously raising awareness and inspiring others.

4.2.5 Social Privacy Concerns and Behaviours

Social privacy pertains to the concerns around the harms caused by other individuals on the internet having access to their information (Lutz & Strathoff, 2011). Participants reported how they control the flow of information by managing the audiences to their posts, posting anonymously and censoring the information that they share. The codes were grouped (Figure 5) by whether excepts were describing concerns or mitigating behaviours. The following sections explore these behaviours and the privacy motivations behind them, such as the audiences that they intended to avoid.

4.2.5.1 Audience Management

Participants described different techniques they use in order to control the imagined audiences to the information they self-disclose about their IBD. The motivations for audience management varied depending on their personal preferences and motivations. For instance, for individuals whose aim is to raise awareness and advocate for IBD, the idea of employing behaviours to limit who can see what they post about their illness *“goes against the grain for what I’m trying to achieve, which is [that] I’m trying to raise awareness,”* (P/36).

Firstly, Facebook *“groups are private so no-one will see that apart from the people in the groups,”* (P/23) which enables individuals to self-disclose to an audience that have *“got exactly the same issues as me”* (P/37) and can provide advice as well as empathetic support. The motivations reported by patients to use Facebook Groups centred around impression management as *“you can speak openly and freely without boring your best friends to death about how you’re feeling,”* (P/23). Participants believed that their Facebook Friends will perceive them to be *“moaning”* (P/23 & P/25), *“whining”* (P/8) and *“self-centred,”* (P/25) if they post too much about how their IBD is impacting their lives. Participant 28 described how they use Facebook Groups to talk about their health because they don’t want to upset their family members with what they are living with. This idea that people are private from some audiences, but open with others supports O’Hara (2016) who posited that “a person may be private as part of a group, but not be private within that group” (p.87).

Because Facebook Groups provide a *“safe”* and private space for individuals with shared experiences to come together, participants reported how posts are more *“graphic”* and *“personal”* than in other environments. Participant 2, who created their own Facebook Group and also uses Twitter and Instagram described: *"[groups have] a little more privacy to it people are more inclined to share a little more than they would normally. Or ask questions that you know on a different forum they might be criticised for or made fun of"*. Participant 37 who uses all three platforms again said *"people disclose a lot more in a closed group. Definitely 100%"* describing that:

> *"In closed groups, trust me, I've seen everything. From naked stoma's, they call them, right through to somebody, blood in the toilet, somebody off their head because they've just come out of a colonoscopy, fingers up going, yes, I made it. Like those kinds of things, I got through it, I'm alive. That type of thing. I've seen posts where people are in intensive care, where they've done then and now type of thing. I've seen posts where people have been clearly, visibly crying and you can just see the desperation on their face, that they need help or someone to talk to."*

Another way imagined audiences are managed is the use of different platforms and multiple accounts. Participant 11 described using Twitter as a space to talk about their symptoms and experiences with treatments, saying that *"Twitter is my safe space; also there are not a lot of work colleagues on there"*. Participant 26 said that it's *"weird"* they don't share on Facebook because *"obviously they're the people I actually know, but there's a lot of professional relationships on there with people that I actually work in the same office with"* and they don't want to have people in their *"real life"* asking them about what they post online about their health.

Others who use Twitter and Instagram similarly described managing more than one account on the platforms; each of these accounts were described to satisfy different purposes and audiences. Participant 17 described having two Twitter accounts as *"it's better for me to talk about my IBD through my own personal one rather than having it go into my work account".* Through their personal account they share a lot about their mental health as well as their IBD as a *"mechanism of coping"* and *"it's not really a thing where I expect people to react to or anything,"* (P/17). On Instagram, some participants described creating separate accounts to segregate their audiences, using a public account to advocate for IBD to share their positive and negative experiences. Participant 26 described how their IBD account is public while their other account is private because they *"want to be able to share pictures of me and my friends in a private space"* which indicates that they are strict about how much they share about other areas of their life with the community. Conversely, Participant 17 uses their separate account to document their experiences with UC and an eating disorder, specifically to avoid their family members and friends, separating their illness from their identity. Not all participants described using multiple accounts however, suggesting that they talk about their IBD experiences as part of their identity.

Some participants described how they will routinely audit their audience and take the time to remove friends, followers and block accounts that they do not want to see or have follow them because *"there's some weirdos out there."* (P/2).

Participant 34 said *"I just think being careful and being aware of those people that are following you and what their intentions are"*.

Each platform offers privacy settings that enables an individual to add controls over who can see what they post. On Twitter and Instagram, profiles can either be public or private, while on Facebook there are additional settings that can determine the extent people who are not 'Friends' can see. On Facebook, participants described applying privacy settings on their Facebook not because of their illness but because *"I thought it was a tad creepy that people who weren't your friends could just go through every aspect of your Facebook profile"* (P/17).

As a result of their Facebook privacy settings, people felt protected from potential employers trying to find information about them, *"I can't see that they would actually go on my Facebook profile, it's all private so I don't know what they would find on there apart from photographs that they can see."* (P/23).

Finding and understanding the privacy settings were also described as *"a complete nightmare to bloody get at"*(P/28) which can be indicative of both the complexity of navigating the settings as well as the importance of digital literacy to help make this process easier.

Finally, for individuals to have a selective and private conversation with another person, participants described using direct message *"because nobody else can read what you're writing"* (P/6) enabling people to go *"into a bit more detail of how they're feeling"* (P/36). This was more frequently discussed amongst individuals who use Instagram than Twitter and Facebook, because as previously mentioned Instagram Story replies are through direct message. People described how others have directly messaged them asking for advice and sharing more detailed aspects of their condition *"rather than write on my post"* (P/26) as participant 27 described *"purely because comments can be viewed by hundreds of thousands of people whereas a direct message can really be viewed by one or just a few"*. Having one-to-one detailed and personal discussions has been reported to help *"build up a friendship or a support mechanism with that person"* (P/29).

4.2.5.2 Anonymity and Pseudonyms

For participants who want to actively engage in OHCs, particularly over public platforms like Twitter and Instagram described the use of a pseudonym to help distinguish their IBD life from their real life. Participant 16 uses their first name with a pseudonym Instagram handle:

> *"I don't want someone for whatever reason to be like searching for me on Google and being like here's LinkedIn, here's her academia.edu, here's her Twitter and oh here is this Instagram where she talks about you know her toilet habits and you know pain and suffering. So it's a way of keeping things a little more private even though I'm very open about it," (P/16).*

Meanwhile, Participant 29 described their pseudonym as an alter-ego saying that he's a "different person […] So it was just almost being someone else whilst being the same person, almost like… I always try to compare it with like Clark

Kent and Superman". Having a different name appears to "add layer of anonymity to the whole thing" (P/26), giving people the confidence to talk about a condition that carries stigma and embarrassment.

Others use a pseudonym, not necessarily to mask their real identity, but as a self-branding method as Participant 8 described: *"my name is [*redacted pseudonym*] and people know me as that now I suppose that's kind of like my - it's like my brand people will read and people will acknowledge, listen and share what I've put on there because it's come from me in my professional manner".*

4.2.5.3 Self-Censorship

Participants described using self-censorship as a method to control how much information they self-disclose. Though the majority of the participants in this study had declared to self-disclose about their illness, some participants described feeling uncomfortable with sharing a lot about their condition because *"me and my condition is still very private,"* (P/9) and *"You don't want your health history out there, do you, particularly?,"* (P/38). For others, there are certain elements of their IBD experience they feel is too vulnerable to share such as *"surgery actually because [...] it was very traumatic for me"* (P/33) and symptoms because *"symptoms are undignified"* (P/26).

For others, self-censorship was reported to be employed as a means of reducing the amount of information imagined audiences, such as current or potential employers and family members, can have access to. For instance, Participant 11 said *"if I am applying for a new job, my tweets and my Facebook goes a little bit more sanitised because I think if somebody wants to check me out,"*. Across many interviews, participants described a discomfort with potential employers doing social media searches as it is not *"a reasonable way to decide whether someone is suitable for that job"* (P/24).

4.2.5.4 Trolling

When broadcasting to and communicating with strangers on the internet, there is no guarantee that everyone will be civil, which is something that cannot be controlled through audience management, anonymity or self-censorship. Notions of 'trolling' and receiving hurtful comments from other internet users was identified as a risk for six of the interviewed participants. Participant 18, who publicly shares health information to increase awareness and advocate for the illness, said that receiving unkind comments should be expected as part of the social media experience:

> *"I think you've got to be ready for negative feedback. Quite a lot of... obviously you're going to get quite a lot of positives and negatives from people and everyone's got an opinion so as long as you don't take the negative points too personally because you can, I get so invested in it and I can see why people become quite obsessed with it but you know some people don't like it. And that's just something you've got to be ready to take so I think that's one of the drawbacks."* (P/18).

Another participant described how these hurtful and *"derogatory"* comments are made by *"keyboard warriors"* (P/20). Keyboard warriors, similar to trolls, are described by Hardaker (2010) as internet users who are "maliciously impolite," (p.237) though it can be difficult to determine if someone is intentionally being malicious or whether it is in the audience's interpretation (Hardaker, 2010).

4.2.6 Information Privacy

Information privacy refers to the data collection and processing practices conducted by online companies and institutions (Lutz & Strathoff, 2011). Considered to be complex, unnoticed (Lutz & Strathoff, 2011), and protected by intellectual property law, it is difficult for internet users to gain knowledge in what information is collected, how it is processed by algorithms, and what algorithmic determinations are used for. Regardless, to understand how far privacy is considered by IBD patients using social media platforms, interview questions explored the perceptions and behaviours pertaining to information privacy.

The following three sub-sections outline the extent to which participants were concerned about advertising, data processing and third-party interest in their data. Attitudinal themes (Figure 5) intersect and underpin why participants feel a particular way about information privacy concerns. The notion of trust is then discussed before presenting findings of how participants reported on their actions towards any information privacy concerns.

4.2.6.1 Advertising does not Present as an Information Privacy Concern

With the obfuscated data practices by social media platforms, advertising was identified as a visible product of data processing. Some participants observed that *"[social media platforms] like to show me adverts of things that I've either looked at on my internet pages or stuff"* (P/1) and *"particularly on Instagram I will get ads through my feed of something that I've searched on Amazon"* (P/17). Being sold personalised and targeted adverts however was noted as something that participants *"expect"* (P/17) and are *"used to seeing them"* (P/26).

Although there is an awareness that advertising is linked with previous behaviours, participants were more articulate about the impact of advertising. For instance, several interviewees described how advertising can fuel misinformation online, offering alternative treatments to desperate people, that can ultimately cause more harm. Participant 2 was concerned with the advertising of alternative and unregulated medicine *"they hear these ads and they go 'oh this is going to be the magic bullet for me'"*.

While algorithmically personalised advertising is conducted by social media platforms, many participants reported on being directly advertised to through direct message from companies such as *"Juice Plus [and] Forever Living"* (P/28) offering *"miracle"* (P/25) products where *"there's no actual proof in it or* *anything like that"* (P/25). Although none of the participants described why they felt they were receiving advertising messages, Participant 8 talked about how *"there's a lot of businesses that follow you [on Instagram]"* that are using similar techniques to access the OHC as the patients themselves, such as searching hashtags.

Conversely, some participants reported on how receiving relevant advertising can be useful for patients. For instance, Participant 8 described their experience with ostomy companies on social media:

> *"I think that the ostomy companies are very good at it. They will share inspirational posts and they won't use it to then say 'you know you can buy our brand'; they're very much patient facing and that's why people like their stuff because they don't just offer brands, they offer support and that's incredibly important and it's not even like it's a sly ploy, they're genuine about it and I think that's good."*

This indicates how particular companies have built trust with its consumers to provide them with services that support them beyond the products they might be promoting.

Although personal preferences to advertising differs between individuals, participants described how they can interact with ads to alert the platform that the advert is not relevant: *"if it's on Facebook sort of targeted advertising then you have the option to opt out of the product or whatever that may be and so doesn't really bother me too much"* (P/12). It was inferred that individuals feel a sense of control over the ads that they are getting served to *"tailor"* (P/36) their online experience.

Finally, even amongst participants who made efforts to reduce the amount of information is collected about them held an attitude that *"I don't really worry about the greater effect of [advertising], in terms of collecting health information. I should probably worry more about that, but… Yes, more advertising is what bothers me,"* (P/38) and they do not *"feel like I'm personally in any danger,"* (P/32) as a result of data processing. The following section describes how individuals had typically not previously thought about how social media platforms handle their information.

4.2.6.2 Perceptions of Data Processing

Corresponding with previous research that indicate low engagement with terms and conditions (Reidenberg et al, 2014; Rao et al, 2016), only one participant in this study reported to have read them, as a result of their career in cybersecurity. The majority (n=31) did not read the terms and conditions at all while a small number (n=6) reported to have skim read them.

When participants were asked about what they believed social media platforms collect about them, there was great variability in the responses. For many of the participants, they had either *"never really thought about it"* (P/18) or believed that the platforms broadly *"collect everything that you do"* (P/10). Meanwhile, less than a quarter (n=9) were able to identify specific data types.

However, participants with professional experience working in online advertising and cybersecurity were typically more articulate as Participant 30 explained:

> *"let's see we've got: location, age, we have pretty much any demographic, sex, gender, interests, accounts you follow, when they're online, they have your location, they may have you payment information, they have who you're connected to, I can go on for quite a long time".*

This indicates that there may not be a general understanding of what information is collected by online platforms; only with those who have professional experience with digital services were able to demonstrate their knowledge in the data types.

Similarly, when asked what participants believed happens with the data that is collected, there was a mixture of responses. While some had not previously thought about it (n=9), others were unsure (n=10), and many (n=17) recognised that their information has to be used in some way to *"target certain populations for marketing purposes"* (P/2). Meanwhile, Participant 24 reported that their social media experience is informed by their information: *"I think they manipulate what you see on your feed, what groups- like they can advertise pages they think you might be interested in that you aren't necessarily a member of or have liked".* As reported in the previous section, while advertising is seen as a product of data processing, people *"don't worry about the greater effect of it,"* (P/38).

A small number of participants hoped that social media platforms do not sell data to third parties, as Participant 1 described: *"I haven't really thought of that. I hope nothing illegal. What would they be doing with my information? I hope they aren't selling it onto anyone that's terrible. I really don't know actually"*. However, others small number (n=4) were confident that this does occur: *"I can tell you that they sell information for profit"* (P/34). This demonstrates that there is a wide range of beliefs of what platforms do with people's information, indicating a lack of general understanding.

The other concern raised by two participants was that of government surveillance and the risk of having their welfare benefits revoked as a result of their social media activity. Participant 24 describes how they're mindful of this:

> *"you need to be careful about saying certain things if you're saying it on your profile and not in a closed group but then other people could be on a closed group because I do know that PIP assessors have looked on people's profiles to see how active they are if they've done this, that or the other and I don't know if they're that sneaky that they would go onto closed groups or not I don't know"*

Although many self-reported to have strong knowledge over how social media platforms collect and process their information, some participants believed that *"it could be quite scary"* (P/15) to find out more. On the other hand, throughout the interviews other participants were inquisitive, asking the researcher for clarity and were interested in learning more: *"I need to research this stuff actually, it's really annoying me"* (P/1). Others believed that *"people* *should be aware of what's happening with their information. But some people don't want to know because they're not really that bothered, which is fine. But I think it should be accessible, to be able to find out about easily, for those that do want to know"* (P/37) which indicates the significance of people's attitudes towards privacy. Finally, Participant 28 reflected *"until you go away and really think about it, you don't think of the repercussions of all this sort of thing. And it's something they certainly don't discuss at any point in time when you register on Facebook"* which reiterates how the terms and conditions are both not read and *"even you read every single word, you don't really know what it means"* (P/33).

4.2.6.3 Legitimate Third-party Interests

When participants contemplated third parties having access to social media data there were mixed reactions to the appropriateness of its use and benefits to society. For instance Participant 24 described how using social media data can support pharmaceutical companies improve their products"

> *"because not everyone is aware of how to relay a side effect of a medication, we have the yellow card system - I think it's called the yellow card system where we can go online and say we've had this side effect from a medication, and then that would be then fed back to a pharmaceutical company."*

Another participant supported this idea believing that using methodologies that examine self-disclosure is *"smart of them to do that because I think that they're getting less planned out answers,"* (P/10).

On the other hand, participants questioned the legitimacy of third-party use. Participant 6 remarked: "to take somebody's honest broadcast of their personal well-being and not are necessarily in the best way, it seems that [they are] trying to turn a profit on a negative situation and I don't like that aspect". There is the indication that the expectation for self-disclosing health information is to receive support from other people, however, the possibility of secondary uses (and a context collapse (Marwick & boyd, 2010)) can feel uncomfortable. While Participant 24 believed that social media data informing pharmaceutical development can be useful, "if they were just trying to [use information to] target, no - I think we should be able to choose what they can have and what they can't have and that's quite difficult". This requirement for informed consent prior to data use was a common theme across participants. A recently diagnosed participant explained:

> *"I think if the group was approached by it and everybody agreed in that group that that was a thing to go ahead then I could—it would be an issue to me personally but I think a few people would have an issue with it if it wasn't told that that was the situation and people going and taking that information without having any authority to do so,"* (P/23)

Some participants expressed that their posts are uninteresting and would not reveal much about themselves, which indicates that they may not place much value on their personal information. As participants deliberated over how their data might be used, some perceived that social media platforms *"must be pretty blummin' bored to collect my information,"* (P/11) believing that *"not sure how much they can glean"* (P/30) from their posts. Another participant believed that *"it would take a lot of research to extract the information that would be useful to them,"* (P/5) which would be a costly exercise.

Meanwhile, the attitude of 'having nothing to hide' similarly arose during interviews with participants who believed that they are not concerned because *"I'm not tweeting anything that I think would be a security risk or I wouldn't want -- I'm not doing anything on there that I shouldn't be doing,"* (P/11). Indeed, on the theme of national security, one participant said: *"I'm more uneasy that they might hold information on, for instance, terrorist events or people that are suicidal or doing stupid things, and then they don't do anything with that information,"* (P/28). This presents a friction between what can and can't be collected and processed by online platforms to both preserve a sense of contextual integrity and supporting society.

4.2.6.4 Trust

Trust was a theme that was identified as having an unexpected relationship with a low understanding of data collection and processing (Figure 5). Previous literature (Wilton, 2015) posits that in the absence of knowledge, users rely on trusting the integrity of the company's using data appropriately and in-line with its users' values. However, in this study, participants reported to have little trust in social media platforms to effectively protect their privacy.

Though previous research indicates that trust positively impacts on disclosure and continuance intention (Iryna et al, 2013; Taşkın & Taşkın, 2019), many participants reported to have low trust in social media platforms to handle their data ethically and responsibly: *"I don't trust big corporations. I think if they can make a sale then they will so. I don't feel my information is safe and secure,"* (P/32). Other participants reported to trust that social media platforms will conform to regulation because *"there would be a serious amount of uproar"* (P/18) if they were found to be mishandling people's data.

Despite low trust, participants described that there is a trade-off. If they wish to continue to connect with OHCs, family, friends, and other networks, then data collection and processing for profit is *"one of those things that you have to accept on social media"* (P/19). Participant 34 described how they were *"not happy about it but equally at the same time I'm not sad [because] you are giving them something so you get something,"* suggesting that their data is the commodity or currency to 'pay' for the otherwise free service. Nevertheless, it appeared that *"rewards far outweigh any risks"* (P/20) and participants "*still use them and I probably wouldn't stop using it because of [data processing]"* (P/24).

4.2.6.5 Personal Responsibility

Though social media platforms *"can do whatever they want with whatever you post,"* (P/10) and there is a "trade-off" that should be accepted, some participants described how *"if you don't read the small print, it's your fault if [data mishandling] does[happen],"* (P/22). There was an attitude that it is an individual's responsibility to be more informed about how their information will be used before deciding to self-disclose as Participant 27 explained:

> *"if you want to post something up online whether that be on the internet or social media, that's your decision and if you're not comfortable posting something which they could be taken and used, you shouldn't be posting it".*

This attitude raises questions around who's responsibility it is to ensure that information is handled ethically and appropriately. From this perspective, when social media platforms can do what they want, the only agency that individuals can exercise is whether or not they use the platforms or indeed self-disclose on them. When people are unaware of data handling and would *"probably fall asleep if I tried to read Facebook's terms and conditions,"* (P/24) placing responsibility on people using the platform presents challenges around how awareness can be increased (Matzner et al, 2016).

Conversely, one participant who self-reported to work in online advertising reflected on the recently reported Cambridge Analytica scandal:

> *"The companies need to take responsibly to try and keep [information] as safe as possible but even they can use it as they want and if they have the money and*

> *the lawyers, can they really not get away with most things? Probably. Who's the single person to say 'I want to sue you now because you did this and this about my health information' how do you prove it? What funds do you have to take on a corporate? So I'm not sure it's even a fight you know, so I think it's something we always have to consider. Whatever we put up then it's always there and even if you delete it is probably still somewhere on a server which is kind of scary to think about but it's kind of true."* (P/33)

This participant reiterates how individuals relinquish control over their personal information to online platforms and how there is little that any individual can do to challenge them.

4.2.7 Information Privacy Behaviours

With limited knowledge of what information is collected, how it is processed, and what the impacts are, very few participants reported on actively changing their behaviours to curb information privacy risks. Two participants with computer science backgrounds described the additional use of third-party services to obfuscate behavioural information such as masking their Internet Protocol (IP) addresses through Virtual Private Networks (VPNs) and plugins like *"Privacy Badger and others"* (P/38) that block tracking cookies in the browser.

The other "key principle is to limit what insight they have into your world" (P/34) through self-censorship. Participant 7 said that "everything that I do is fairly anonymous even down to birthdays," indicating that they provide inaccurate details about themselves. As previously discussed, although some participants believe that it is a personal decision what is shared on social media platforms, few reported on self-censorship as a tactic to mitigate information privacy risks.

Even to those who indicated a discomfort with how social media platforms collect and process information, they are not all aware of the different services available to them to better control their information flows. This may be because, when considering how their information is collected and processed, people do not often take the time to think about how they can have more agency. While the interviews were taking place, some participants were looking through their settings discovering additional controls available:

> *"Yeah I'm now going to do it, I'm going to look- ah I'm actually in account settings and oh location services is on, so I'm going to turn that off and now I've just done it. It sounds really stupid that even though I don't like it, it's never really occurred to me to look into it. That makes me sound really stupid."* (P/24)

Finally, the social privacy tools that are available to users may provide a false sense of security; one participant believed *"that [Facebook] won't [share information] because they're closed forums,"* (P/28). Meanwhile, Participant 1 said *"I think that because [the group is] closed they shouldn't do anything with that data but I suppose if it's put on their platform then they have the rights to it. Interesting. I really haven't thought about it".* There may therefore be misunderstandings over what information is private from secondary use (by platforms).

4.3 Discussion

The social media platforms Facebook, Twitter and Instagram provide individuals with IBD online spaces for them to connect as a community, share their personal experiences and seek support. The 38 interviewees, each living with Inflammatory Bowel Disease, emphasised the importance of social media to receive and share information and support in a convenient manner. While participating in online health communities on the same platforms that people might use for their day-to-day social networking, participants were acutely aware of their social privacy concerns and articulated how they mitigated risks. Similar to studies pertaining to the challenges of information privacy knowledge (Patterson, 2013), participants in this study were less clear about these concerns and indeed how to manage their behaviours.

Addressing the first research question (**RQ1a**) which seeks clarification of how people living with IBD use contemporary social media platforms, this study found that most participants had reported to use more than one social media platform to access support. This suggests that just as the general population across the world uses on average 8 platforms (Chaffey, 2020), people living with IBD also adapt their use to incorporate accessing support.

To understand how people's experiences differ between the platforms, the SCENA model of therapeutic affordances on social media (Merolli et al, 2014) was adapted and used to organise the transcripts. The affordances of self-presentation, connection, exploration and narration were all associated with particular platform features, some functionality boasted different affordances, depending on how they were used by individuals. This study however did find that the therapeutic affordance of *adaptation* was not specifically associated with an interactive platform feature, more that health status can motivate both increased and decreased engagement with the OHCs as a whole.

Significantly, Facebook, Twitter and Instagram shared homogenous features that enable people to share posts on their profile, reply to others in comments, and chat privately in direct message. The ways in which the platforms' features are integrated and used by individuals had an impact on how therapeutic affordances were realised. For instance, bonding social capital through one-to-one conversations was most frequently discussed on Instagram, which meant that people were building stronger relationships with others. One reason for this, is that direct message is the default response function to Instagram Stories, which normalises the use of direct message with strangers. In a similar guise, the functions described on Facebook were mostly reported in the context of Facebook Groups, which adds a privacy barrier between members and non-members.

While not as frequently discussed, people's previous social interactions on particular platforms also played a role in people's experiences. A poignant example of this is reporting of disputes and misinformation sharing in larger Facebook Groups. Previous scholarship has critically explored the development of community cultures through social networking technologies; the notion of deindividuation offers an explanation that in larger group sizes, self-consciousness decreases which can be attributed to more hostile behaviour (Postmes & Spears, 1998). Notably, as described by a recently diagnosed participant (P/23) there is a wide range of Facebook Groups and platforms available to people so they can find Groups and tailor their networks to suit their needs.

The motivations and intentions of individuals was also recognised to shape their behaviours and their experiences (Ajzen, 1991; Bazarova & Choi, 2014). For instance, people who regarded themselves as advocates, raising awareness of IBD, reported not using privacy settings to increase the reach of their experiences. They described the benefits of having a big support network, but also have had to learn to deal with trolling online. Indeed, people's personal privacy preferences also shaped their behaviours and how they used different features on the platforms.

While platforms and features can be leveraged by the people using them according to their motivations, there may be limitations and constraints over what the features can do, which in turn can impact on how they are used. One example in this study was Twitter's character limit that impacts on self-disclosure and therefore the affordances of self-presentation and narrative. Another is how the privacy settings that surround Facebook Groups create a ‘safe’ environment that people feel they can self-disclose in more detail. This bidirectional relationship speaks to Winner (1986) who posited that “technologies are not merely aids to human activity, but also powerful forces acting to reshape that activity and its meaning” (p.6).

While there were commonalities between people’s experiences in using each platform from a functional affordance level, the social and relational affordances perceived by participants indicates that each person will inevitably have a unique experience. Participants in this study reported conflicting opinions about how different platforms ‘feel’; some believed Twitter feels public while others found it to be a ‘safe space’ and more personal. These findings support the notion of imagined affordances that take into account the features, personal experiences and emotional attachment to particular technologies (Nagy and Neff, 2015).

To address **RQ1b** on the privacy perception of people living with IBD using social media, the transcriptions were analysed through a dual lens, dividing the notion of privacy into two distinct categories: social and information privacy (Lutz & Strathoff, 2011). In these findings, the two privacy types were imagined differently. Participants identified that using social media yields therapeutic affordances, such as feeling a sense of community, however, they also understood that there are social privacy risks, such as impacts to their personal relationships and careers.

Notions of social privacy, that "describe the fear of intrusion caused by other people," (Lutz & Strathoff, 2011: p.85) were well articulated by participants. They understood that they share information about their health in a particular context, with an imagined audience for the purpose of receiving support, giving support, sharing their story and/or raising awareness. Similar to research on young people (Marwick & boyd, 2010), participants described how they were able to maintain contextual integrity (Nissembaum, 2004) through the use of audience management techniques and self-censorship. Through mitigating actions to reduce the risks, participants in this study were still able to reap the positive outcomes of using social media for health-related support. The ability to reduce the net concern as a result of mitigating action is indicative of what scholars refer to as the "risk calculus" (Li, 2012). This mental model supposes that individuals perceive a sense of self-efficacy, reducing their concerns and being able to participate comfortably online.

Conversely, information privacy was not imagined in the same way, with many participants indicating that they had not given much, if any, thought about what and how information about them is used by the platforms they self-disclose health information on, which disputes previous research suggesting that risks and benefits are calculated (Barth & Jung, 2017). Participants correctly identified a connection between their online behaviours and the advertising that they see. While these observations are true beliefs (Gettier, 1963), the extent to which they are justified is questionable. To elaborate, a significant majority of participants in this study did not read the terms and conditions and were unsure about what data is collected and how it is processed, supporting previous studies' findings (Debatin et al, 2009; Patterson, 2013; Rao et al, 2016; Obar & Oeldorf-Hirsch, 2020). Indeed, while their observations that adverts are based on their previous browsing experience are true; there was a fundamental lack of understanding how that happens. Instead, people were more actively concerned with other issues that they face as a result of advertising, which have clear potential harms, such as the spread of misinformation, which supports Sillence et al (2013) who found that for health websites that have advertisements, they expressed lower trust in them. This was partly attributed to the friction between commerce and health. Participants were concerned that advertising can fuel illegitimate treatments and therapies that have not been proven to improve health status.

Though it wasn't known to be true, hypothetical discussions of third parties, such as pharmaceutical companies, having access to social media data reiterated how individuals were sensitive to the contextual integrity of their health information. Though some were less concerned, participants described an appeal for informed consent if another party wanted to use the information they shared on social media. This is predicated on the belief that they shared their information to receive support or to directly help others with similar experience and support third-party research should be an opt-in exercise.

As such, participants described an asymmetry in power (Lightfoot & Wisniewski, 2014), believing that individual actions can have a minimal impact on how social media platforms process data. There was a common belief that seeing personalised advertising and having data processed, without much knowledge, was an accepted and normalised part of their social media experience.

Most participants reported to not have experienced an information privacy-related breach and the felt that they are not going to be personally harmed by data processing. This finding supports previous research that propose how optimism bias has an effect on people's perception of risk (Acquisti, 2004; Cho et al, 2010). Indeed, Hallam and Zanella (2015) propose that there is a temporal imbalance in risk perception suggesting that near-future intentions are more likely to be acted upon than those in the distant future. With risks that are far in the future and/or are difficult to predict and imagine, they are discounted as a 'true' risk that requires action.

It was deduced that the affordances of social media platforms outweighed any information privacy concerns with participants reporting "*the usefulness outweighs the possible downside of it*" (P/24). When taken together, if the benefits outweighed the risks then a trade-off was made, where individuals assumed all risk without mitigation. This is reminiscent of the privacy calculus (Li, 2012; Zhang, 2017). However, although most participants had reported to have given little thought to their information privacy, coupled with the low levels of knowledge and ability to process new information (Acquisti & Grossklags, 2005; Bashir et al, 2015), it should be assumed that the rational privacy calculus is rarely conducted (Lutz & Strathoff, 2011; Kosyfaki et al, 2017). Indeed, supporting Kehr et al (2015), while the calculation of benefits and risks may not be rational, instead participants may more heavily rely on experiential thinking, which further contributes to the importance of optimism bias.

While many participants demonstrated a low level of information privacy literacy, during the interviews some participants were simultaneously searching for new settings on their devices. Some also recognised their unfamiliarity with information privacy flows and expressed an interest in learning more. For others, however, they expressed an apathetic attitude, stating that they did not have the time to learn more and that they had ‘nothing to hide’.

It should be noted that the Facebook and Cambridge Analytica scandal broke headlines during participant recruitment which may have increased people’s attention to their information privacy; however, there was not enough evidence to validate that claim from a small number of interviews

4.3.1 Model

To visualise the relationship between the affordance model of SCENA (Merolli et al, 2014), privacy concerns and behaviours, Figure 6 was created. It displays factors from this study that can influence perceived benefits, social privacy concerns and information privacy concerns.

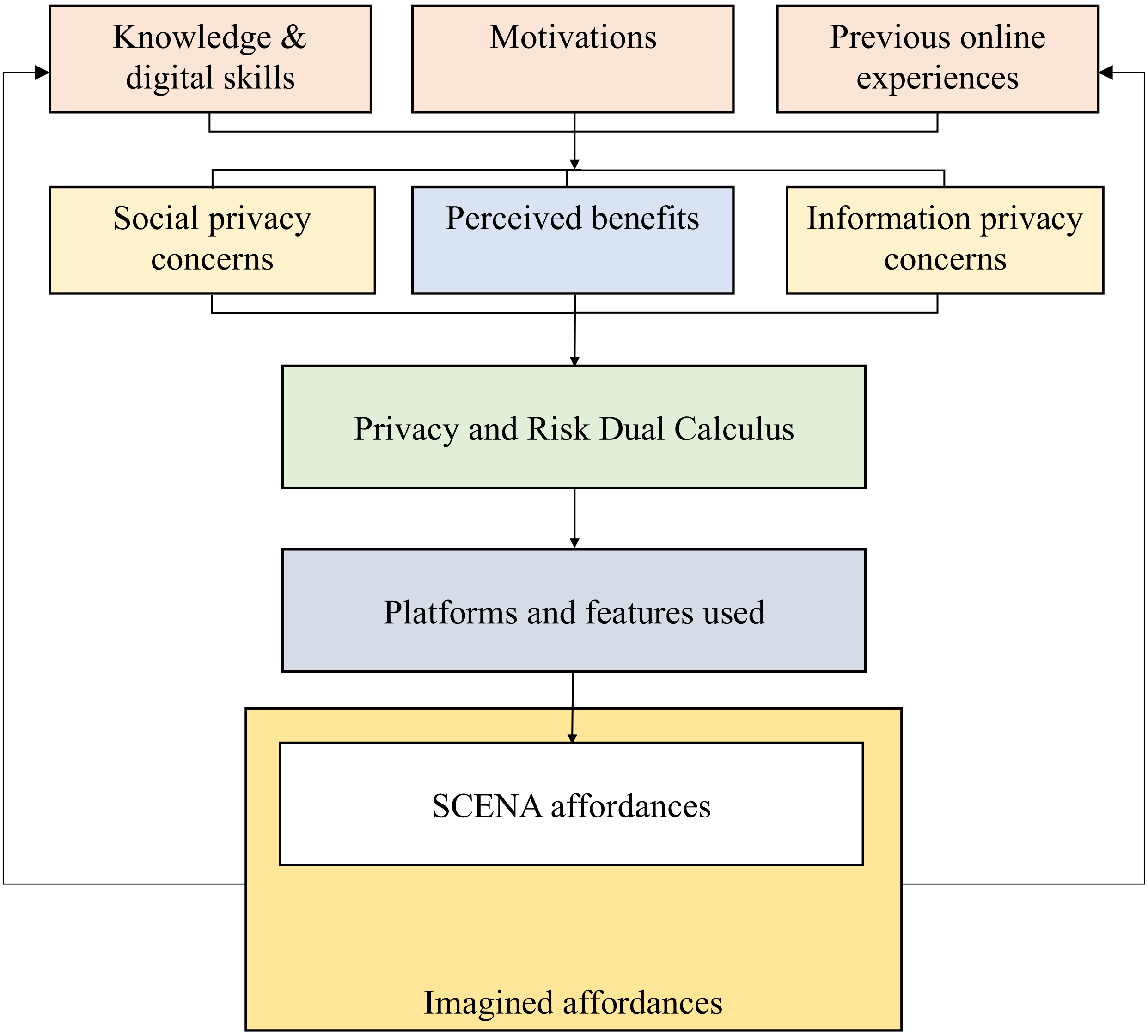

Figure 6 Model visualising connection between privacy and SCENA model

Firstly, knowledge and digital skills, or ‘digital literacy’; participants who have acquired knowledge and digital skills of how they can recognise and mitigate risk appear to demonstrate the risk calculus model for their online behaviours. Their digital skills therefore might influence the platforms they use and the features they use on them, such as privacy settings or using a pseudonym. Conversely, those with less knowledge or skills may be more likely to adopt to the privacy calculus whereby they make a trade-off instead of reducing risk with mitigating action.

Individuals’ motivations for engaging in online health communities can vary from those who are newly diagnosed seeking information compared with advocates. These motivations may have an impact on their privacy perceptions. Such motivations include, but are not limited to, awareness raising; seeking information about the disease; and, receiving empathetic support from people with shared experiences. Positive and negative experiences can affect perceptions of risk; participants described how they had not personally felt a harm from information collection and sharing and therefore could not easily identify risks.

As a result of the actions taken on social media platforms, individuals will benefit from different affordances of *self-presentation, connection, exploration, narrative* and *adaptation*. However, as previously described, individuals personal experiences may influence imagined affordances (Nagy & Neff, 2015) that are less tangible, such as the *feeling* of safety. The experiences that people have may then indeed contribute towards their future perceptions and behaviours.

4.3.2 Limitations

All participants self-declared to have felt well enough to take part in the research. The motivation behind asking participants as part of the recruitment and consent process was to reduce the risk of burden and stress. However, it is recognised that by speaking to individuals who felt their IBD was stable, this sample provides a limited perspective. However, to mitigate this sampling limitation, participants were asked to describe whether their social media motivations and behaviours differ depending on how well they feel.

In addition, the majority of the participants that were spoken to in this study were from the United Kingdom, with other users representing America and South Africa. It should be noted that the views from this study reflect the views of Western democracies. Perceptions and behaviours however may be different in other countries.

Indeed, interview-based research is vulnerable to response bias whereby participants will answer with socially desirable responses (Welbourne et al, 2013). Secondly, in agreement with HCI research, researchers often use self-reporting measures to understand behaviours; however, this method threatens the validity of the results. Speaking to participants about their behaviours rather than being able to observe their actual behaviours, such as in an ethnographic study, means that the researcher must rely on what was self-reported to be accurate (Williams et al, 2017).

4.4 Conclusions

The findings in this study demonstrate that the affordances social media platforms offer for people seeking support online are highly valued by members of the IBD online communities using Facebook, Twitter and Instagram. Though platforms share homogenous features, their application contributes towards imagined affordances, where people may feel ‘safe’ or welcome in particular spaces. The asynchronous, geographically boundless communities are self-sustaining with individuals reporting to engage with them differently depending on their health status, needs and advocacy motivations.

Social and information privacy are not thought about equally. While participants were articulate about social privacy risks and mitigating actions, they were less certain about information collection practices, ultimately amounting to a privacy trade-off mentality. Crucially, however, during discussions, some individuals expressed an interest in learning more about how their data is used. With coverage of the Facebook and Cambridge Analytica scandal circulating in the news, some participants had a heightened sense that they were perhaps ill-informed about their information privacy.

Though there was a recognition that there is a relationship between data collection and the advertising seen by participants, the interest in learning more about these practices was identified as a point of research interest. The next chapter addresses how privacy is perceived by other stakeholders in the community and their opinions on privacy-enabling interventions.

CHAPTER 5: STUDY TWO – Focus Groups with Community Stakeholders

5.0 Introduction

The findings from the previous chapter offered an in-depth view of how people living with IBD use social media platforms to access support. The functionality of Facebook, Twitter, and Instagram presented relationships between platform features and therapeutic affordances; however, people's experiences were formed through a combination of their interactions with the technologies, other users, as well as their motivations, and personal preferences. Analysing people's reported behaviours through an online privacy lens, the findings in Study 1 demonstrated that individuals with IBD are sensitive to the contextual integrity of their health information. Though attitudes and behaviours towards social privacy were more clearly articulated across the interviews, there was a reported discomfort with their information being used for purposes beyond social support.

This chapter aims to build on the results from the previous study by exploring the OHCs from a different perspective. boyd (2012) advocates that the narrative of privacy and personal data centres around individuals and there is a need to critically research privacy as a networked phenomenon. While OHCs are mostly made up of individuals with lived experiences, there are other stakeholders that are involved, including forum administrators, charities, medical professionals, and other community leaders (Antheunis, Tates & Nierboer, 2013). While some of these people may also have a lived experience of the illness, their role is different from that of a community member. For example, administrators, as described by participants in Study 1, safeguard Facebook Groups by restricting access and enforcing community rules.

Engaging in a multi-perspective approach can help to build a more comprehensive understanding of online communities and the role of privacy; other stakeholders can identify challenges and observations that might go unnoticed by community members.

Study 2 had three key objectives in mind. The first concerns the perceived affordances of social media orientated support though community leaders' perspectives. The SCENA model (Merolli et al, 2014) that was applied in Study 1 was developed through individuals' experiences and so, this current study adopts a more inductive approach in understanding the perceived affordance through the perspective of community leaders.

The second objective was to investigate what are the perceived privacy challenges facing people living with IBD engaging in social media for online support. As discussed in the literature review, previous research has outlined challenges that inhibits people's ability to understand how their information is collected and used, such as inaccessible policy documents (Wang, 2017; Patterson, 2013; Reidenberg et al, p.83, 2014; Rao et al, 2016).

The third objective for the current study was to explore how the digital well-being of patients can be improved. In particular, the study builds on the awareness gap of personal data collection and processing, that was identified in Study 1. A recent Ofcom report indicates that 6 out of 10 people in the UK are unaware of the different 4 ways data is collected (Ofcom, 2019). It is not surprising when the report also suggests that 7 out of 10 of people do not read the terms and conditions, which is supported by 8 in 10 people in Study 1. As described in the privacy literature review, Rao et al (2016) indicate a significant disconnect between people's expectations of data use and what is described in privacy policies.

This lack of understanding serves as a sticking point that helps explain the privacy paradox (Lutz & Strathoff, 2011). When individuals are unaware of the facts of how their personal information is collected and used (O'Hara, 2016), it is unreasonable to expect individuals to consider the information privacy implications and how they might behave accordingly. In order for individuals to have more control over the contextual integrity of their information, increased awareness is required.

There are many reasonable methods to raise awareness and understanding to individuals about how their data is collected and processed by social media platforms. Currently, there are several existing programs and tools available for free. However, what is appropriate for a health-related community may differ from interventions created for other audiences, such as young people

(Livingstone et al, 2019), librarians (Data Privacy Project, nd), victims of domestic violence (Hack Blossom, n.d) and the general public (Glass Room, 2016; Do Not Track, 2015; Me and My Shadow, 2012; EFF, n.d).

5.1 Aims and Objectives

The main aim of Study 2 was to examine the affordances and role of privacy from the perspectives of community leaders operating in the IBD OHCs on social media. Specifically, the study was concerned with addressing these questions:

RQ2a	*According to community leaders, what are the affordances of social media-based online health communities?*
RQ2b	*What are the privacy challenges perceived by community leaders?*
RQ2c	*What types of interventions do community leaders believe would benefit the IBD online communities?*

The chapter continues to describe how these research questions were addressed through focus group studies community leaders who represented a national charity as well as self-organised patient leaders.

5.2 Methods

5.2.1 Participants

Two UK national charities were approached via email and invited to participate in a focus group study. One charity, located in the South of England, accepted the invitation while the other could not commit to the disruption to their daily operations. 8 UK-based community leaders and ambassadors were invited via social media and email to join a second focus group based in Coventry in July 2019.

Two focus groups were formed for this study; one representing a national charity and the other patient community leaders. One charity dedicated to improving the welfare of children and young people with Crohn's and Ulcerative Colitis, accepted the invitation for participation. Three people represented their team within the research study and would be considered a "naturally occurring" group (p300, Kitzinger, 1995). Herein this will be referred to as "Focus Group One" (FG1). While generalisable sampling is not a primary objective of focus group research, as the discussions taken place offer rich shared understandings of particular contexts, it should be noted that the conversations and priorities of this organisation may not be entirely shared with other charities in the UK and indeed globally.

For the second focus group, four participants were recruited from the IBD online community, representing three online communities distributed across Facebook, Twitter, and Instagram. These individuals were patients advocating for improved support for the IBD community. While they themselves have personal experiences as patients, they have significant experience as community leaders supporting others. This was determined by the length of service they have demonstrated supporting the communities, with a combined total of 17 years (mean = 4.25 years) and their engagement across different platforms. Accumulatively, they have fostered communities on Facebook (n=31,803, mean=10,601), Twitter (n=10,026; mean=3342), and Instagram[18] (n=20,936; mean=6979). Herein this will be referred to as "Focus Group Two" (FG2).

Focus Group	*Participant no.*	*Role*	*Organisation*
FG1	1	Chief Executive	CICRA
	2	CICRA employee	CICRA
	3	CICRA employee	CICRA
FG2	1	Co-founder	Get Your Belly Out
	2	Co-founder	Get Your Belly Out
	3	Chief Executive Officer	IBD Relief
	4	Community founder	Instacrohns

Table 6 Demographics table of focus group participants

5.2.2 Data collection procedure

To address the research questions for this study, focus groups were selected. Similar in its approach to semi-structured interviews, group interviews are a qualitative methodology that makes data-collection more efficient for researchers (Frey & Fontana, 1991; Kitzinger, 1995; Morgan, 1996). Frey and Fontana (1991) organised the different approaches to group interviews into a typology.

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[18] Figures accurate at time of access (July 2020)

They identified 5 group interview methods: focus groups, brainstorming, nominal/Delphi, field-natural, and field-formal. The method adopted is influenced by the setting, role of the researcher, question format and the purpose.

Focus groups, a common group interview method adopted for groups in qualitative research, demands an active role of the group facilitator to focus the discussions on particular themes and questions (Frey and Fontana, 1991). The researcher can also become an active and empathetic participant of the discussion themselves, but they should exercise control over the discussions to remain focused on the topics in question. They are typically planned ‘formal’ meetings where participants meet in pre-set locations, away from the environment that is being discussed. The purpose of focus groups can be exploratory to further understand the social contexts; test the feasibility of future studies and research enquiries; and “identify nuances of a research setting that could impact the investigation” (Frey & Fontana, 1991: p.177). Focus groups can also be used to test surveys intended for wider rollout; they provide an opportunity to receive feedback on readability, comprehension and other factors.

A second group interview method considered was brainstorming (Frey & Fontana, 1991). This method observes the researcher taking a more passive role whereby they offer different ideas and let the participants critically discuss their thoughts, experiences and opinions to generate new ideas. The brainstorming strategy however is criticised for creating superficial and potentially unusable data. Usually taking place in more informal and spontaneous settings to explore avenues and solutions, the research questions in this study demanded more focus and involvement from the facilitator. Nevertheless, 'brainstorming' was adopted in the final part of the focus groups in this study to explore different interventions that could be created for the communities.

While there are benefits of group interviews, they are not without their limitations and challenges. Firstly, researchers need to be cautious of group size and sensitive to the dynamics in the groups. There are different recommendations of group sizes, with some ranging from 4 to 8 and even 10 participants (Kitzinger, 1995; Frey & Fontana, 1991). Groups of strangers will present different challenges to groups, such as co-workers, who have previously established patterned relationships (Frey & Fontana, 1991). Scholars have commented on the accessibility and acceptance of researchers into pre-established groups; however, given the author's personal experiences of the IBD online community, this was not a concern for the current study. The following sections will outline how the focus groups were designed and delivered in order to answer the research questions.

The setting for FG1 was at the charity's offices in the South of England during their working hours. Participants met in a board room, around a large table. With participants of FG2 distributed across the UK, the focus group took place in Coventry City Centre on a weekend. To create a relaxed environment and as a token of appreciation for their time, participants in FG2 met in a private room at a restaurant where food and drinks were provided. A portable projector was used so that all participants could view a presentation and the room was organised buffet style to further create a relaxed, shared space. Participants of FG2 were additionally offered vouchers for their time.

The focus groups both followed the same format and lasted between 90 and 120 minutes. Firstly, participants were provided with another opportunity to read the study information sheet (after having been emailed the same document at least 1 week prior) and had the chance to ask any questions. A consent form was given to participants, which they filled out, signed and returned to the researcher, if they were happy with the terms of their participation. Following the consent process, the researcher shared some insights from the previous study of how patients with IBD perceive their social and information privacy. The slides were used as a tool for participants to respond to and have critical discussions about their experiences and responsibilities as community leaders.

The discussion part included semi-structured questioning by the researcher to understand the complexities of privacy in the support context. Questions were also employed to gather their suggestions for how to improve people's privacy when engaging in online health communities on social media. Discussions focused on different approaches that can be taken, and critically questioning their feasibility as well as the nuanced challenges that can be faced by this particular community.

Voice recorders were placed in different areas of the room to reduce the risk of data loss. Audio recordings of each focus group were transcribed by the researcher. The transcriptions were then analysed using NVivo, a qualitative analysis software for research. Thematic analysis was employed to make meaning from the discussions held by both groups. The coding structure can be seen in Table 7.

5.2.3 Analysis procedure

Code	**Theme**
• ***Impact on treatment and care*** • ***Easy access to social media and support*** • ***Empowering patient voice*** • ***Patient advocacy***	Digital civic engagement
• ***Terms and conditions*** • ***Complexities of digital economy and algorithms*** • ***Need for precedent*** • ***Awareness and understanding of GDPR***	Current privacy awareness challenges
• ***Advertisements*** • ***Normalised experience*** • ***Long term users***	Phenomenology – Doesn't feel like a privacy invasion/harm.
• ***Welfare benefits*** • ***Employment*** • ***Charities***	Legitimate 3rd party access
• ***Personal responsibility*** • ***Self-regulation by social media platforms*** • ***Government regulation*** • ***Organisations interventions***	Responsibility
• ***Independent platforms*** • ***Pop-up warnings*** • ***Information guide***	Potential interventions
• ***Requirement for support***	Ethical considerations

Table 7 Coding structure for Study 2 Focus Groups

The author transcribed the audio recordings of each focus group and read the transcripts before beginning formal analysis (Braun & Clarke, 2006). Using NVivo 12, the transcripts were inductively coded. These codes were then grouped into an overarching theme (Table 7). Examples of the coding can be found in Appendix 2e (Page 389) The coding structure was reviewed and agreed with the author’s supervisors without any additional comment.

5.3 Findings

The findings section is divided into 6 sections; firstly the findings will discuss the most frequently discussed positive outcome of online health communities from the perspective of community leaders. Then themes pertaining to privacy challenges and concern, including poor awareness. Finally, the results of how participants discussed potential solutions to better improve the digital wellbeing of patients, in the context of privacy.

5.3.1 Digital Civic Engagement

Through shared observations, focus group participants reported on how people living with IBD who have engaged with OHCs are motivated to influence systemic changes to the healthcare system. Participants in FG2 discussed how they are approached by the civil service and companies to represent people living with the condition when decisions are being made. The community leaders become spokespeople for the collective group because *"it's more powerful when it's coming from patients than from the national charity,"* (Participant 2, FG2).

> *"I think we're able to take that patient voice and like [P/2] was saying taking them to people who can make those differences. The community is really opinionated, wants to get involved, but they don't necessarily know how to go about it so we have unlocked that barrier and you know it's not as scary to give feedback to a company or the NHS or you know. It's empowering patients," (Participant 1, FG2)*

For people living with IBD in the UK, there is a set of nationwide standards that should ensure that all patients receive the same level of care (IBDUK, n.d.). When patients share their experiences of their healthcare providers on social media, it means that they can compare others' experiences to the service that they receive. Participant 3, FG2 remarked "*it's made patients have the knowledge of what the standard of care should be or could be and it's helping to see that,*" while Participant 1 agreed that having these comparisons encourages people to advocate for IBD nurses.

5.3.2 Legitimate Third-Party Interest

When discussion turned towards third-party involvement and use of self-disclosed health information, the theme of legitimate interest became central to the discussion. Participants recognised that the information that is shared by members of the community can be really valuable to healthcare providers and pharmaceutical companies to improve services and products. However, what is considered a legitimate interest was difficult to describe:

> *"It's one of the things at Facebook at the moment, what constitutes a legitimate interest and there is no consensus, it's what they feel and their lawyers."* (Participant 3, FG1)

The charity believed that the financial motivation of organisations plays a role in their legitimacy to have access to information. For instance, the charity uses a Facebook cookie on their website, so that if visitor is logged into Facebook they will receive an advert in their news feed about their free membership to the charity. This is believed to have "*a moral purpose to it*," (Participant 1, FG1) because they are solely interested in supporting patients and parents, without financial reward. However, if an organisation is running adverts and accessing data to generate a profit, then their involvement in the community is not entirely for the benefit of the patients.

Across both groups, there were short discussions about the legitimate role of government access to information on social media, particularly around the topic of welfare benefits. For the community leaders, in particular, this access was seen as particularly problematic for a non-visible illness like IBD.

> *"We've got people who have changed their names on Facebook purely for that reason. They click to join again and I think that's the same person. They said they had to change their name because of it.* (Participant 2, FG2)

> *"It's bad that somebody would have to do that though because if you're purposefully trying to conceal anything for a reason that's your doing but if you're just trying to avoid being looked at in the wrong way, you don't want people to believe you're absolutely amazing. It goes down to the whole invisible illness thing doesn't it. It's not always there to see so you don't want to give people the wrong impression."* (Participant 4, FG2)

5.3.3 Current Privacy Awareness Challenges

While there are extremely positive outcomes for individuals and patients as a group, conversations turned towards the challenges around information privacy awareness and concerns. Focus group participants reported that information privacy is not routinely thought about by individuals:

> *"I honestly think that some people don't even think. It doesn't even come into their brain. It's like now with them cookies you go onto websites. You just go yes, 'cos you're just like 'I wanna see what I wanna see' it's just there, go away." Participant 2, FG2*

A key challenge discussed in FG1 was how data collection and processing is "so complicated for your average person to get their head around that let alone properly consent to," (Participant 1, FG1)

Between the two focus groups it was agreed that with the current attitudes and attention paid towards data collection and practices, information privacy will "*not [be] considered until a need. i.e. something goes wrong or they're not happy about*" (Participant 4, FG2).

> *"Unless it actually happens to you, it's kind of one of these things that until it happens to you you're not going to worry about it." (Participant 2, FG1)*

While there was an agreement that people would be more likely to take notice of their information privacy if they had experienced a privacy violation, one participant described how data breaches, just as personalised advertising, are becoming a normalised part of people's online experience:

> *"I think particularly after Cambridge Analytica people wouldn't be, they wouldn't go 'oh gosh that's a surprise' but they wouldn't think about it in advance so if it turned out 'oh gosh my personal health data is being used to do with insurance' I think now people wouldn't be particularly surprised by it but they may still not have thought about it before sharing." (Participant 1, FG1).*

One reason that participants perceived to be a particular challenge was the difficulties in understanding the complexities of data collection and practices by online platforms. Participants agreed that the privacy policies should serve as a clear informative document to communicate what information is collected and how it is used. Instead, they were described as *"terrible"* (Participant 3, FG1) and too time consuming to read and understand. Participants in FG2 discussed how for people who urgently require social support, they do not have the time to process the verbose policies prior to engaging in OHCs.

Furthermore, because social media platforms are used for multiple reasons and not solely for health-related support, individuals may have been using them for years prior. While they may never have read the terms and conditions at the outset, focus group participants thought it would be unlikely that individuals would have returned to them before self-disclosing health information:

> *"The problem is that people likely are going with Facebook, not especially Instagram but people may have signed up seven or eight years ago so maybe there's some whether they may be obliged every two or three years to say 'by the way here are the terms and conditions'" (Participant 3, FG2)*

Terms and Conditions aside, the average person isn't believed to fully understand the data collection and processing that occurs by social media platforms (Ofcom, 2018). One participant described that high self-disclosure behaviours might be indicative of a low understanding of the digital economy:

> *"I used to work with a cancer charity and some of the personal stories that people put in comments or post on the page, they possibly couldn't have known. It doesn't happen very often but it did occasionally. People couldn't possibly know or have understood how Facebook works or social media in general." (Participant 3, FG1)*

A participant in FG1 described how the General Data Protection Regulation (GDPR) that was enforced in May 2018 that promised increased privacy safeguarding to individuals, may have given a false sense of security:

> *"One thing I do wonder with recent times whether GDPR has been a bit of false sense of security for people because that's a bit of a mine field in itself, trying to get your head around all of that. But I do wonder if people think 'there's the new rules in now and they can only do this and that with my information and you have to opt in and if you haven't opted in then it's fine' so whether or not there*

> *is also a little bit of people who have relaxed thinking that they're all covered by that nowadays." (Participant 2, FG1).*

While GDPR provides a legal framework (2018), it does not necessarily mean that individuals understand what the regulations mean for them. In each focus group participants described how legally the charity and the community leaders are 'covered', but whether patients understood and given true consent is unknown.

> *"So they've consent in a legal, so legally we're fine. But whether they legally understand what that's meant." (Participant 1, FG1)*

> *"I think it might be an idea for us as a company, a CIC*[19]*, to let people know that they are covered by GDPR as well." (Participant 2, FG2)*

A final challenge in getting people to think more carefully about the impacts of data collection and sharing, is that there are few examples that set a precedent of what can happen. Once there is enough evidence to suggest a harm, then both individuals and government can work towards creating safer spaces for self-disclosed health information:

> *"If negative impacts can be identified first then it's a lot easier to say 'in order to avoid this, we suggest you do this' but we don't really know what if anything is happening." (Participant 3, FG1)*

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[19] A CIC is a community interest company

5.3.4 Phenomenology

Phenomenology, in this context, refers to how people don't feel like there is a privacy harm, when there may or not be one. As such, advertisements were reported to be a normalised and accepted part of the social media experience. It was agreed across both focus groups that personalised adverts can provide more relevant information to individuals:

> *"The question you were talking about before I think it was Twitter and it asks what adverts do I want to see. I think it's accepted that you're going to see adverts regardless so do you want to see adverts that are tailored to you or do you just want rubbish in your newsfeed so in a way you give in and say sure, at least it's what I'm interested in rather than all the things that I don't need." (Participant 1, FG2)*

> *"It's almost better to have personalised ads because there's a new thing that Facebook has talked about, that you can opt out. It looks like they're going down the route of you have to opt out of individual websites, you can't just opt out of everything. I think that's the way it's going but also there is an advantage of not doing that because at least you will see ads that are relevant to you. You're still going to get ads." (Participant 3, FG1)*

Using illness related hashtags and following particular accounts could expose individuals to targeted advertising. Participants in FG2 described the challenges around companies sending unsolicited messages directly to individuals through messaging services built into the platforms. Participants described how the widespread actions of companies offering unproven therapies can cause serious harm to individuals. The focus groups discussed how the technological infrastructure and social privacy controls has curbed direct marketing through Facebook, but still occurs on other platforms:

> *"I suppose a negative of that is people with a 'cure' they can target people and like... they've changed it now so you can't see the members that are in a group. Whereas before people were adding people because they could see that they were in the group and they were targeting. I suppose that's more on Instagram these days how these companies will see who they're all following and give them all them an inbox so that's a negative of that information being out there because you can find all these people." (Participant 1, FG2)*

5.3.5 Responsibility

With regards to making change to improve the contextual integrity of self-disclosed health information on social media platforms, it was agreed that social media platforms are unlikely to self-regulate and volunteer to support privacy, based on their business models:

> *"he's [Nick Clegg] Facebook's PR type thing and he said a couple of weeks ago that it's not up to Facebook to self-regulate, governments need to do it." (Participant 3, FG1)*

> *“I think it would be worthwhile for Governments but I just can’t see individual organisations taking responsibility and if they did they would all have different methods. It has to be government thing.” (Participant 3, FG1)*

Both the charity and the patient community leaders described to what extent should they, as advocates in the community, take responsibility to better safeguard information privacy. The Facebook Group community leaders described how they have both a Group and a Page on Facebook. The Group is for support while the Page is to raise awareness. They have actively tried to differentiate the look of the page, through a different banner page, to indicate to users to what audience they are posting to:

> *“I think sometimes people have thought they posted in the closed group but they actually posted on the page and then you know they get cross with us, when really if they look... half the time there was one the other day, they were saying ‘as it’s a closed group, I’ll share my picture’ and I deleted that for her benefit and messaged her and said ‘I don’t think you’re aware but you posted it and I’ve removed it in case you didn’t mean to make it public’. Sometimes that’s good because people say it’s out there now because people on their friends list now know about it, but as you say who’s to blame for that, but they have to take some responsibility themselves. As much as they don’t like to do that.” (Participant 1, FG2)*

> *“Even our heading, the colours in our headings are different for that very purpose. So that people know the difference because if it looks exactly the same*

> *then fair enough, but they're completely different colours. One's black and one's pinky purple." (Participant 2, FG2)*

Although a top-down regulatory approach can provide users with better information on privacy protections, in the short term, participants questioned whether individuals should take some responsibility for their online behaviours.

> *"Or does it fall on the user for not having their privacy settings and everything. It's hard." (Participant 4, FG2)*

When it is perceived by community leaders that there is a low awareness of data collection and processing, but there is a need for individuals to take some responsibility to protect their own information privacy, there becomes a need to educate patients. Participants were describing to what extent it is their responsibility to promote awareness and understanding.

> *"Is it our responsibility really to be worried too much? If they're choosing to instigate a conversation about something that of course as long as we're responding appropriately and we're aware of the basics, then how deep do you go? It's the dilemma I guess." (Participant 2, FG1)*

> *"We should all do a collective post of some kind over the next month, same format, same style and do like a blanket message about privacy. Like a simple one liner – do you know where your information goes. Just something to get people talking." (Participant 4, FG2)*

5.3.6 Potential Interventions

The final part of the focus groups was to engage participants in a discussion of what interventions can be developed to help support people's online privacy. The following section explores the different suggestions that were deliberated. In FG1, participants described an intervention integrated into social media platforms whereby after a period of time data is deleted or disregarded from further processing:

> *"Or even either it's automatically at a certain point in the past, like your data from 5 years an older automatically not deleted necessarily but completely hidden from anyone but yourself. So it's an automatic thing that every day that day five years ago goes behind a firewall as it were. Or whether you just have an option where people can – I suppose in theory if I went into my settings on Facebook and went through them all, I could literally delete myself from it and none of it would exist." (Participant 1, FG1)*

A second suggestion was that a pop-up or notification would alert an individual as they were writing a post, inviting them to think carefully about what they're posting and the privacy implications:

> *"Or something just as you're about to post, at the bottom that says 'be warned' some kind of warning or a reminder of what they're about to put out there is going to be out there," (Participant 2, FG1).*

There is a risk however that popups and notifications become fatigued (Wilton, 2017), similar to cookie notifications on website, so its design should be carefully considered.

> *"It's like now with them cookies you go onto websites. You just go yes, 'cos you're just like 'I wanna see what I wanna see' it's just there, go away." (Participant 2, FG2).*

When individuals have been on some social media platforms for a long period of time, it was thought that they should have to give consent again, after having the opportunity to review the terms they are agreeing to:

> *"the problem is that people likely are going with Facebook, not especially Instagram but people may have signed up seven or eight years ago so maybe there's some whether they may be obliged every two or three years to say 'by the way here are the terms and conditions'" (Participant 3, FG1)*

However, the terms and conditions should be much more understandable and not like "*reading war and peace*" (Participant 2, FG2) and again, there is the same dilemma that individuals will passively accept in order to access the platform and support:

> *"They are under some sort of obligation, whether it's legal or their own, to present their terms and conditions and what happens with the information and data. In an understandable format because the GDPR does say that you must do it in a way that can make sense." (Participant 1, FG1).*

Finally, both focus groups discussed the need to raise awareness directly to patients using social media for support. It was believed that something general should be presented to individuals that describes how all platforms operate and what their business models typically entail:

> *"I think people need educating about the digital sphere in general and here's almost, here are some things to think about in the digital sphere wherever you're going, whatever you're doing. And almost forget about the terms and conditions from all the different companies because it's just, you know, particularly online it's click there click there click there and in ten minutes you might have gone to twenty different websites and looking for a bit of information and if you've got to understand genuinely what they're going to do with your information and if you're connected to Facebook they might then pick up what you've written on Facebook or whatever." (Participant 1, FG1)*

The core aim would be to present information about data collection and processing in a simple manner. It should provoke individuals to *"think more"* and reflect (Participant 1, FG1) on their privacy values and what sharing health information on these platforms might mean:

> *"Yeah bullet points like that are simple but eye-catching to me. If I was going to sign up to I don't know a website, just to let you know anybody can get this," (Participant 4, FG2)*

With participants in Study 1 reporting to not have a lot of time to dedicate towards learning about information privacy, focus group participants described a two-step intervention. The first step would be a post directly on the platforms to capture attention, with more information being available on a website for them to learn more. The first step would have to be engaging, but how it is presented would have to change depending on platform:

> *"It would have to be simple, easy on the eye. Engaging for people. I know it's a bit different but I seen the Lifeboat Association stories on Instagram just telling*

> *you what to do if you fall in cold water, it's literally like a 6 second ad but I remember it now. It was a six second thing. Something really engaging can really work – that ad has stuck with me all day I can remember it now." (Participant 4, FG2)*

> *"It might depend on the recipient in terms of. So it might be the fundamental message is X and then how you deliver it varies whether it's platform, recipient, you know? Not making it too complicated…" (Participant 1, FG1)*

There are limitations to how much information can be shared in one post; videos can be engaging however, there is a limit to how long someone might want to spend on a video about privacy.

> *"People don't really watch a video, unless they're really engaged they won't watch videos that are longer than a minute. I wouldn't even say that long most people, unless you're really engaged with it." (Participant 2, FG2)*

One participant reported on how future generations joining social media platforms will have had more digital literacy education in schools; however, there should still be a place for an individual to learn more if they need.

> *"It is about keeping it simple isn't it. I think as the generations go through school. I mean my six year old talks to me about internet safety and she doesn't use the internet. She's got it from school. She says things and I'm like alright okay. We have been offered workshops to go in and talk to people around internet safety. I think they are becoming more aware of it, so having a reminder and you know maybe if you want to know more, go here so that it's not in your face too much." (Participant 2, FG1)*

5.4 Discussion

Through the perspective of community leaders, this study has identified how online communities serve as an important role not only to individuals but to wider stakeholders. It also further establishes the nuanced challenges that the community faces to preserve contextual integrity, increase awareness and prevent harm. The following discussion will position these findings into the wider context of this research.

Towards understanding the wider benefits to the community at large (**RQ2a**), this focus group study has provided some insights as to how patients can become more actively involved in meaningful decision-making around their care. When patients share their experiences of their illness and the care that they have received, comparisons are made by others who measure other people's experiences with their own (Mo & Coulson, 2012). As observed in Study 1, social media platforms afford information sharing which means that people living with IBD can become more aware of the different aspects of their illness. Supporting previous research (Lamas et al, 2017; Loane & D'Alessandro, 2014) that argues how the asymmetric relationships between patients and their care providers are challenged as a result of online support groups, with patients becoming more knowledgeable and empowered. The findings from this study indicates that patients can mobilise on social media to make effective systemic changes that impacts the care of many. While sometimes this can occur directly with community members, this study also highlighted the role of community leaders who act as intermediators between the community, policy makers and healthcare providers and companies. They can take direct recommendations from the community members to change-makers that can ultimately improve their care and experiences. Taking findings from Study 1 and 2 together, there are both individual and group benefits that have been experienced as a result of OHCs organising on social media platforms.

RQ2b queried what the community leaders identified as current privacy challenges facing the IBD OHCs using social media. The findings from this study further evidences the complexity of privacy on the internet and how contextual integrity can be improved.

The first challenge is around people's knowledge and understanding of how information is collected and used by social media platforms. A significant issue that was identified was how complex the digital economy is for an average person to understand. While participants discussed the role of privacy policies and terms and conditions, there was a general consensus that these verbose documents were unclear, which supports previous research by Lebanoff & Liu (2018) and Strahilevitz & Kugler (2016). Additionally, participants in FG1 talked about how each platform has their own policies, adding additional burden for people to read and understand how each company will be processing personal information. This supports previous research that highlights how a significant amount of effort is required for individuals to understand and manage their information (Angwin, 2014; Matzner et al, 2016), which often can lead to people giving up trying (Schermer et al, 2014).

Additionally, the focus groups also discussed how the emotional state of a person who is ‘desperate’ for social support will negatively impact on their willingness and cognitive ability to think about, and understand, the information privacy implications of seeking help on social media. Participants noted how the time spent on learning about the long-term privacy implications of their illness will be temporally discounted (Hallam & Zanella, 2015; Acquisti, 2005) in favour of seeking immediate support.

Focus groups echoed findings from Study 1 that the consideration for information privacy is less likely to happen for those who have not already had a negative experience, and that data misuse may become more normalised and expected. Indeed, this perception follows empirical work that has focused on comparative optimism (Min Baek et al, 2013; Debatin et al, 2009) which concludes that people assume negative privacy outcomes are more likely to occur to others than themselves, unless they have previous experiences. The point raised about how people using social media for IBD support are likely to have previous experience with the platforms for other networking. This plays into the notion of comparative optimism and the cognitive bias (Min Baek et al, 2013; Debatin et al, 2009; Kokolakis, 2015; Cho et al, 2010) whereby people’s previous positive experiences influence how they judge their privacy and safety.

While comparative optimism offers one explanation of why people are less likely to take time to learn about their information privacy, focus groups also highlighted the lack of evidence that verifies what the possible information privacy risks are. To date, there are some anecdotal stories reported in the media about unexpected negative outcomes from health information inferences and sharing by companies such as Target (Hill, 2012); Patients like Me (Angwin & Stecklow, 2010); Facebook (Osborne & Parkinson 2018); Health Apps (BBC, 2019); Insurance (BBC, 2018). The focus groups in this study remarked that without a threat of harm, or relevant precedent of negative outcomes from how personal data is used, it is difficult to communicate what the broad concerns are and how people can work together to mitigate risk.

Finally, with regards to the current privacy challenges (**RQ2b**), participants in FG1 described how the highly publicised recent regulatory changes, notably the GDPR, can lure individuals into a false sense of security, putting a considerable amount of trust in compliance. However, like data collection practices by companies, the focus groups believed that people do not understand how GDPR impacts them and what their rights are.

The findings of the current study raise a number of different recommendations to improve the digital well-being of patients with IBD using contemporary social media platforms (**RQ2C**). The most salient of which is the 'need' for increased awareness of data collection and processing practices, particularly as social media platforms are increasingly more embedded into society.

Given the pervasiveness of social media and its widespread use across demographics, the focus group participants recommended that individuals should not be directed to other purpose-built environments. Challenges to charities building their own platforms include user retention; continued active engagement; set-up and running costs; as well as regulatory compliance. When patients can set up their own communities on social media, where there are thousands of IBD patients, there are few business incentives for charities to build a new platform. Agreeing that purpose build platforms for online support, through privacy-by-design and value-based design principles, would not be built, the focus groups deliberated on alternative recommendations to improve the digital well-being of community members.

The first recommendation was longitudinal data deletion. After a period of time, such as 5 years, an individual should have the option to have their data made irretrievable by others, including the platform provider. This can present some difficult challenges to ownership, business and technical execution. Information on platforms is backed up on multiple servers to increase safeguarding of information from ransomware attacks (Thomas et al, 2018). For the information to only be retrievable by the user, all backups would need to be wiped from the servers and moved to an alternative encrypted server that only the individual has access to. Issues of ownership then similarly arise for information about a person, such as a tagged photo, that was uploaded by another user. Ultimately, this would require significant resources to deliver and it would not be in a company's interest to do this when their business model centres around data processing; it would end up being a free archive storage system. Finally, while information that is five years old could either be deleted or made unreadable, the data has already been processed and inferences made about an individual.

A second recommendation is a language analysis plug-in that alerts users when they are typing sensitive information onto social media. This would act as a plug-in that individuals download and authorise to be active on their web-browser. Its use would rely on self-selection bias, therefore individuals who have not considered their information privacy are unlikely to search for a plug-in like this. Current trends indicate that the internet is accessed through mobile devices and some social media platforms are only available through mobile apps (Ofcom, 2019). In 2019 the BBC launched the Own It app (BBC, 2019) for children and young people that installs a keyboard to mobile devices that offers real-time advice on the safety of self-disclosure on the internet. While this app presents new opportunities to create a keyboard that works across different applications, this particular instance is specifically aimed at young people.

In terms of platform use on a web-browser, having popups alerting users of sensitive information sharing can become fatigued, similar to cookie notices (Choi et al, 2018). Coupled with unclear potential harms to users, as a consequence this technology risks losing trust in its ability to help protect individuals. Individuals will not only need to trust that the technology is serving their privacy, but that the technology itself is not an intrusion of privacy. In order to do this, the plug-in must work locally without collecting data, or employ differential privacy[20] to better protect user privacy (Dwork, 2006). Finally, when considering phenomenological attitudes, it is possible that a plug-in that detects what an individual is typing feels like a privacy violation, which presents another risk to continue the active use of such a technology.

Revisiting the consent process was the third recommendation. As individuals may have signed up to social media platforms years ago, potentially prior to using them for health-related discourse, it is likely that the terms have changed as well as their privacy preferences (O'Kane et al, 2013; Lutz & Strathoff, 2011). In theory this process sounds like a good opportunity for participants to familiarise themselves with the privacy policies; however, there are wider issues around the consent process that need to be addressed. Firstly, reports, supported by findings in Study 1, indicate that most people do not read the terms and conditions. Without a change in attitude towards policy reading, it is unlikely that re-presenting them to users will change this behaviour. Study 1 indicated that individuals lack a sense of agency over their personal information believing that online platforms have the power to do what they want; terms and conditions are non-negotiable so it's a case of accepting or stop using the platform

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[20] Differential privacy enables patterns in datasets to be identified without revealing any one individual (Dwork, 2006)

entirely. Therefore, it would seem irrelevant if the terms and conditions are presented to them periodically. If the terms and conditions were presented in a different format, such as in a more visual way more time might spent considering how control over their personal information can improve (Jones et al, 2017).

The fourth recommendation is the increase people's awareness of how online services collect and use their information. A simple, easy to understand intervention should be created to encourage individuals to think more critically about their information privacy. As described in the findings, one of the privacy challenges is its complexity to understand, without a foundational knowledge of some of the technical infrastructure. One of the key challenges therefore is to present the current landscape of data collection practices without becoming too technical or platform specific, in order to provide simplicity.

Without presenting previous harms caused as a result of misuses of personal information, encouraging individuals to think seriously about their privacy can become difficult. Therefore, a collection of previous stories could be made available to intervention users to learn more about what has happened in the past.

Similar to the plug-in suggestion, the awareness intervention may also fall subject to self-selection bias as individuals who have a pre-disposition to privacy may be more likely to engage. The focus groups suggested a two-tier intervention strategy whereby posts that are shared on social media, where they access support, can invite them to learn more on another website. Whether this is something that would appeal or encourage individuals to learn about data collection and processing practices is something that should be explored.

5.4.1 Limitations

The focus groups that took place for Study 2 were recruited through a combination of stratified and cluster sampling techniques. While there was the possibility for several homogenous groups to occur, such as influencers/community leaders specific to each platform, one focus group was made up of community leaders who had experience of at least two online platforms. As patient led communities were built organically and in people's spare time, conducting the focus group had to be respectful of people's time, especially when additional travel was involved.

There is a limited number of Crohn's and Ulcerative Colitis charities in the UK to have recruited for this study: Crohn's and Colitis UK, the largest charity in the UK, declined to participate in this study. While the contribution from CICRA has been insightful, their experience with adults and online health communities is limited. Participants in FG1 represent a children's charity. While they represent people living with IBD, their perceptions of privacy with respect to children and young adults may be different than for a charity that broadly supports adults. The charity described how they often support parents of patients and they do not facilitate online communities for children and young people. Therefore, their personal experiences of children and young people's online health communities are limited. Future studies should consider how parents and carers of young people living with IBD perceive privacy of their children when using social media for support.

Having online focus groups was considered to broaden the demographic pool; however, for groups of people who were not necessarily familiar with one another, having a physical space with food and drinks to reduce research formalities was chosen to foster comfortable and equitable discussions. The other group was a made up of employees at a charity; however, to keep consistent, a face-to-face focus group was opted for in this instance too. For a consistent approach, participants and representatives from overseas were unable to take part in this research which means that the findings from this study are from a UK perspective.

5.5 Conclusions

The findings in this study demonstrated that the IBD online communities face complex privacy-related issues. While there was an agreement that there are privacy challenges involved with social media-based online communities, there are also many benefits. The popularity, pervasiveness and convenience that contemporary social media platforms have to offer means that thousands of people have access to support from a captive audience. The creation of support-specific social networking apps presents difficulties to charities such as technology maintenance, community managers, legal compliance as well as user engagement and retention. With the majority of communities online being voluntarily run by patients, charities would also be competing with these groups, which hampers the feasibility of purpose-built platforms.

With the challenges to migrate online communities to alternative platforms, the focus groups offered alternative arrangements to improve information privacy for people. Participants interacted and deliberated over the feasibility of each suggestion with regards to the communities' needs and time conditions. Though many different solutions were recommended by the focus groups, the most feasible and short-term course of action was creation and rollout of an online privacy awareness intervention. The aim of which would be to simply explain the practices, provide case studies of incidences of malpractice, and tools for individuals to use should they wish to take more control of their information.

Less clear, however, is whether an awareness intervention, such as the one described in the focus groups, would be something that individuals in the community are going to engage with. While a lack of knowledge may be one explanation for the privacy paradox as indicated in Study 1, if individuals are given the opportunity to learn, is there an appetite to do so? The following chapter outlines how Study 3 executed the recommendations and examined the attitudes to learn.

CHAPTER 6: STUDY THREE: Privacy Literacy Interventions

6.0 Introduction

Study 1 and 2 provided rich qualitative data from people living with IBD and community leaders to further understand how social media platforms benefit and support IBD communities. With a research focus on privacy, there was a strong indication that while social privacy concerns and behaviours have been well established by individuals, there are particular concerns with the lack of knowledge around information privacy. This study chapter takes a quantitative approach to see whether inferences from Study 1 are supported by a larger sample size as well as further understanding the attitudes towards learning more about information privacy.

With Study 1 focusing on the perceptions of people with IBD, there is not any evidence to indicate that people with IBD have more privacy concerns than those who would be considered as healthy. Previous studies that have compared privacy concerns between healthy people and people living with illnesses have yielded different results on this matter. Bansal et al (2010) and Tisnado et al (2006) found that people with health conditions are more sensitive to privacy concerns than healthy individuals. In contrast, a more recent study that explores self-disclosure intentions, Zhang et al (2017) found that there was a higher willingness to self-disclose amongst people with a health condition. However, it should be noted that self-disclosure should not necessarily be taken for low privacy concern, when privacy is contextually constructed (Nissembaum, 2004;

O’Hara 2016). Finally, with a sample of healthy volunteers, people were not concerned about how their self-disclosed health information would be used in a commercial setting (Ostherr et al, 2017). Indeed, to understand whether there are any disparities between people with IBD and healthy people’s privacy concerns, the first research question for this study was:

RQ3a *Do people with IBD report to have a disposition to social and information privacy concerns?*

As previously discussed in the literature review, knowledge (Trepte et al, 2014; Lee et al, 2017) and cognitive bias (Acquisti, 2004; Kosyfaki, 2017; Acquisti & Grossklags, 2005) have been shown to have an influence on people’s perceptions of privacy and their ability to mitigate concerns. In 2015 the UK Government released a Basic Skills Digital Framework (UK Gov, 2018). It recognises low digital literacy rates among adults and encourages employers, charities, academics and individuals to support digital literacy training. With the rapid changes in digital technology, digital literacy is subject to *lifelong learning*; people informally up-skill themselves and should be aware of the evolving challenges that engaging with these technologies present.

With this in mind, non-formal learning environments and experiences are key to help support people’s continuing digital literacy. Online resources enable formal and informal learners “to create the learning environment that is most appropriate for their personal learning needs and preferences," (Kalz, 2015: p.95). However, there are many perceived barriers for people to access and engage with informal learning resources such as low income, time, understanding and facilities to learn from home (Kalz, 2015).

In privacy and digital literacy research, time and attitudes have been identified as barriers to learning and acting on privacy concerns. For instance, in a mixed methods study on privacy values, Vervier et al (2017) reported that participants "mostly confirmed" (p.87) that privacy protecting behaviours were too time consuming. Furthermore, in Study 1 of this thesis, some participants reported that they wouldn't have the time to learn about their online privacy; meanwhile in Study 2 community leaders expressed how time spent understanding privacy policies would prevent people from accessing immediate support.

Motivations to protect online privacy are linked with privacy concern (Weinberger et al, 2017) and taking preventative action can reduce the net privacy concerns (Lee et al, 2017). People who express higher privacy concerns are more likely to take protective measures to protect their privacy (Boyles et al, 2014; Weinberger et al, 2017) and are more likely to learn about how they can increase their self-efficacy (Park, 2011). Conversely, in Study 1 of this thesis, people who expressed the attitude that they do not have anything to hide, may be less likely to want to learn about their online privacy.

To understand how these factors impact on people's barriers to learning about their online privacy, the following question was asked:

RQ3b *To what extent does (1) disposition to privacy concern, (2) time, (3) perceived technical knowledge, and (4) access to learning materials impact on barriers to learning?*

While findings from Study 2 suggested that there is a need for increased awareness of how information is collected and used by social media platforms, it is not yet understood whether, given the opportunity, people would be interested in learning more. With a lack of clarity over whether people with illnesses are more concerned about their privacy (Bansal et al, 2010; Tisnado et al, 2006; Zhang et al, 2017), it is unclear whether they would be any more likely than healthy people to learn more about how their information is used. As such, this inspired the third research question for this study:

RQ3c *Is there an appetite amongst individuals with IBD to learn more about data collection and processing practices by social media platforms?*

Previous educational interventions for privacy awareness have yielded successful results in understanding, yet marginal changes in attitudes and future behaviours (Vanderhoven et al, 2014; Martens, 2010; Duran et al, 2008). In a long-term 13-week privacy literacy program, Sideri et al (2019) yielded more positive results on a student sample taking active steps to change their settings and adjust their settings. Sideri et al's study (2017) boasts that 91% students recognised the need to balance the benefits from the risks when disclosing on social media sites and 87% "were more conscious about the practices that [they] should adopt when acting in SNSs" (p.89). Though it is unclear what the content of the course was, it should be maintained that how people behave online should reflect their own personal preferences and concerns. All of these studies however have explored literacy interventions in formal education settings. For people who may perceive their privacy to be more important, as a result of sharing more sensitive information about their health, it is possible that a short-term online resource intervention may yield different effects. To understand the impacts of the resource, the following research question was raised:

RQ3d *How are information privacy concerns, perceived control and, likelihood to act on their privacy preferences impacted by awareness interventions?*

Community experts who participated in Study 2, believed that there should be more learning resources for people to understand the implications of using social media for health-related support. A resource made for the purpose of this research should be designed with the intention of public release. In order to best prepare such a resource, this study serves as an opportunity to understand users' experiences and feedback to improve the resource. This leads to the final research question:

RQ3e	*What are people's experiences of the Health Privacy Toolkit, and how can it be improved for public release?*

6.1 Methodology

6.1.1 Patient and Public Involvement

In line with the commitment to the responsible research and innovation principles, this study adopted Patient and Public Involvement (PPI) that aims to "enhance the quality, appropriateness, acceptability and relevance of research" (Staniszewska & Denegri, 2013, p. 69). In this case PPI was consciously used to scope the appropriateness and enhance the quality of the educational resource. Its primary aim was to ensure that the content that was being shared with end users was balanced, accessible, and informative. The biggest risk that PPI set to mitigate was that the resource could disempower people to the extent that they no longer felt comfortable in using social media platforms to seek valuable support.

While PPI has been applied for more than 10 years, there have been criticisms in how it is reported in research. The GRIPP2 forms were developed through an international evidence base and aims to improve the "quality, transparency, and consistency" (Staniszewska et al, 2017: p.1) of PPI reporting. The GRIPP2 short form (Table 8) has been used in this thesis, acting as both a summary of how PPI has been used, as well as an index for where more information can be found throughout this study.

While a PPI board exists at the University of Nottingham to support research, because the intended study participants have a specific shared condition, a small PPI group was created out of self-selecting participants from Study 2. Initial content and design ideas were drafted in response to the findings from Study 2. The PPI group were subsequently emailed different content and design ideas, asking for feedback on the aesthetics and appropriateness for the communities they were intended for. This was iterated throughout the design process to refine both the social media post and the Health Privacy Toolkit to a point that met their ethical and design standards.

Section and topic	Item	Page no.
1: Aim **Report the aim of PPI in the study**	The aim of the PPI in this study is to create an intervention that is informative, relevant and that safeguards patients using social media.	213
2: Methods **Provide a clear description of the methods used for PPI in the study**	Four community leaders who work across Facebook, Twitter and Instagram were sent a series of design ideas for a social media post. These compromised of questions, facts and stories. They were asked to provide feedback on the design appeal as well as the appropriateness of the content. The options and instructions for review were sent via email and feedback was responded through email.	214
3: Study results **Outcomes—Report the results of PPI in the study, including both positive and negative outcomes**	Two community leaders expressed their concern with the content being too provocative, risking the induction of fear and uncertainty amongst individuals to use social media for support. However, another community leader advised a more open-ended reflective question: *have you thought about the long term impacts of sharing information about yourself on social media?*	
4: Discussion and conclusions **Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects**	While difficult to prove to what extent, the PPI influenced the outcome of the resources used within the study. Their involvement was successful in that participants did not feel worried nor have been known to have withdrawn involvement in OHCs.	283
5: Reflections/critical perspective **Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**	The PPI went well. In future different mode of communication, such as scheduled synchronous discussions, would be beneficial.	283

PPI=patient and public involvement

Table 8 GRIPP2 Short Survey

6.1.2 Participants

Similar to the strategy in Study 1, participants were recruited through posts shared on Twitter, Instagram and in 3 Facebook Groups whose admins granted permission. Study participants were recruited in two stages. The first focused on people living with IBD, using community hashtags and inviting people with Crohn’s disease of Ulcerative Colitis to participate. The second invited people without IBD to participate as a control group. People could learn more about the study prior to the consent process by clicking the link in the social media posts. The information sheet detailed the purpose of the study, the nature of participation, how they can withdraw, and how their data would be used. Participants had the option to enter a prize draw to win £150 of Amazon vouchers from their participation.

The study was visited 137 times and yielded 128 responses with informed consent. 4 data cases were removed as a result of duplication; participants may have left the survey part way through and restarted. A total of 124 responses from Survey 1 were used for analysis.

Four different collector links were generated for different platforms, enabling the researcher to identify where participants arrived from. 42.7% were recruited through Twitter (n=53), 32.3% through Instagram (n=40), 4.8% through Facebook (n=6), and 20.2% through a control group link (n=25). Unfortunately, 26 did not complete Survey 1, yielding a retention rate of 79%. 57 completed Survey 2a and 27 for Survey 2b, yielding a study completion rate of 67%. The completion rate for those who did access the resource was 51%.

Data was used from 124 of the participants; 98 people living with IBD (79%) and 26 as a control ‘healthy’ group (21%) of users who self-declared as not having IBD. The majority 96% (n=119) had not participated in the researcher’s previous studies for this thesis (Study 1 and Study 2): 5 users self-declared that they had taken part in previous research; however, this did not have any statistical relationship with their privacy concerns.

The median age group was 31-40-year-olds across the data set; however, 46%, (n=57) of the participants were under the age of 30. To understand whether the distribution of age groups was even between the IBD and Healthy group the Mann-Whitney U Test (non-parametric) was conducted. The results indicated that while they were different sample sizes the distribution of the age groups was statistically similar.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of What is your age range? is the same across categories of Healthy or IBD.	Independent-Samples Mann-Whitney U Test	0.24	Retain the null hypothesis
Asymptotic significances are displayed. The significance level is .050.				

Table 9 Mann-Whitney U Test: distribution of age between IBD/healthy participants

There was an uneven distribution across gender, with females representing three quarters of participants (n=91), with 25.8% male (n=32) and 1 person identifying as queer. While participants are self-selecting, this finding supports observations made in Study 1 and Study 2 that there are more women engaged in online health communities than men. Also similar to the first study, more participants self-declared to have Crohn's disease (n=70) than Ulcerative Colitis (n=28).

Geographically, 75% (n=94) participants self-declared to be from the UK, 8.1% (n=10) from the USA and 16.9% (n=21) from other countries, which included Australia (n=3), Europe (n=10), Canada (n=1), India (n=1), Peru (n=1) and the Philippines (n=1). Proportionally, participants represented countries with data protection regulations.

6.1.3 Data Collection Procedure

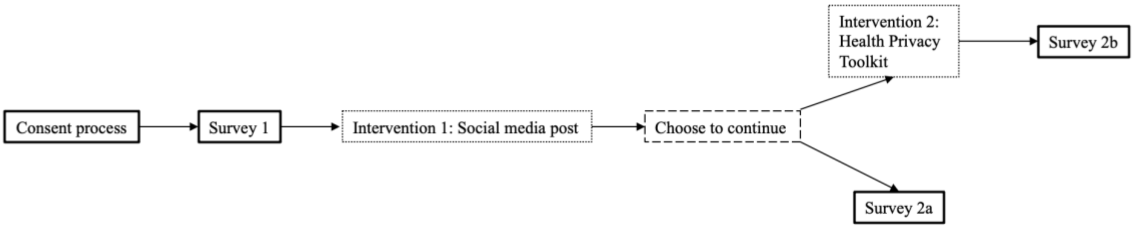


Figure 7 Study Procedure

This study was broken down into different stages (Figure 7) and participants conducted the study in an unmoderated manner (Marsh, 2018). Following a consent procedure, participants were directed to the first survey in the study. The design of the surveys will be detailed in the following section. After a series of questions in Survey 1, participants were shown a hypothetical social media scenario (Figure 9) and at this point they decided whether they would have liked to learn more about their online privacy or not. Participants who wished to learn more were given a hyperlink to the Health Privacy Toolkit and given instructions to go to their second survey (2b) after finishing with the Toolkit. If the second survey results were not received within 24 hours, an email was sent to the participant with the link. Those who decided that they did not want to continue proceeded to Survey 2a.

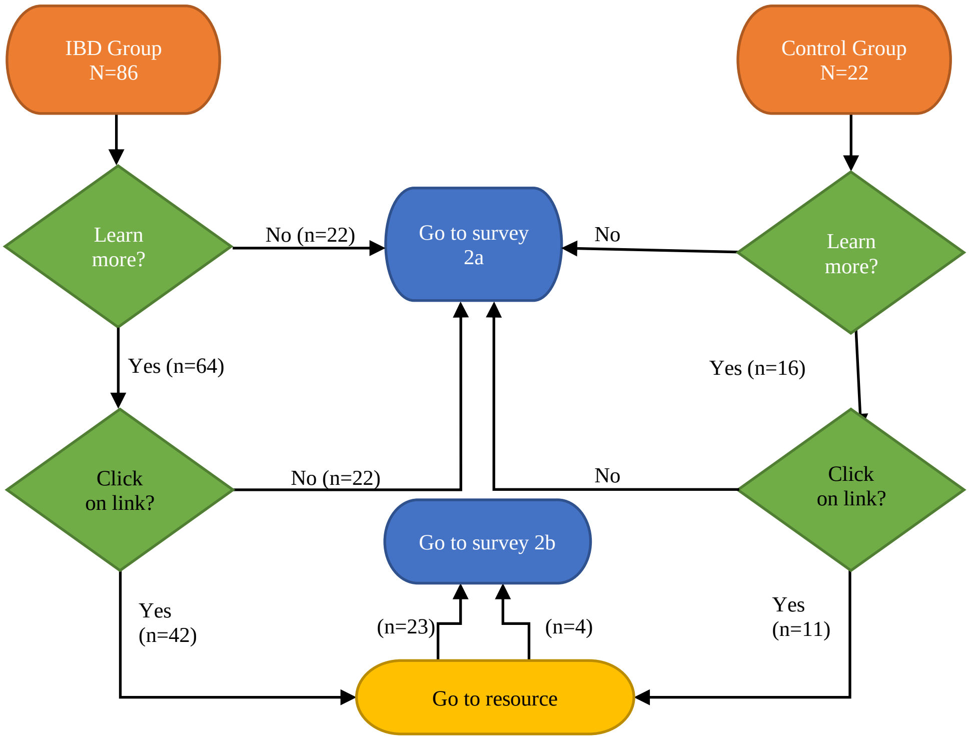


Figure 8 Flow diagram presenting decisions made through study

Surveys are a commonly used quantitative research tool to examine the relationship between specific variables in a sample of the population, which can be generalised to the population (Kraemer, 1991). Surveys can be conducted in person, through the post, over the phone, and indeed online (Fink, 2013). Online surveys are widely accepted in contemporary research (Evans & Mathur, 2005; Evans & Mathur, 2018). They offer a convenience to both researchers and participants (Sue & Ritter 2012). Software reduces the administrative load of distributing surveys and inputting data, with responses being instantly made available to the researchers in a usable format (Dominelli, 2003; Sue & Ritter, 2012). This also makes surveys more cost effective, minimising the resources spent preparing, distributing and collecting data. With the globally connected web and social media networks, there is an increased potential for researchers to obtain larger data sets to study. Meanwhile, participants can access online surveys from any location with an internet connection at a time that is convenient to them. They can undertake it at their own pace and have the ability to contact the researchers in a timely manner through email.

Although there are benefits to online surveys there are also limitations. Similar to interviews, participants who undertake surveys are self-selecting. Previous research indicates that in specific online communities, those who are more willing to participate in online surveys are also more likely to be more heavily involved in the community activities (Khazaal et al, 2014). The sampling therefore may be unintentionally biased towards more active members in the community, who media scholars indicate represent a small minority (Nonnecke & Preece, 2002; Jenkins et al, 2013). While half the world's population is connected to the internet (Internet World Stats, 2020), boasting potentially large sample sizes, the reality is that online surveys face poor response rates and incomplete data sets (Fahimi 2015).

Surveys are an archetypal method to analyse effectiveness of interventions in different research fields (Vanderhoven et al, 2015; Sideri et al, 2019; Abildgaard et al, 2016). The application of pre and post-questionnaires focusing on specific questions enables researchers to observe any statistical changes across the data set. Though interviews have also been used to examine the effectiveness of interventions, it is noted that researchers can “gain valuable information about key issues from a large proportion of the sample using few resources” (Abildgaard et al, 2016: p.7) through quantitative methods. For intervention studies that examine cognitive processes Likert scales are often applied to measure attitudes.

Likert scales usually vary between 5- and 10-point scales to measure cognitive processes such as attitudes towards particular constructs. The agree to disagree scale can be used to measure a wide range of different constructs (Revilla, Saris & Krosnick, 2014) and can capture the essence of those constructs. Likert scale matrixes can be used as an efficient way to ask participants their agreement on particular statements. Survey designers, however, must be sensitive to biases including response fatigue and *LongString* response patterns; when participants click the same answer going down the statements (Meade & Craig, 2012).

Likert scales are sometimes considered as an interval scale, as the Likert type items express a ‘greater than’ relationship; however, particularly for Likert items that do not express numbers on the scale, there is no certainty in how much greater one response is from another (Boone & Boone, 2012). However, there is some controversy over what scale of measurement Likert scales should be categorised as (Harpe, 2015), with Cohen et al stating “though one can find very many examples where this rule has been violated, and nonparametric data have been treated as parametric data,” (2011: p.390). In this study, the scales were not marked with numbers, which gives confidence in using non-parametric statistical tests.

This study applied a 7-point Likert scale design. Previous studies have demonstrated how participants responding to 5-point scales were more likely to respond between points, which indicates that 5-point scales may not allow users to accurately respond (Finstad, 2011). Instead a “larger (step by step) spectrum of choices offers more independence to a participant to pick the ‘exact’ one (which he prefers most) rather than to pick some ‘nearby’ or ‘close’ option,” (Joshi et al, 2015: p.398).

Despite the limitations of online surveys, it was considered to be the most appropriate method for this study to see whether there were changes in attitudes and perceptions pre and post intervention.

Pre-survey 1 was adapted from Xu et al (2011). In that study, Xu et al (2011) developed an online survey that focused on information privacy concern, perceived risk, perceived control, effectiveness of privacy policies, perceived effectiveness of industry self-regulation, and disposition to value privacy. The most critical adaptation made to the original survey was to add questions pertaining to social privacy. Secondly, Xu et al’s scale (2011) was tested with a sample that was not specifically health-related; the questions therefore were also adapted to focus on perceptions of privacy over health information. Finally, additional questions around behaviours, such as platforms they used, were included for both general social media use as well as health-specific social media use.

Questions relating to trust were included to understand whether this variable had an impact on privacy perceptions; in the literature there is evidence to suggest that for regular social media use and internet use, trust has a negative correlation with privacy concern, and positive correlation with disclosure and continuance intention (Mesch, 2012; Pentina et al, 2013; Taşkın & Taşkın, 2019).

Finally, to help answer RQ3c that asks to what extent do people living with IBD want to learn more about online privacy. Participants were asked whether they would like to learn more, which in turn would impact on their journey through the study.

Post-resource Survey 2a was answered by participants who decided not to continue to the website-based resource. The survey captured changes in information privacy concerns; privacy control; privacy awareness; and, activity to learn. It also asked for feedback on the social media post design and ask why individuals chose not to continue to the resource. The aim of Survey 2a was to understand why there was not an activity to learn and whether there were any changes to privacy and control perceptions with only having access to the hypothetical social media awareness post (Figure 9).

Survey 2b was answered by participants who decided to continue to the website resource. Similar to Survey 2a, this survey was used to measure any changes to information privacy concerns; privacy control; privacy awareness;

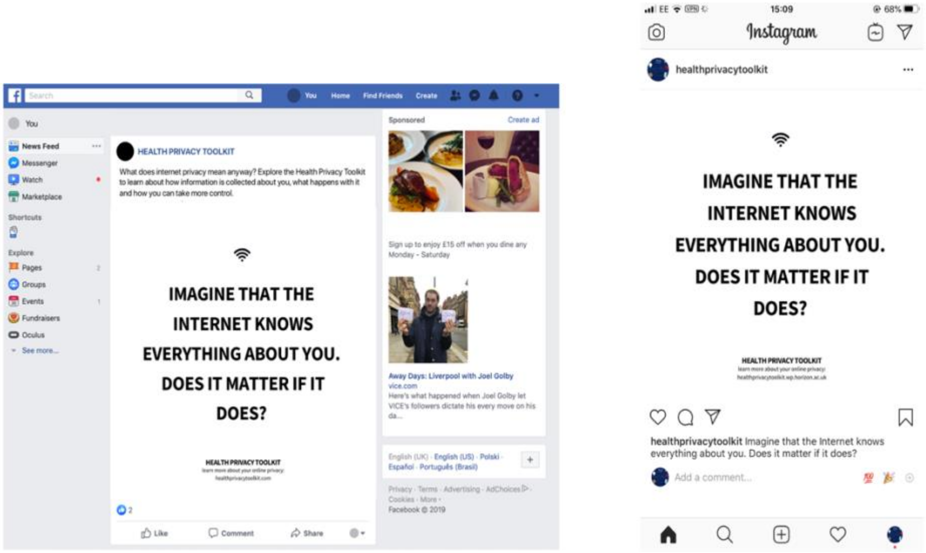
and, activity to learn. Questions about the resource's content and design were included to ascertain how it can be improved in the future.

6.1.4 Intervention Design

Augmented social media post

At the end of Survey 1 participants were shown an augmented social media post displaying a hypothetical scenario when they are browsing on different platforms. From Study 2 and throughout the PPI process, having awareness posts directly embedded into social media platforms was considered to be important. However, given the thesis' position on privacy, through contextual integrity, deploying a social media campaign 'in the wild' was deemed inappropriate and curbing on privacy violations. People accessing online support should not be subjected to research enquiries without their informed consent. This position on contextual integrity was also echoed in interviews from Study 1 with participants advocating for informed consent for secondary data purposes. Therefore, a controlled environment with a hypothetical scenario was chosen for this pilot.

Through PPI, there was a requirement for a balanced campaign, designed with the intention not to scare people out of seeking online support. Different phrases and designs (Appendix 3g, page 420) were sent to a self-selecting group of people with IBD, who were also community leaders, for feedback. The chosen post by the PPI group can be found in Figure 9, and it was considered to be thought provoking without offloading facts or speculations.



HEALTH PRIVACY TOOLKIT

What does internet privacy mean anyway? Explore the Health Privacy Toolkit to learn about how information is collected about you, what happens with it and how you can take more control.

Sign up to enjoy £15 off when you dine any Monday - Saturday

Away Days: Liverpool with Joel Golby
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Here's what happened when Joel Golby let VICE's followers dictate his every move on his da...

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healthprivacytoolkit Imagine that the Internet knows everything about you. Does it matter if it does?

Figure 9 Intervention 1 design

Health Privacy Toolkit

The Health Privacy Toolkit online learning resource was adapted from the London School of Economics (LSE) myprivacy.uk project led by Livingstone (2019). That toolkit was created to support young people learn more about their online privacy and digital rights. A comprehensive description of how the Health Privacy Toolkit was designed and created can be found in this section. In summary, the website was divided into different pages that explored different areas (Table 10).

Page	Purpose
Home	Provides a background to why the resource was created and why people might be interested in reading and engaging with it. It also introduces the author of the toolkit and their motivations.
What’s the issue?	Unpacks what privacy means on the internet, distilling the differences between social and information privacy.
Who gets my data?	Explaining how information is collected through devices and services, and what happens with it
What can go wrong?	Presentation of a series of case studies the demonstrate privacy short comings in the past by online companies.
Take control	A selection of resources and tools so people can explore further and take steps to taking more control over their personal information.

Table 10 Summary of Health Privacy Toolkit pages

An illustrator was consulted to design assets that would help bring visual aids to the information provided, with careful consideration for how the website responds on both desktop and mobile devices (Figure 10). Again, the toolkit was shared with the PPI group for feedback, receiving feedback on clarity, layout and overall feel. The pilot resource can be found at: https://healthprivacytoolkit.wp.horizon.ac.uk

HEALTH PRIVACY TOOLKIT

WHAT'S THE ISSUE

What does 'privacy' mean on the internet?

We share a lot about ourselves online – our looks, our friends and what we enjoy or dislike. Other people share information about us too – like when you are tagged in photos and at locations by friends or family. We may be happy to share some things with other people online, but there are other aspects we'd rather keep to ourselves

Figure 10 Screenshot of Health Privacy Toolkit

Patient and Public Involvement, which is the inclusion of a panel of patients or stakeholders, supports this PhD's position to support an inclusive, ethical and meaningful research. Participants from Study 2 self-selected to be part of this panel and agreed to provide iterative feedback on the social media intervention and the web-based resource.

Starting with the web-based resource, participants in Study 2 presented key design requirements that included:

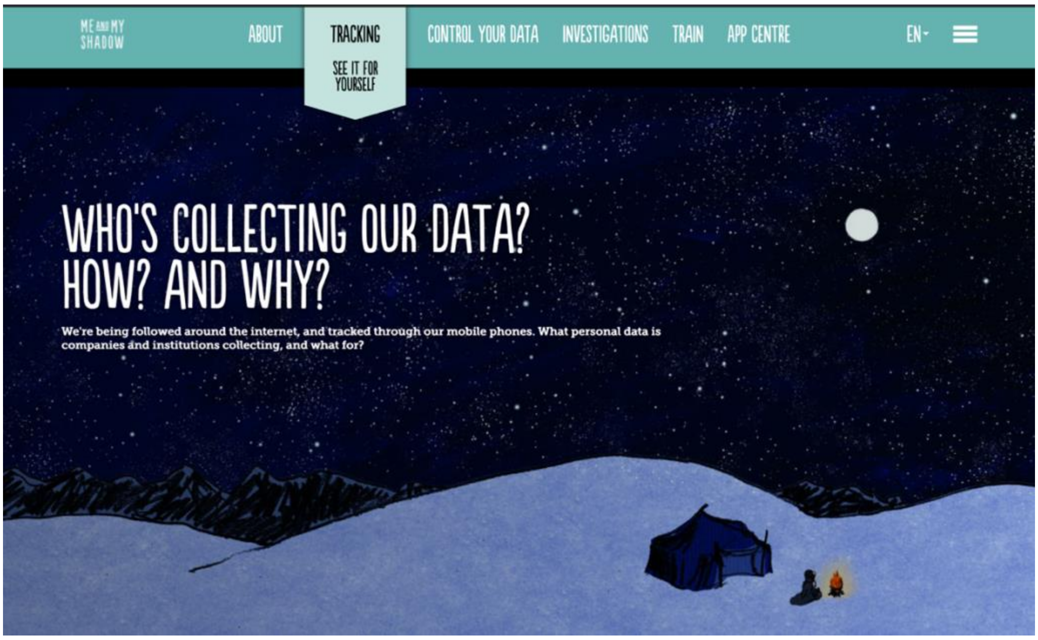
1. Clear use of language; no jargon
2. Easy navigation
3. Balance of information and practical support
4. Not too time consuming

Firstly, a systematic intervention review was conducted to identify whether there were current resources that could be used in Study 3 or appropriated. The collation of contemporary online privacy resources was achieved through web searches as well as a call on Twitter, encouraging responses from technologists and educators.

As a requirement to support lifelong learning, online educational resources should be freely accessible to use; online courses that required payment were discounted. Given the distributed nature of people living with chronic illnesses across the world, it was necessary that asynchronous resources and courses were identified; synchronous courses were discounted. It was also necessary that the information presented in these resources included notions of social privacy and information privacy. In total 9 resources were identified for review.

The Data Detox, presented by Mozilla and Tactical Technology Collective is a PDF guide taking individuals through steps to take better control of their digital selves. It does this by looking at both social and information privacy, asking readers to review their social media settings as well as their cookie settings on the browser, as a couple of examples. The eight-day programme raises a number of challenges. The first being user retention and prolonged engagement; from the results from study one, people report on Not having sufficient time to dedicate too learning about online privacy. Therefore offering a programme that last eight days might appear daunting and a burden on time. Secondly, the detox is presented in a PDF format. Originally presented as a booklet the PDF offers a digitised alternative, however this does not provide a rich digital experience that would encourage continued engagement. Finally, having a series of tasks prescriptive tasks assumes that there is a correct way to achieve information privacy online; this neglects people's personal preferences and other values including security. While there are elements of the data detox that can be repurposed for a different context, on its own It would not be appropriate for its use with a vulnerable health community.

The *Do Not Track Documentary* series offers a highly interactive web-based experience which gives people the opportunity to learn about how information about them is collected and used. It requires the use of cookies to be able to make personalised experience for the user. Created in 2016 and yielding several awards, unfortunately this intervention Is not without its limitations. The first being time; there are 7 episodes in the series, and they are designed to be viewed sequentially. Because of its interactive nature, while it can be viewed on mobile devices, the full interactive experience is only available on browsers on laptops and desktop computers. Finally, 4 years following this documentary series, there have been regulatory changes to how personal information is handled.



WHO'S COLLECTING OUR DATA?
HOW? AND WHY?

We're being followed around the internet, and tracked through our mobile phones. What personal data is companies and institutions collecting, and what for?

Figure 11 Screenshot from Me and My Shadow

Created by tactical tech, *Me and My Shadow* (https://myshadow.org/) is a web-based resource for people of all ages to learn about digital footprints. Available on the browser, different pages can be found at the top of each page. Each page has an interactive interface that enables visitors to engage with the information to learn more about information privacy. The page ‘Trace my Shadow’ offers a checklist style interactive map that visualizes how many trackers an individual might have according to the services and services they use. Another page takes an interactive view of privacy policies, highlighting poignant parts. Finally, under the tab 'control your data' there is are suggested tools to reduce internet tracking which provides users with practical solutions to any information privacy concerns they may have. Unfortunately, *Me and My Shadow* is no longer supported and has been deemed as an archived project by Tactical Tech; this means that it is not up to date.

The *Surveillance Self Defense* by Electronic Frontier Foundation (https://ssd.eff.org/en) offers “Tips, Tools and How-tos for Safer Online Communications”. IT offers a comprehensive overview of creating strong passwords, tool guides of how to encrypt communications and devices, as well as other things to consider. While comprehensive, this website and its information pages are text heavy making them less engaging.

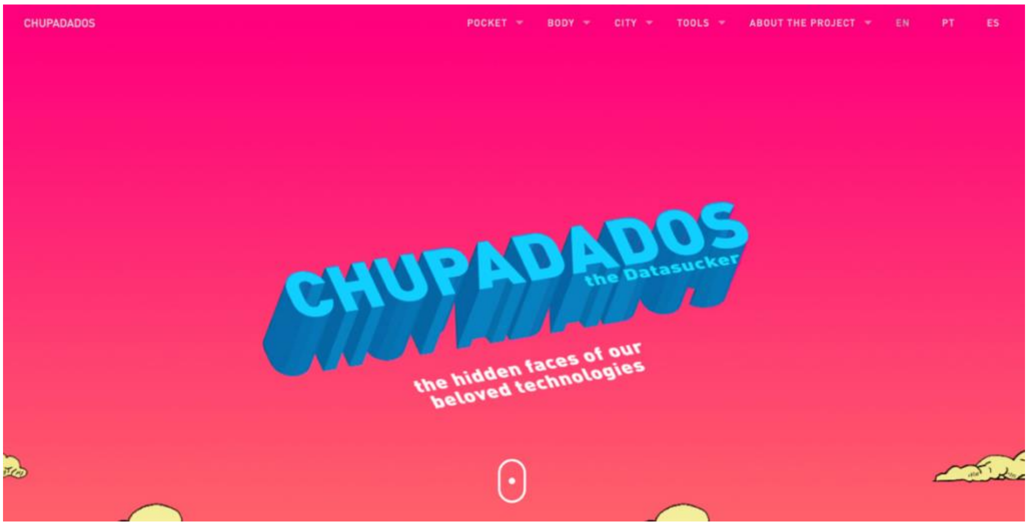


Figure 12 Screenshot from Chupadados

Chupadados (https://chupadados.codingrights.org/en/) is an online resource by Coding Rights that collates stories from Latin America concerning mass data collection and processing. It provides relevant stories to people in Latin America about how data is collected from the devices in their pockets, in the home and in the city. As a website, this resource is available on all devices and in Spanish, Portuguese and English. It also provides a suggestion for a tool for people to find their Facebook advertising preferences.

Security Checklist (https://securitycheckli.st/) is a resource the provides a checklist of actions that can be taken to improve privacy and security, such as changing browser, search engine and installing a VPN. *Digital Self-Defense* (https://dataethics.eu/digital-selfdefense/) by *Digital Ethics* similar to *Security Checklist* provides a substantial list of tools and services to increase information privacy and social privacy provisions. It also offers a simplified list of rights people in the European Union have under GDPR.

DIY Cybersecurity for Domestic Violence

A resource of privacy + compassion by HACK*BLOSSOM.

Figure 13 Screenshot of Hack Blossom

Hack Blossom (https://hackblossom.org/) is a web-based resource tailored for women and more specifically victims of domestic abuse; it therefore focuses heavily on cybersecurity and social privacy protection from particular individuals. Available in German and English, it introduces readers to a security threat risk model to help them rationally approach their online behaviours with respect to their privacy and safety. Unfortunately, Hack Blossom has been on hiatus since February 2019.

Image Credits: Becky Morris CC: BY

What's this all about?

Thanks for stopping by! Some people may know that privacy both analogue and digital is super close to my heart. I am a co-learner and I have found myself shoulders deep in this stuff because I find myself asking more questions than having real answers. #privacyUG is my way of trying to figure out the answers: some of you here are completely new to this and others less so, this is a space to ask questions. To those of you I have invited that are a little more clued up, please help us learn faster and share your insights.

Figure 14 Screenshot of PrivacyUG

PrivacyUG is a blended asynchronous learning experience created by the author of this thesis. Over three consecutive weeks, different topics were presented to learners with a video and separate learning materials. Participants were encouraged to share their thoughts on Twitter through #PrivacyUG to join a wider conversation about what privacy means in the post-digital age.

My Privacy UK (http://www.lse.ac.uk/my-privacy-uk) is an online toolkit aimed at young people. Each page asks questions such as “what is the issue?”, "what can go wrong", "what are my rights" and "how to protect my privacy". In each of these pages there is a short text overview to answer these questions, illustrations and links to further resources.

Overall, while each of the resources presented appropriate information in engaging formats, they each had critical limitations which excludes them from their ability to be repurposed. The most common factors included out of data information and inappropriate content for a health community audience. Aspects of the interventions were implemented into a new design for Study 3: The Health Privacy Toolkit.

Health Privacy Toolkit Design

Through the review of current online privacy awareness resources and the suggestions given by participants, the Health Privacy Toolkit took particular inspiration from the My Privacy UK toolkit by London School of Economics. It adopts a similar approach to how information is presented, by using questions:

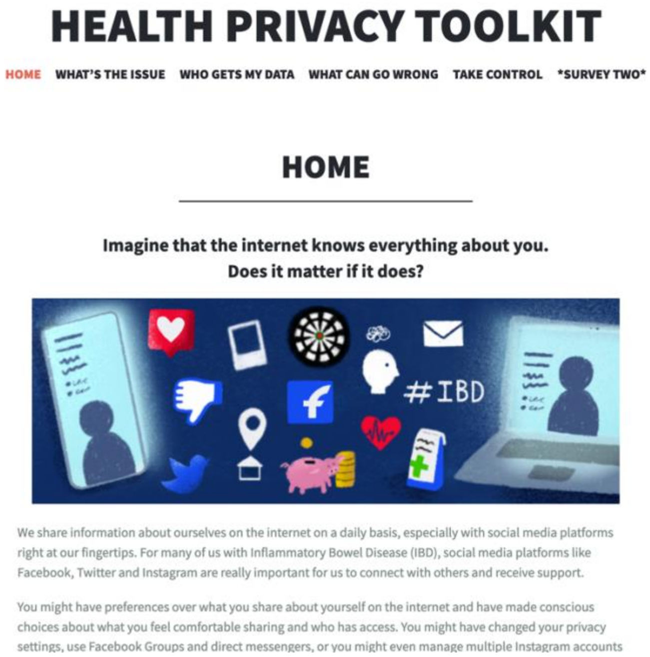
- What's the issue?
- Who gets my data?
- What can go wrong?
- Take control

When an individual arrives at the resource, on the home page, they are asked the same question as on the social media post "Imagine the internet knows everything about you. Does it matter if it does?". It provides a summary of how important the internet and social media is for people living with IBD, and what people might already do, but asks the additional question about how much we know about how information is collected and used. It follows by providing an overview of what the Health Privacy Toolkit is and who is responsible for its creation, to add an additional layer of trust for participants.

What's the Issue deals with the question "what does privacy mean on the internet?". It provides and overview, with illustrated graphics, of the difference between social and information privacy. It then provides information about the issues with Terms and Conditions and other jargon associated with online privacy.

Who Gets my Data provides insights into how information is collected through apps and the browser. It then details ways in which the information is used and how long it might stay online. *What Can Go Wrong* explores anecdotal published stories that detail data misuse in the past. To ensure that the content is relevant for a health community audience, these stories are tailored towards health-related violations and misuses. Finally, drawing inspiration from *Security Checklist, Surveillance Self-Defense* and *Digital Self-Defense,* the page *Take Control* details how people can detox, prevent tracking, and adopt other tools to mitigate any privacy concerns. To respect people's personal preferences over what they want to share online, the tools and additional resources on this page are not presented as a checklist, which assumes that all of them need to be actioned. Instead, the resources are presented to provide audiences with options.

To reduce the amount of text on the Health Privacy Toolkit, an illustrator was commissioned to create visual pieces to help communicate more challenging concepts. To improve accessibility, a simple and responsive Wordpress theme was installed so that it was compatible with mobile devices as well as on desktop browsers.



HEALTH PRIVACY TOOLKIT

HOME

Imagine that the internet knows everything about you.
Does it matter if it does?

We share information about ourselves on the internet on a daily basis, especially with social media platforms right at our fingertips. For many of us with Inflammatory Bowel Disease (IBD), social media platforms like Facebook, Twitter and Instagram are really important for us to connect with others and receive support.

You might have preferences over what you share about yourself on the internet and have made conscious choices about what you feel comfortable sharing and who has access. You might have changed your privacy settings, use Facebook Groups and direct messengers, or you might even manage multiple Instagram accounts

While PPI was applied with optimism, some of the panel members were unable to provide feedback due to their commitments; however, one person said *"I really like the look of the posts, colourful, engaging and a real statement piece! My only suggestion would be to remove the bullet points at either side of the text, maybe to be replaced with another symbol but other than that it would definitely be something that I'd be interested in engaging with".* After iteratively reviewing the content with supervisors, the illustrator and colleagues, the pilot of the Health

Privacy Toolkit was ready for Study 3, where more feedback was requested in Survey 2b.

Social Media Intervention Design

While an in the wild study was not possible, given the identified ethical shortcomings of this method in this research context, a hypothetical social media post was designed in the study. From Study 2, participants reported that having social media posts that get people to 'think more'. From this a series of posts were sent to the PPI group for feedback (Appendix 3g, page 420). Feedback included:

> *"As things stand we feel unable to share these as they all seem to have negative connotations relating to Facebook which is where we carry out the majority of our support for the IBD community. From our experience Facebook are working heavily on improving health related groups and communities. As discussed we do think the point your making is relevant however the context its given in we cannot share. If you do revise the posts then we would happily look at them again," and "I've had a look through all of the proposed media and in particular I like Q6 which touches on getting people to think about the long term impacts of sharing information across Social Media. The image is bold and easy to read, it creates a big impact and I imagine would be useful to get people thinking about this topic. If I was to see this on my feed, it would defiantly stop me in my tracks and promote conversation. My only feedback would be to swap the colours of F2 with Q6 however the overall message i feel would have the most impact."*

From the feedback, it was clear that the wording needed to be much more balanced. It was agreed that the wording, taken from the My Privacy UK toolkit was more balanced: “Imagine that the internet knows everything about you. Does it matter if it does?”. The final design was implemented into Survey 1 and feedback was taken in Survey 2a.

6.1.5 Data

The data was downloaded and opened with SPSS Statistics; a statistical software package provided by IBM. The data set was separated into two groups: the test group (people living with IBD) and the control group (healthy volunteers). The data from Survey 2b, which was a survey created in a separate space, was combined with the data from Surveys 1 and 2a. All the pre and post responses were then available in three sheets*: test data, control data*, and, *all data*. The survey data was mixed with both quantitative and some qualitative responses, thus requiring different analytical methods.

The survey questions (Appendix 3d, page 412) in Survey 1 firstly pertained to demographic information whereby the answers were both considered nominal and ordinal. Demographic information collected included age group (ordinal), gender (nominal), education (ordinal), time as a social media user (ordinal), residence (nominal), and IBD diagnosis (nominal). The remainder of Survey 1 and Surveys 2a and 2b were predominantly made up of statements with agreement Likert scales.

6.1.6 Ethics

As previously described, this study and the supporting materials were created through principles that align with responsibility (ESPRC, n.d) and contextual integrity (Nissembaum, 2004). The study was approved by the University of Nottingham's Computer Science Ethics Committee, with a reference number CS-2019-R12. The ethics application can be viewed in Appendix 3a (Page 394).

6.2 Findings

6.2.1 Social Media Use

Social media platforms have been establishing since the mid 2000s, with Facebook starting up in 2004 (Bellis, 2020). In this study, participants were asked for how long they have been social media users. Most participants, 58.3% (n=70), declared to have used social media platforms for more than ten years. There was a positive skew indicating that social media platforms have been used over a long period of time with only 13.3% (n=16) having reported to have used social media for less than 5 years. Using Spearman's chi-square test, there was a moderate negative correlation (-0.242, $\rho < 0.01$) between time using social media platforms and age across the whole data set. This suggests that younger people adopted social media platforms much earlier than older individuals, who have started using it more recently..

In terms of how long participants had been using social media platforms for OHC engagement, Figure 15 displays the distribution of responses. Further breaking down the social media use by people using it for less than one year, 14 participants had used social media for IBD communications between 6 and 12 months, 6 between 1 and 6 months, while 1 reported to have used them for less than a month at the time of response.

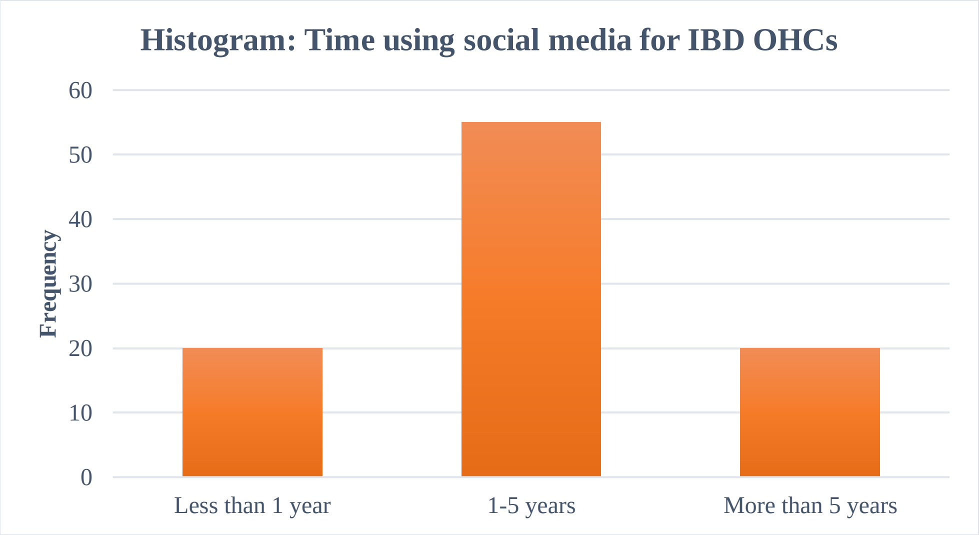


Figure 15 Histogram presenting distribution of how long people with IBD have been using social media for IBD-related support

As demonstrated in Figure 16, smartphones were the most reported device to access social media with laptops, tablets having a much less frequent use. This supports national reports from Ofcom (2019) that indicates an upward trend in internet access through smart phones over other less portable devices.

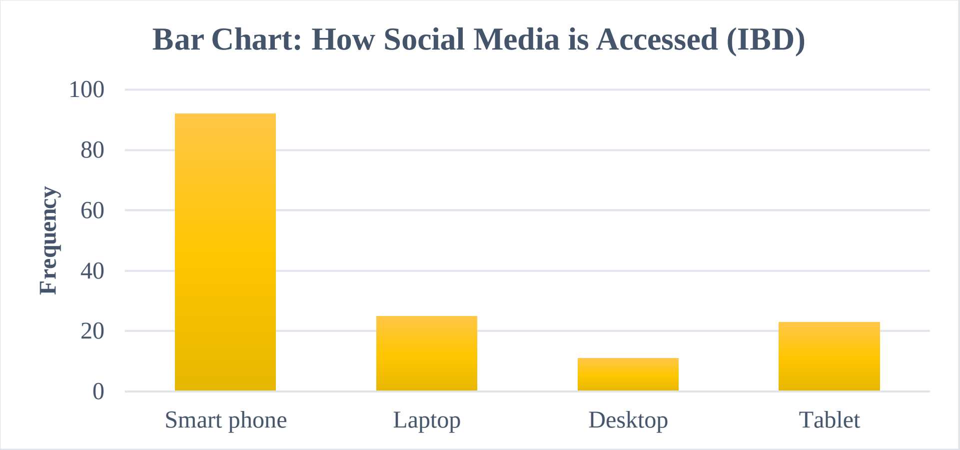


Figure 16 Bar Chart: how social media is accessed (IBD group)

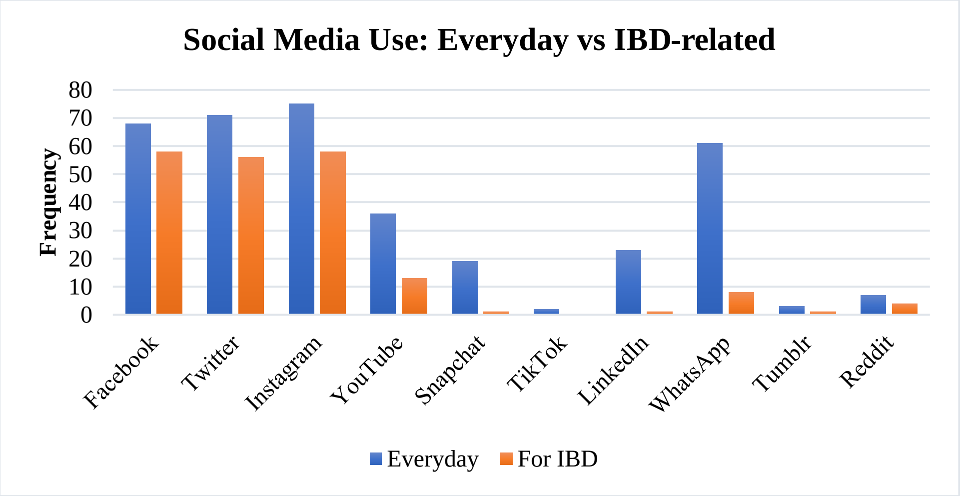


Figure 17 Bar chart - Social media use for everyday vs IBD support

Participants were asked to select which social media platforms they use on a regular basis as well as for IBD-related communications (Figure 17). Facebook, Twitter, Instagram and WhatsApp were the most popular social media platforms used on a daily basis. Only 8 declared WhatsApp users (12.5%) used the messaging service for health-related support. The following findings therefore specifically focus on Facebook (n=59), Instagram (n=59) and Twitter (n=57). 31.6% (n=30) of people with IBD did not use Facebook Groups for health-related support, while 68.4% (n=65) reported to have used one or more. The results indicate that it is common for individuals who use Facebook Groups to be a member of more than one (Figure 18).

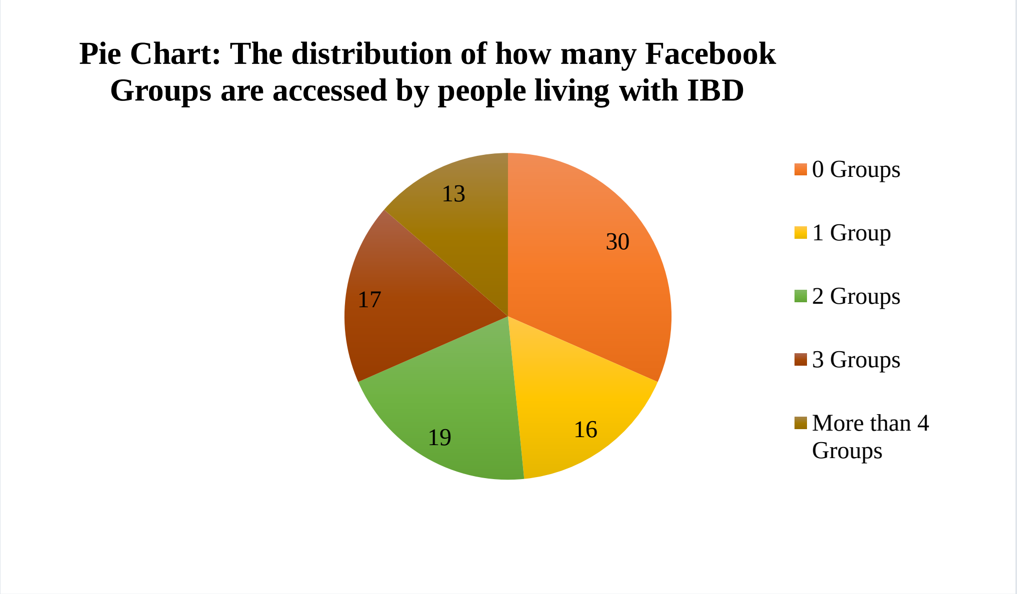


Figure 18 Pie Chart showing distribution of Facebook Group use

62.7% of participants with IBD (n=66) reported using more than one platform to seek support, with an average (mean, mode and median) of using two platforms. There was a strong correlation between Instagram users and multiple platform use (.566, $\rho < 0.01$) indicating that people who use Instagram are more likely to use another platform for IBD support.

Participants were asked to describe their experiences using social media for IBD support. The answers were exported into NVivo 12, a program to support qualitative analysis. Running a word frequency protocol, the most commonly used words were IBD (n=31), support (n=29), people (n=29), post (n=26), and others (n=25). The results were visualised into a word cloud (Figure 19). Unsurprisingly, the most popular words were centred on notions of connectivity with other people and support.

Figure 19 Keyword visualisation

6.2.2 Privacy Concerns

Constructs		Survey statement
Social Privacy Concern (SPCON)	SPCON1	I am concerned about sharing personal health information on social media because of what other people might think of me.
	SPCON2	I am concerned about sharing personal health information on social media because of what other people might do with it.
	SPCON3	I am not concerned that other people can find private information about my health from social media.
Information Privacy Concern (IPCON)	IPCON1	I am concerned that social media platforms can make assumptions about my health.
	IPCON2	I am concerned about sharing personal information about my health on social media platforms, because it could be used in a way I did not foresee.
	IPCON3	I am concerned that the information I share on social media about my health could be shared with other companies.
	IPCON4	I am concerned that companies/government/organisations can find private information about my health from social media platforms.

Table 11 Table of Privacy concern variables

To answer RQ3a (Do people with IBD report to have a disposition to social and information privacy concerns?), the following section will explore the variables of privacy concern, demographics, perceived control and trust. Firstly, to investigate the information and social privacy concern variables, participants were asked questions pertaining to their social (n=3) and information (n=4) privacy concerns in Survey 1. While Factor analysis examines the extent that shared variance exists between the different measures, the sample size from this study would provide instability in the results (Bandalos & Boehm-Kaufman, 2009). To demonstrate the close relationships between the variables pertaining to social privacy concern (Figure 20) and information privacy concern (Figure 21), scatter plot matrixes were used to show the correlations between the variables and the distribution of the responses.

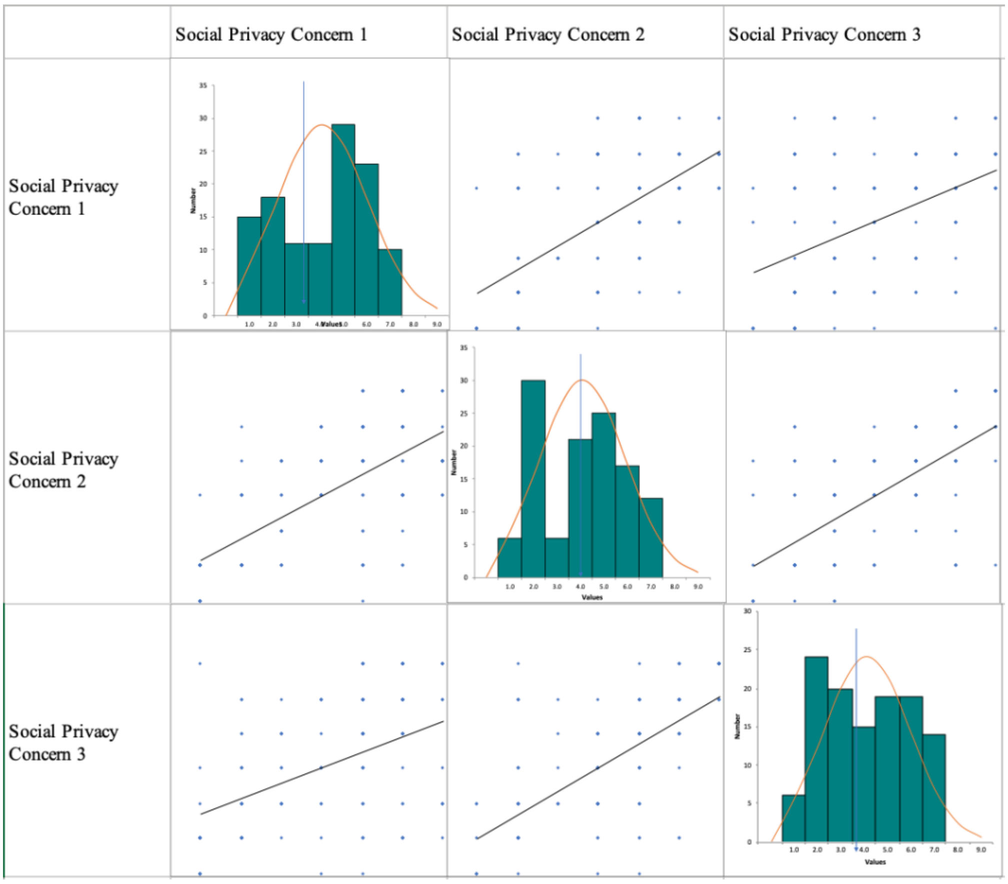


Figure 20 Scatter Plot Matrix: Social Privacy Concerns Variables

Figure 20 presents a scatter plot matrix for the variables concerning social privacy concern. It was made to demonstrate how closely linked the variables are to one another. There are positive correlations ($p < 0.05$) between each of the variables which indicates that they have a strong relationship and can all be attributed to the overarching theme of social privacy concern. The histograms for each of the variables presents a reasonably even distribution of responses, with the peak of the bell curve sitting at the neutral response (neither agree nor disagree). This suggests that while some people might feel a concern for their social privacy, others are less concerned. As previously recognised in the literature review, previous studies have attributed feelings of control to varying levels of privacy controls, where net privacy concern reduces as a result of mitigating behaviours (Li, 2012; Lee et al, 2017). Analysis of how feelings of control and privacy-related behaviours are linked to social privacy concern can be found in Section 6.2.4.

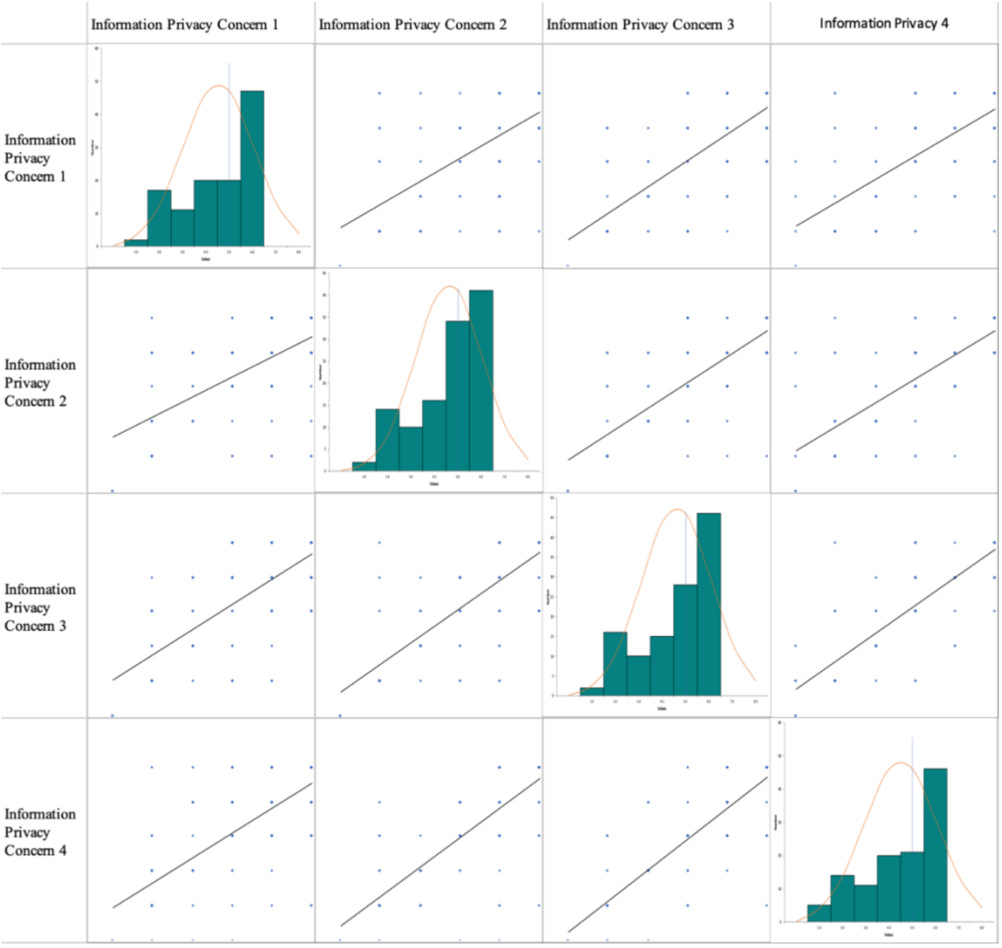


Figure 21 Scatter Plot Matrix: Information Privacy Concern Variables

Figure 21 shows a scatter plot matrix for the information privacy concern variables and their relationship with one another. There is a stronger positive correlation between the information privacy concern variables than the social privacy concern variables; correlations ranged between 0.638 - 0.729 between information privacy variables, with the social privacy concern correlations ranging between 0.458 – 0.675. The histograms for these variables however demonstrate a positive skew towards agreement with the Likert scale items. This suggests that there was more agreement in the sample that there is a shared concern for how social media platforms use their health-related information. Given the strong relationships between the items, these variables were combined into overarching factors: social privacy concern and information privacy concern.

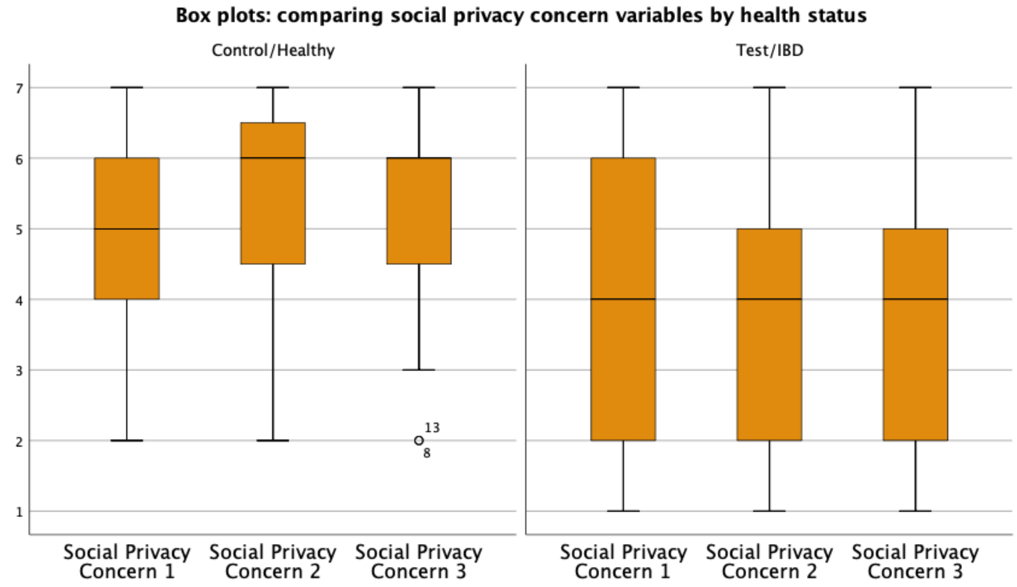


Figure 22 Box plots: comparing social privacy concern variables by health status

The box plots (Figure 22 and Figure 23) displays the distribution of agreement to the statements between the test group (with IBD) and control group (healthy volunteers). The Likert scale ranged from 1=Strongly Disagree to 7=Strongly Agree, with 4 representing Neither Agree nor Disagree. Overall, participants from the control group demonstrated higher concerns for their social and information privacy than those in the test group. The medians for each variable were higher up the agreement scale, with a smaller degree of variability. To answer **RQ3a**, that asks whether people with IBD are more likely to demonstrate increased privacy concerns, the social and information privacy responses were compared between the IBD group and the control. From the results, in this sample people with IBD were less concerned for their social and information privacy than the control group.

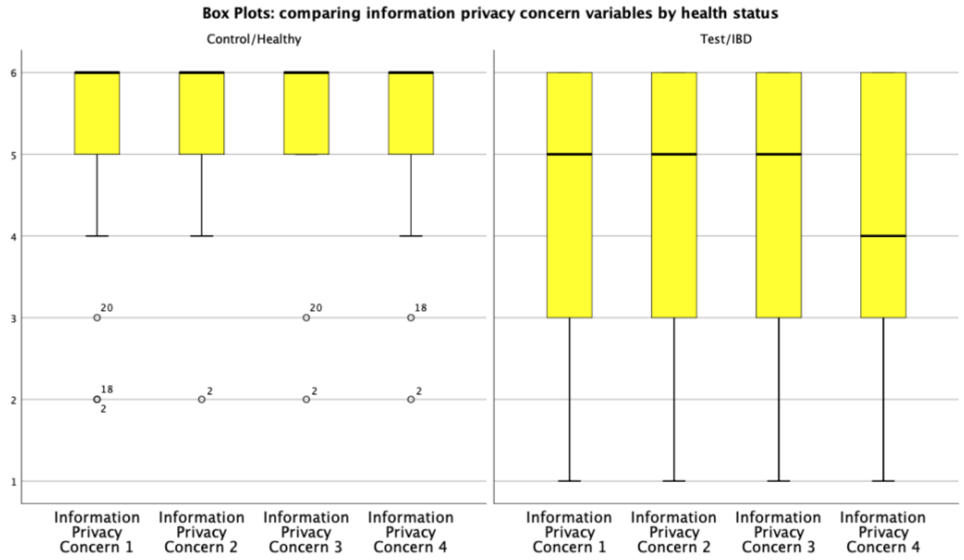


Figure 23 Box plots: comparing information privacy concern variables by health status

To understand whether there was a relationship between demographic information (age, gender, education) and privacy concern (social and information), non-parametric chi-squared test (Spearman) was used (Table 12).

For this, the variables of social privacy concern and information privacy concern are made up of all their associated variables. The results indicated that there was no significant correlation between the variables of age, gender, and education level and social privacy. However, there was a weak correlation between age and information privacy suggesting that older participants were more concerned about how their information is used by social media platforms.

Indeed, additional factors including years of social media use; trust; and previous negative information privacy experience were measured against social and information privacy concerns. While there was no correlation with social privacy concern, both trust and negative experience had a significant (positive and negative, respectively) correlations with information privacy. This suggests that those who have higher trust in social media platforms, have a lower information privacy concern; and those who have perceived a privacy violation from social media platforms also had a higher information privacy concern.

Correlations

			Information Privacy Concern	Social Privacy Concern
Spearman's rho	Age	Correlation Coefficient	.224*	0.078
		Sig. (2-tailed)	0.031	0.455
		N	93	93
	Gender	Correlation Coefficient	-0.137	-0.015
		Sig. (2-tailed)	0.189	0.886
		N	93	93
	Education	Correlation Coefficient	-0.002	-0.006
		Sig. (2-tailed)	0.988	0.956
		N	93	93

	Social Media Use (in years)	Correlation Coefficient	0.088	0.065
		Sig. (2-tailed)	0.401	0.534
		N	93	93
	Trust	Correlation Coefficient	-.353**	-0.056
		Sig. (2-tailed)	0.001	0.602
		N	88	88
	Previous negative information privacy experience	Correlation Coefficient	.357**	-0.18
		Sig. (2-tailed)	0.001	0.095
		N	87	87

**** Correlation is significant at the 0.01 level (2-tailed).**

*** Correlation is significant at the 0.05 level (2-tailed).**

Table 12 Correlations between demographic information and privacy concern

6.2.3 Impacts on Privacy Concern

Constructs		Survey statement
Perceived Information Privacy Control (PCTL)	IPCTL1	I believe I have control over what information about me (including about my health) is collected by social media platforms
	IPCTL2	I believe I have control over how information about me is used by social media platforms

Table 13 Table of privacy control variables

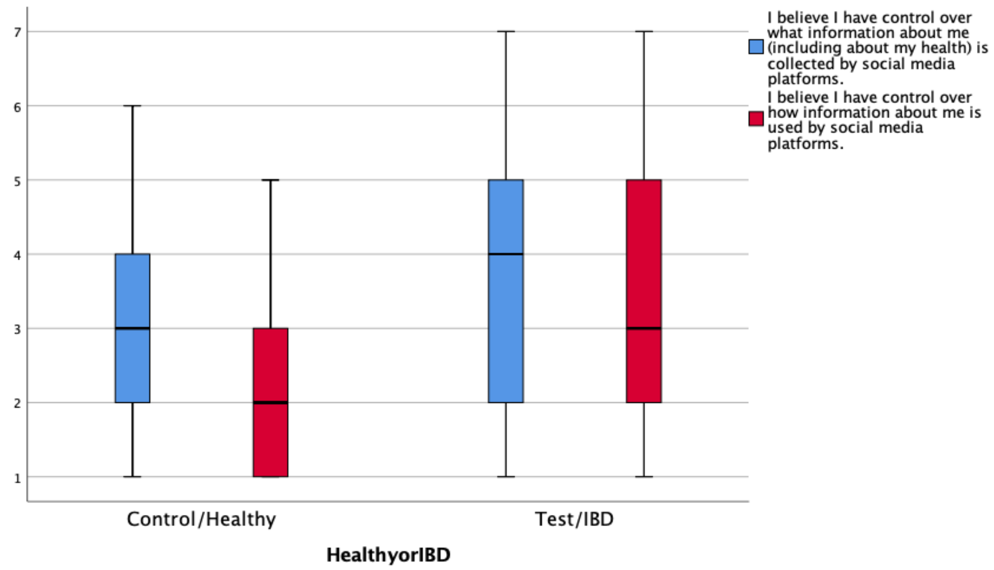


Figure 24 Box plot: Perceived control of personal information comparing healthy vs IBD groups

It is observed in the risk calculus that when individuals perceive a sense of control and exhibit privacy-enabling behaviours, their net privacy concern reduces (Li, 2012; Lee et al, 2017). Participants were asked how far they believe that they have control over what information is collected by platforms (PCTL1) as well as their perceived control over how it is then used (PCTL2). Figure 24 visualises the distribution of the results which indicates that healthy participants typically believed they had less control over their personal information. Given the variance in sample sizes, a one-way non-parametric ANOVA test (Independent-Samples Kruskal-Wallis Test) was conducted to test whether the distributions between the test and control group were the same. The results shown (

Table 14) that there was a significant difference in the distribution between the samples, supporting that in this study people living with IBD believed that had more control than healthy participants. However, while participants with IBD may perceive slightly more control, the median was scored at 4 (neither agree nor disagree) for control over what is collected and 3 (somewhat disagree) for how their information is used. This overall indicates that while they might feel more in control than healthy participants, the results suggests that they do not feel positively in control.

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of IPCTL1 is the same across categories of Healthy or IBD.	Independent-Samples Kruskal-Wallis Test	.041	Reject the null hypothesis.
2	The distribution of IPCTL2 is the same across categories of Healthy or IBD.	Independent-Samples Kruskal-Wallis Test	.004	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .050.

Table 14 Independent-Samples Kruskal-Wallis Test for variables of control between groups

A factor analysis test was conducted to test the variance between the two variables of control, finding that there was a factor loading of .912. This indicates that together they can be classed as a new overall variable of ‘control’. Given that the size of the data set gives way to weakness in factor analysis, Spearman’s chi-square test was performed to demonstrate the strong relationship between these two variables ($0.681\ \rho < 0.01$).

To test whether there was a correlation between perceived control over personal information and information privacy concerns, the Spearman’s chi-squared test was used. The results (Table 15) show that for people living with IBD, there were significant negative correlations between perceived control and information privacy concerns, where the privacy concern variable (IPCON) is made up of four variables (IPCON1-4). There were however no statistically significant correlations in the control group. This indicates that perceived control over personal information reduces the net privacy risks perceived, coinciding with the risk calculus for patients with IBD.

Correlations

Spearman's rho			IPCON (IBD test)	IPCON (Healthy control)
	IPCTL1	Correlation Coefficient	-.254*	-0.001
		Sig. (2-tailed)	0.016	0.998
		N	90	23
	IPCTL2	Correlation Coefficient	-.285**	-0.025
		Sig. (2-tailed)	0.006	0.91
		N	90	23

**** Correlation is significant at the 0.01 level (2-tailed).**

*** Correlation is significant at the 0.05 level (2-tailed).**

Table 15 Spearman's correlation between control and privacy concern

A Spearman chi-squared test was used to understand what the relationship is between demographic information and perceived control (Table 16). Yielding similar findings as for information privacy concern, age had a negative correlation, suggesting that younger people perceive to have more control and thus, lower privacy concern.

While previous research suggests that people learn about information privacy through experience, the Spearman's coefficient did not yield a correlation between length of social media use and both privacy control variables (Table 16).

Correlations			**IBD Group**		**Healthy control**		
			IPCTL 1	IPCT L2	IPCT L1	IPCT L2	
Spearman's rho	What is your age range?	Correlation Coefficient	-.223*	-0.176	0.233	.476*	
		Sig. (2-tailed)	0.035	0.096	0.284	0.022	
		N	90	90	23	23	
	What gender do you identify with?	Correlation Coefficient	0.042	0.077	-0.074	0.178	
		Sig. (2-tailed)	0.696	0.468	0.737	0.418	
		N	90	90	23	23	
	What is your highest level of education?	Correlation Coefficient	0.003	-0.075	-0.251	-0.222	
		Sig. (2-tailed)	0.975	0.48	0.248	0.309	
		N	90	90	23	23	
	For approximately how long have you been a social media user?	Correlation Coefficient	0.057	0.012	0.157	0.095	
		Sig. (2-tailed)	0.594	0.909	0.475	0.667	
		N	90	90	23	23	
	Have you ever felt that your privacy has been compromised by social media platforms?	Correlation Coefficient	0.071	.229*	0.044	0.303	
		Sig. (2-tailed)	0.513	0.033	0.847	0.171	
		N	87	87	22	22	
	I am aware of the privacy issues in our society.	Correlation Coefficient	-0.068	-.220*	-0.405	-0.398	
		Sig. (2-tailed)	0.533	0.042	0.062	0.066	
		N	86	86	22	22	
	How much have you hear/read over the last two years about the use and misuse of information collected from tech companies?	Correlation Coefficient	-0.321**	-0.238*	-0.396	-0.369	
		Sig. (2-tailed)	0.002	0.025	0.068	0.091	
		N	87	87		22	22

*** Correlation is significant at the 0.05 level (2-tailed).**
**** Correlation is significant at the 0.01 level (2-tailed).**

Table 16 Correlations between demographic information and perceived control

However, there was a significant correlation between previous information privacy violations and perceived control over how information is used (.229 $\rho < 0.05$), indicating that people who believed their privacy has been compromised by social media platforms perceived to have less control over how their information is used.

While education level and experience using social media platforms did not appear to have a significant relationship with perceived control, participants were asked about their awareness of specific privacy-related issues from the media. There was a moderate correlation between both variables about control (collection and use) and how much individuals had read about privacy breaches in the news (-.312 ($\rho = 0.002$) and -.238 ($\rho = 0.025$), respectively). This indicates that while people with higher perceived control over their information have lower information privacy concerns, they are also less aware of information misuses by tech companies.

With the control group, on the other hand (Table 16**Error! Reference source not found.**), there was a strong correlation between age and control over how social media platforms use information (.476 with $p<0.05$). This suggests that older individuals perceive more control over how their information is used, which offers a contrasting finding to the IBD group. Yet, there were not any other remarkable relationships between the other variables.

What these findings suggest is that people with IBD perceive to have more control than healthy individuals. Those who have perceived more control over what information is collected, and how it is used, similarly indicate lower concern for their information privacy. This supports the risk calculus (Li, 2012) and might explain why individuals with IBD report lower privacy concerns than the control sample. Nevertheless, those who had reported to have been made aware of privacy violations in the news, also were more likely to have a higher information privacy concern (.289 $\rho < 0.01$) and a lower sense of control (-.321 $\rho < 0.01$).

Participants were asked how far they agreed with privacy-related behaviour statements as well as what their health-related social media disclosure behaviours are. In this study there was a significant relationship between self-reported behaviours reflecting their privacy concerns and lower social privacy concern, which indicates that, as demonstrated in Study 1, people have a good understanding of how to mitigate social privacy risks. While in Study 1 audience management and self-censorship were described as the prominent methods of social privacy mitigation, in this study, health-related self-disclosure was the only variable that had a statistically significant correlation with people's online behaviours (-.265, $\rho < 0.05$) and social privacy concerns.

For information privacy concerns, however, online behaviours were associated with two information privacy concern variables (See Appendix 4, page 430). These variables were the concern over social media platforms making assumptions about their health (.215, $\rho < 0.05$) (IPCON1) and sharing this information with third parties (.261, $\rho < 0.05$) (IPCON3). Despite this, there was not a significant correlation between online behaviours and perceived control over information privacy which indicates that while some individuals may perceive to have more control over what is collected and how it is used, their behaviours do not necessarily indicate that they do have control. It should be noted however, that the behavioural items in this survey were not specifically information privacy-related to reduce study length and burden on participants with technical jargon.

Under current regulation, health data is considered to be sensitive and has more protections than some other personal data categories (EU, 2016). Participants in this study were asked how far they agreed that the information they share about their health is more sensitive than other information they share online. There was a positive skew in the distribution of answers, with people agreeing with the statement (Figure 25). To understand the association between perceived sensitivity of health information and privacy concern, a Spearman's correlation test was conducted between variables (Table 17). Indeed, the results suggests that information sensitivity has a statistically significant relationship with both social privacy and information privacy concern variables. However, the only mitigating behaviour associated with information sensitivity is audience management (.347 $\rho = 0.01$).

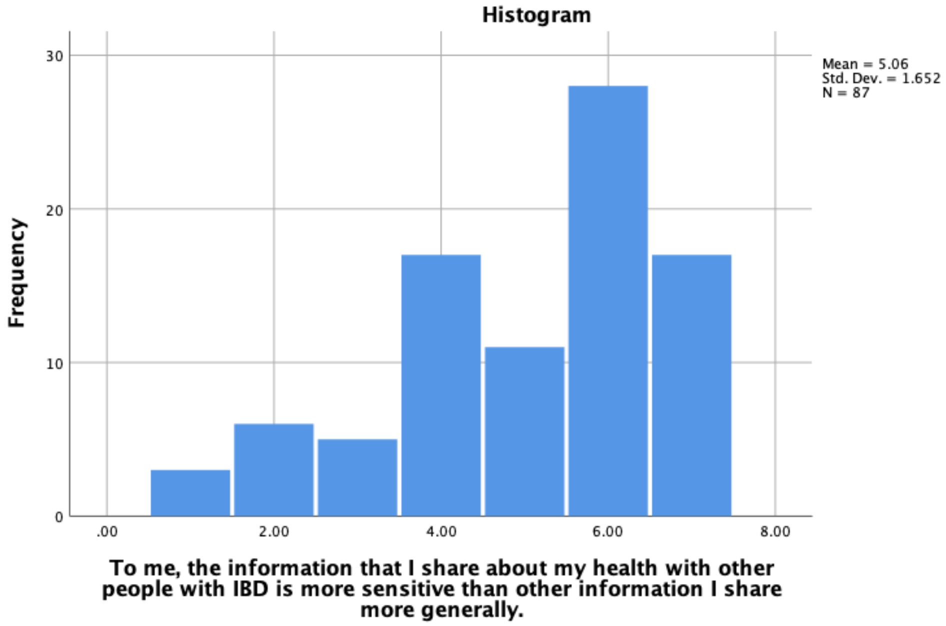


Figure 25 Histogram: frequencies of responses to information sensitivity

In response to **RQ3a**, people with IBD do not appear to have a disposition to have an increased concern for their social or information privacy than healthy individuals; in fact, they demonstrated less concern. However, when taking perceived control into consideration, people with IBD perceive to have a higher sense of control, contributing towards the theory of the risk calculus. Antecedents to perceived control include a low awareness of privacy in the news, suggesting a potential false sense of security, across the test and control group. Age was a conflicting factor between the groups: younger people with IBD perceived more control while older people without IBD perceived more control. Finally, reported behaviours were mostly correlated with social privacy concerns.

Correlations

			The information that I share about my health with other people with IBD is more sensitive than other information I share more generally.
Spearman's rho	I am concerned about sharing personal health information on social media because of what other people might think of me.	Correlation Coefficient	.279**
		Sig. (2-tailed)	0.009
		N	87
	I am concerned about sharing personal health information on social media because of what other people might do with it.	Correlation Coefficient	.224*
		Sig. (2-tailed)	0.037
		N	87
	I am not concerned that other people can find private information about my health from social media.	Correlation Coefficient	0.074
		Sig. (2-tailed)	0.495
		N	87
	I have thought about how social media platforms handle my personal information in the past.	Correlation Coefficient	0.006
		Sig. (2-tailed)	0.955
		N	87
	I am concerned that social media platforms can make assumptions about my health.	Correlation Coefficient	.222*
		Sig. (2-tailed)	0.039
		N	87
	I am concerned about sharing personal information about my health on social media platforms, because it could be used in a way I did not foresee.	Correlation Coefficient	0.084
		Sig. (2-tailed)	0.438
		N	87
	I am concerned that the information I share on social media about my health could be shared with other companies.	Correlation Coefficient	0.176
		Sig. (2-tailed)	0.103
		N	87
	I am concerned that companies/government/organisations can find private information about my health from social media platforms.	Correlation Coefficient	.282**
		Sig. (2-tailed)	0.008
		N	87
	My online behaviours reflect my privacy concerns	Correlation Coefficient	0.124
		Sig. (2-tailed)	0.253
		N	86
	What I share about my health online differs depending on who I am sharing it with.	Correlation Coefficient	.347**
		Sig. (2-tailed)	0.001
		N	87
	I use Facebook Groups to control who can see what I post about my health on Facebook.	Correlation Coefficient	0.162
		Sig. (2-tailed)	0.134
		N	87

**** Correlation is significant at the 0.01 level (2-tailed).**
*** Correlation is significant at the 0.05 level (2-tailed).**

Table 17 Spearman's correlation: information sensitivity

6.2.4 Activity and Barriers to Learn

Constructs		Survey statement
Activity to learn	ACTL	I would like to learn more about how information about me is collected
Barriers to learn	BAR-T	Perceived insufficient time
	BAR-O	Perceived insufficient opportunities
	BAR-LOWDL	Perceived low skills/technical understanding
	BAR-ATT	Perceived low importance (attitude)

Table 18 Activity to learn variables

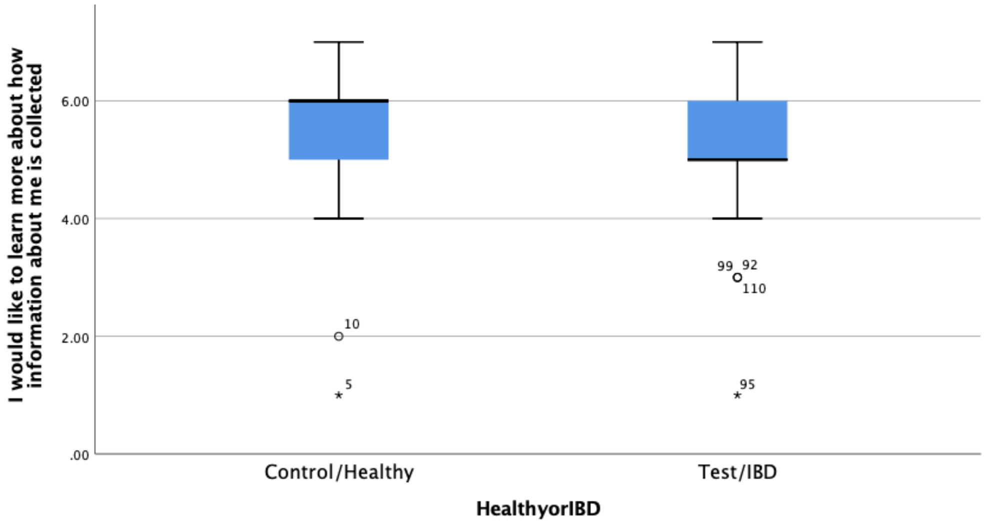


Figure 26 Box-plot displaying distribution of responses to people's activity to learn

To answer **RQ3b** (To what extent does (1) disposition to privacy concern, (2) time, (3) perceived technical knowledge, and (4) access to learning materials impact on barriers to learning?) and **RQ3c** (Is there an appetite amongst individuals with IBD to learn more about data collection and processing practices by social media platforms?), participants were asked in the first survey whether they would like to learn more about how their information is used by social media platforms. Figure 26 shows the distribution of the agreement with the ACTL (1=Strongly Disagree, 4=Neither Agree nor Disagree, 7=Strongly Agree). In both groups, while there are some outliers, the majority of the participants agree with the statement showing that everyone, both healthy and with IBD were interested in learning more. An independent samples Mann-Whitney U-Test reported a statistically non-significant difference between the samples (U=779.5 $\rho = .188$).

Constructs		Survey statement
Activity to learn	ACTL	I would like to learn more about how information about me is collected
Barriers to learn	BAR-T	Perceived insufficient time
	BAR-O	Perceived insufficient opportunities
	BAR-LOWDL	Perceived low skills/technical understanding
	BAR-ATT	Perceived low importance (attitude)

Hypothesis Test Summary - One-Sample Wilcoxon Signed Rank Test

		IBD test sample			Healthy control sample		
	Null Hypothesis	Sig.	Observed median	Decision	Sig.	Observed median	Decision
1	The median of BAR-T equals Neither agree nor disagree.	0.002	5	Reject the null hypothesis.	.148	5	Retain the null hypothesis.
2	The median of BAR-O equals Neither agree nor disagree.	0.054	5	Retain the null hypothesis.	.189	4	Retain the null hypothesis.
3	The median of BAR-LOWDL equals Neither agree nor disagree.	0.757	4	Retain the null hypothesis.	.511	4	Retain the null hypothesis.
4	The median of BAR-ATT Neither agree nor disagree.	.000	6	Reject the null hypothesis.	.000	6	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .050.

Table 19 Wilcoxon Signed Rank test for reasons why information privacy has not been previously learned about

At this point in Survey 1 participants answered why they haven't learned more in the past about their online privacy (Figure 27), where 1=Strongly Disagree and 7=Strongly Agree. In the IBD group, technical knowledge (BAR-LOWDL) and previous opportunity to learn (BAR-O) retained the null hypothesis, through a Wilcoxon Signed Rank test (Table 19), which indicates that they were not statistically significant reasons for not having previously engaged in learning more about information privacy. However, both the variables of 'insufficient time' (BAR-T) and attitude (BAR-ATT) were significant factors.

For the control group, the attitudinal variable, which pertains to the belief that learning about information privacy is not important, was the only statistically significant factor that explained why participants had not previously learned about it.

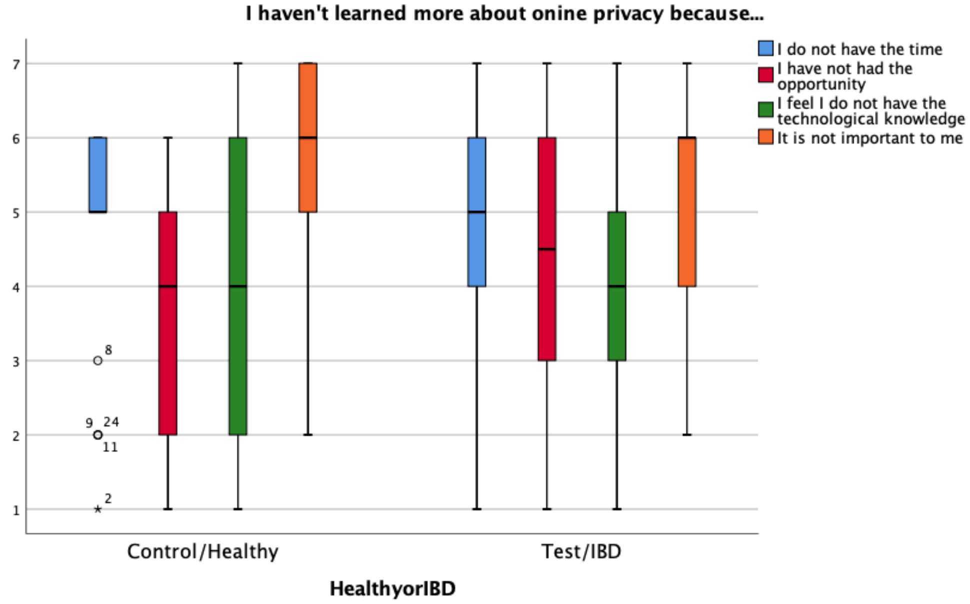


Figure 27 Box-plot displaying distribution of responses to why information privacy had not been previously learned more about

Participants were shown a hypothetical social media scenario where they see a post that said: *"The Internet knows everything about you, does it matter if it does?"* (Figure 9). Participants were asked whether they would like to take the opportunity to access materials to learn more about how their information is collected and used as part of the study. They were asked: *"Would you like to learn more about how your information is collected and processed now? If 'yes', you will be provided with the link to access the Health Privacy Toolkit"* for those that selected yes they were taken to another page with the link. This asked individuals again whether they have clicked on the link or would prefer not to look at the resource at that time. Figure 8 is a flow diagram visualising this process and participant choices. Ultimately, 49% (n=42) IBD participants and 50% (n=11) healthy participants did continue to the resource, however, there was only a 50.9% retention rate through Survey 2b. In answer to **RQ3c**, this indicates that people with IBD are no more likely to learn more about their online privacy than healthy individuals; however a 50% acceptance rate for both categories is still significant.

This next section will focus on the participants who did not choose to go to the resource, thus being directed to Survey 2a. In this survey participants were asked to respond to agreement scales for statements pertaining to reasons why they did not choose to access the resource at that time. Figure 28 visualises the distribution of the responses between the test and control groups, which shows a degree of similarity between the groups. To test the statistical significance of the distributions between groups, an independent-Samples Mann-Whitney U Test (Table 20) was conducted, finding that the distributions were statistically similar for all of the variables besides “I would rather not know how data is collected and used” ($\rho = 0.036$). This suggests that between the groups, people with IBD have a stronger attitude towards not wanting to know, or ‘wilful ignorance’.

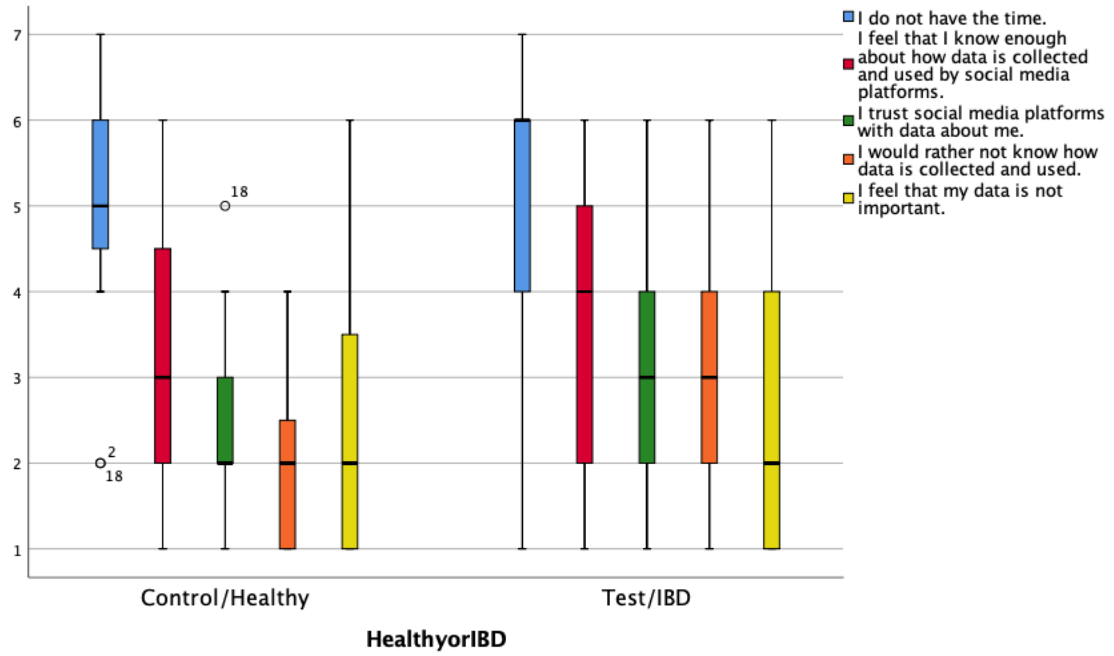


Figure 28 Box plot: distribution of agreement to statements pertaining to reasons for not accessing the online resource

The findings were similar between the test and control groups, however, when comparing these results with the responses from the first survey (Figure 27), there appears to be a change in the responses concerning perceived importance (BAR-ATT), indicating a change in attitudes towards their personal information. To conduct the significance in the changes between pre and post social media post intervention, a non-parametric two-related samples test was conducted (Table 21) confirming that there was a statistically significant difference in the perception of information importance between Survey 1 and 2a. The ranks indicate that 73.2% (n=41) of people with IBD had an increased perception of information importance (BAR-ATT) and disagreed with the statement following the social media post intervention. Meanwhile 22.8% (n=13) further disagreed (from their response in Survey 1) that time was a factor limiting them from learning more. What this shows is that a lack of time should be considered as a significant predictor for people with IBD not learning more about their online privacy. Similarly, the same test conducted for the control group yielded a statistically significant difference between attitudes pertaining to importance (BAR-ATT) ($\rho = .014$) and retained no significant difference with time (BAR-T).

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of I do not have the time. is the same across categories of Healthy (control) or IBD (test).	Independent-Samples Mann-Whitney U Test	0.589	Retain the null hypothesis.
2	The distribution of I feel that I know enough about how data is collected and used by social media platforms. is the same across categories of Healthy (control) or IBD (test).	Independent-Samples Mann-Whitney U Test	0.398	Retain the null hypothesis.
3	The distribution of I trust social media platforms with data about me. is the same across categories of Healthy (control) or IBD (test).	Independent-Samples Mann-Whitney U Test	0.33	Retain the null hypothesis.
4	The distribution of I would rather not know how data is collected and used. is the same across categories of Healthy (control) or IBD (test).	Independent-Samples Mann-Whitney U Test	0.036	Reject the null hypothesis.
5	The distribution of I feel that my data is not important. is the same across categories of Healthy (control) or IBD (test).	Independent-Samples Mann-Whitney U Test	0.68	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .050.

Table 20 Independent-Samples Mann-Whitney U Test: Distribution of reasons why Health Privacy Toolkit was not accessed between groups

Finally, the researcher did not want to assume that all participants would require to learn more about information privacy, the item ‘I feel that I know enough about how my information is collected and used’ was included. Between the IBD and healthy group there was no statistically significant difference in the distribution of responses. Secondly, the median for IBD group equalled a neutral response (4=Neither agree nor disagree), while in the control group, there was a median average of 3=slightly disagree.

Wilcoxon Signed Ranks [IBD test group]

		N	Mean Rank	Sum of Ranks
[2a] Insufficient time. – [1] Insufficient time	Negative Ranks	13[a]	20.5	266.5
	Positive Ranks	25[b]	18.98	474.5
	Ties	19[c]		
	Total	57		
[2a] I feel that my data is not important. - [1] I don't think that I need to know about how information about me is used because it is not important to me	Negative Ranks	41[d]	25.59	1049
	Positive Ranks	6[e]	13.17	79
	Ties	9[f]		
	Total	56		

a. Insufficient time [2a] < Insufficient time [1]

b. Insufficient time [2a] > Insufficient time [1]

c. Insufficient time [2a] = Insufficient time [1]

d. I feel that my data is not important. [2a] < I don't think that I need to know about how information about me is used because it is not important to me [1]

e. I feel that my data is not important. [2a] > I don't think that I need to know about how information about me is used because it is not important to me [1]

f. I feel that my data is not important. [2a] = I don't think that I need to know about how information about me is used because it is not important to me [1]

	Survey 1s *Time* vs Survey 2a *Time*	**Survey 1s *Importance* vs Survey 2a *Importance***
Z	-1.587[b]	-5.154[c]
Asymp. Sig. (2-tailed)	0.113	0
a. Wilcoxon Signed Ranks Test		

Table 21 Wilcoxon Signed Ranks Test: Barriers to learning between Survey 1 and 2a, IBD test group

Non-parametric two-related samples test (Test Group)

6.2.5 The Impacts of the Health Privacy Toolkit Resource

Participants who did decide they wanted to learn more about their online privacy were signposted to the Health Privacy Toolkit, which was designed with PPI input. These participants (n=53) were also invited to complete Survey 2b, which yielded a response rate of 50.9%. In both Survey 2a and 2b, participants were given Likert scale items pertaining to privacy concern and perceived control, which afforded the researcher to conduct non-parametric related-samples tests. These tests were used to understand the impact of the Health Privacy Toolkit on privacy concern and perceived control, which pertains to **RQ3d** (How are information privacy concerns, perceived control and, likelihood to act on their privacy preferences impacted by awareness interventions).

Table 22 Wilcoxon Signed Ranks Test Statistics - pre and post comparisons

6.2.5.1 Impacts on Privacy Concern and Perceived Control

Variable	Survey statement
IPCON1	I am concerned that social media platforms can make assumptions about my health.
IPCON2	I am concerned about sharing personal information about my health on social media platforms, because it could be used in a way I did not foresee.
PCTL1	I believe I have control over what information about me (including about my health) is collected by social media platforms

Table 23 Information Privacy Statements in Survey 2a and 2b

In Surveys 2a and 2b, participants were asked two measures of information privacy concern (Table 23). For the analysis, IPCON1 was chosen to represent information privacy concern and PCTL1 for perceived control over data collection by social media platforms. The Wilcoxon Signed-Rank test was performed to understand how answers changed from the pre-survey (1) and the post surveys (2a and 2b) and the results can be seen in Table 24 and Table 25. The results show that there are statistically significant differences in information privacy concern between Survey 1 and Survey 2a ($\rho = .014$) and 2b ($\rho = .030$). 41.3 % (n=19) participants in Survey 2a and 39.1% (n=9) participants from Survey 2b had reported an increase in information privacy concern, while 43.5% (n=20) and 47.8% (n=11) participants, respectively, reported no change.

Wilcoxon Signed Ranks

		N	Mean Rank	Sum of Ranks
[Survey 2a] IPCON1. - [Survey 1] IPCON1	Negative Ranks	7[a]	11.64	81.5
	Positive Ranks	19[b]	14.18	269.5
	Ties	20[c]		
	Total	46		
[Survey 2b] IPCON1. - [Survey 1] IPCON1	Negative Ranks	3[d]	4	12
	Positive Ranks	9[e]	7.33	66
	Ties	11[f]		
	Total	23		
[Survey 2a] PCTL1. - [Survey 1] PCTL1	Negative Ranks	14[g]	14.75	206.5
	Positive Ranks	11[h]	10.77	118.5
	Ties	21[i]		
	Total	46		
[Survey 2b] PCTL1 - [Survey 1] PCTL1	Negative Ranks	9[j]	9.44	85
	Positive Ranks	8[k]	8.5	68
	Ties	6[l]		
	Total	23		

a. [2a] IPCON1. < [1] IPCON1

b. [2a] IPCON1. > [1] IPCON1

c. [2a] IPCON1. = [1] IPCON1

d. [2b] IPCON1. < [1] IPCON1

e. [2b] IPCON1. > [1] IPCON1
f. [2b] IPCON1. = [1] IPCON1
g. [2a] PCTL1< [1] PCTL1
h. [2a] PCTL1 > [1] PCTL1
i. [2a] PCTL1 = [1] PCTL1
j. [2b] PCTL1 < [1] PCTL1
k. [2b] PCTL1 > [1] PCTL1
l. [2b] PCTL1 = [1] PCTL1

Table 24 Wilcoxon Signed Ranks Test: Comparing Information Privacy Concern and Control Survey 1 vs 2a and 2b

Test Statistics - Wilcoxon Signed Ranks Test

	[2a] IPCON1n - [1] IPCON1	[2b] IPCON1- [1] IPCON1	[2a] PCTL1 - [1] PCTL1	[2b] PCTL1 – [1] PCTL1
Z	-2.460^{b}	-2.167^{b}	-1.211^{c}	-.420^{c}
Asymp. Sig. (2-tailed)	0.014	0.03	0.226	0.674

Table 25 Wilcoxon Signed Ranks Test Statistics - pre and post comparisons

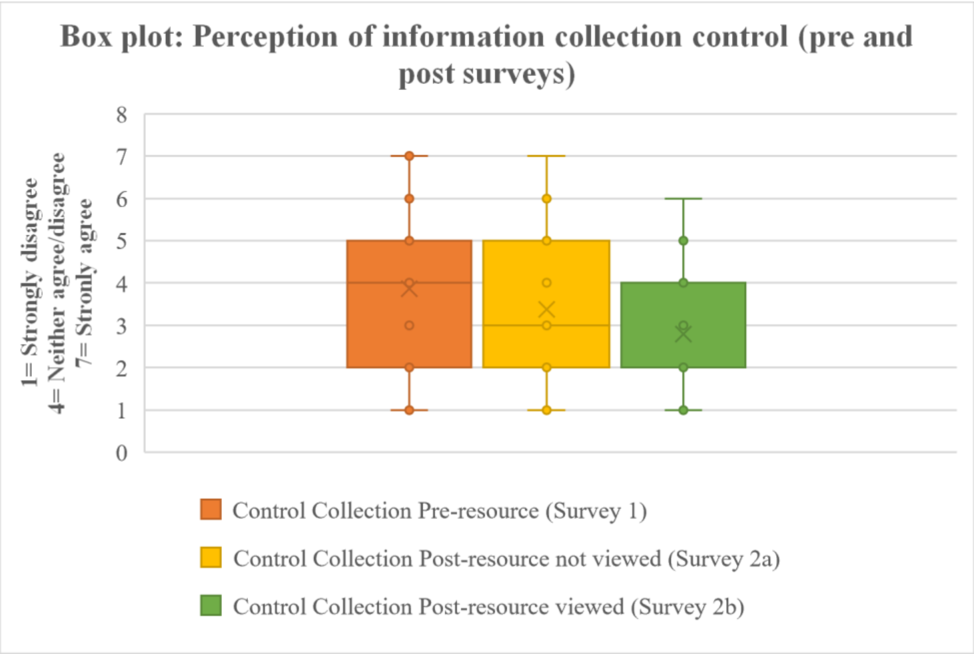


Figure 29 Box plot: perception of information control

In the online resource, participants were offered tools that they can adopt to limit the amount of information collected by platforms, such as a Virtual Private Network (VPN) and cleansing their social media profiles. 71% (n=15) participants of Survey 2b with IBD had reported to have accessed the "Take Control" page. However, despite being given more tools to help increase controls, participants with IBD reported to feel less in control of what information is collected about them in Survey 2b (Figure 29). Given the small sample size from Survey 2b to see whether there was any statistically significant change in people's perception of control over how their information is used by social media platform, the Wilcoxon Signed-Rank test was conducted (Table 25). The results indicated that there was not a significant difference in people's perceptions of control in both groups (2a and 2b). With only 3 participants from the control group having accessed the tools page, there was not enough data to compare with the IBD group.

6.2.5.2 Likelihood to Act

Construct	Variable	Survey statement
Likelihood to Act	REVSET 2a/2b	I am going to review the privacy settings on my social media accounts and my devices in the near future.
	REVPOL	I am going to review the privacy policies of the social media platforms I use in the near future.

Table 26 Variables for Likelihood to Act on Privacy Preferences

In Surveys 2a and 2b, participants were asked about their future intentions to review their privacy settings and the privacy policies (Figure 30). To test the significance of the responses, a one-sample non-parametric test was carried out, which identified that the variable for reviewing privacy policies in Survey 2a retained a hypothesis of a neutral result (Table 27). The findings therefore demonstrate confidence that participants who engaged with the Health Privacy Toolkit were statistically more likely to review their privacy settings. However, both the social media intervention and the Health Privacy Toolkit yielded positive impact on behaviour intention.

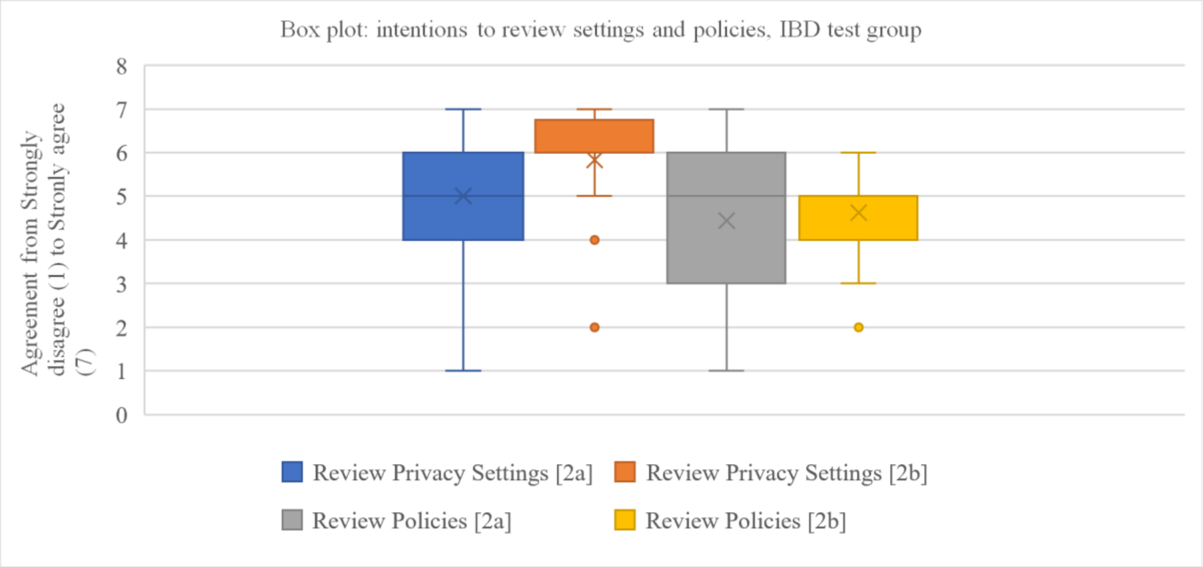


Figure 30 Box plot: intentions to review settings and policies

Hypothesis Test Summary: One-Sample Wilcoxon Signed Rank Test

	Null Hypothesis	Sig.	Observed Median	Decision
1	The median of Privacy settings review [2a] Neither likely nor unlikely.	0.000	5 (Somewhat agree)	Reject the null hypothesis.

2	The median of Privacy settings review [2b] Neither likely nor unlikely.	0.000	6 (agree)	Reject the null hypothesis.
3	The median of Privacy policies review [2a] Neither likely nor unlikely.	0.087	5 (Somewhat agree)	Retain the null hypothesis.
4	The median of Privacy policies review [2b] Neither likely nor unlikely.	0.036	5 (Somewhat agree)	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .050.

Table 27 One-Sample Wilcoxon Signed Rank Test: Privacy behaviour intention variables

6.2.5.3 Experiences of the Health Privacy Toolkit

Finally, to understand how an online privacy awareness raising and resource can have an impact at scale (**RQ3e)**, participants were asked in Surveys 2a and 2b about their experiences and comments on the social media post as well as the online resource. The following findings are from the IBD group, who were the target audience.

Firstly, 7 participants provided feedback on the social media post from Survey 2a (Table 28). Suggestions for improvement included changing the format to "something visual" such as a video or picture. The post could also include more information so that it is clear and informative.

RESPONSES TO: HOW COULD THIS POST BE IMPROVED TO INCREASE ENGAGEMENT?
Design could be improved to attract more attention. A white background with block black text can read as error if you're scrolling.
Don't use the word 'imagine'. Just be blunt and say the internet knows everything about you,
For a lot of people i don't think the subject matters, i think it was stand out enough, it sure you could so more

I think it requires something more eye catching, i do not engage with any posts that aren't instantly entertaining like a video or picture
Make it more colourful
More detail; it doesn't say anything at first reading, so would be skipped
Something visual rather than just words.

Table 28 Participant Feedback from social media intervention design

Participants from Survey 2b were asked about their experience with the online resource. Overall, the experiences reported were positive; participants described the clarity and helpfulness of the information provided (Table 29). When given the opportunity, participants in Survey 2b also provided feedback to improve the resource (Table 30). The amount of information and the way that it was delivered was described by some users (n=5) as something to be reconsidered and improved upon; the inclusion of more media to replace text was suggested, particularly for people visiting the resource from mobile devices. Two participants expressed an intention to revisit the resource *"to take in more"*.

RESPONSES TO "PLEASE DESCRIBE YOUR EXPERIENCE OF THE RESOURCE"
Good
Helpful and concise
It was insightful
It was user friendly and well put together. Given the amount of information, it might be less overwhelming visually to someone on a computer rather than an iphone
I haven't watched the video but i will but it is all very relevant
Ill be more aware of what i'm putting out and think more about if i am comfortable with my data being used by people i don't know
Very informative, will have to go back and reread again a few times to digest everything

Very good. Not too long!
Very detailed but well explained
A lot of obvious stuff, but needs to be said for those who have not thought about it. What was new new to me? The toolkit, and also the power and unexpected uses ai is being put to.
There's a lot of info, will revisit it to take in more.
I found some sections a little wordy so skim read them, but generally the information was clear and engaging. The layout was simple to use and looked attractive.
I thought it was very useful very clear, very measured. Explained the issues and gave some useful advice. A lot of privacy advocate material doesn't acknowledge or sometimes even appear to understand the benefits of social media use.
Easy and straightforward to use. Information was easy to read and videos informative.

Table 29 Responses to experiences of Health Privacy Toolkit

One participant reported on feeling *"wary about uploading the App. Is there a way one can get assurance that this is not a scam, or been hacked?"* which highlights the importance of credibility. Another participant supported this by suggesting that the establishment of the author earlier in the resource was also essential: *"My first question when looking at a resource like this is who has produced it and why. A resource arising from a university research project has credibility, and it's worth highlighting that"*. While the resource was web-based to ensure that it was accessible through all web-enabled devices, one participant suggested that it could be made into a mobile application.

The design and usability of the resource was commended for its ease of use, as one participant remarked that it *was "simple to use and looked attractive"*. Finally, and importantly to address the challenge of balance, one participant said: *"a lot of privacy advocate material doesn't acknowledge or sometimes even appear to understand the benefits of social media use".* The aim of the resource was to provide individuals with more information without causing unnecessary fear, this feedback signposted how the resource met this aim.

95.7% (n=22) of IBD participants who completed Survey 2b agreed that they would share this resource with their Crohn's and UC networks on social media platforms.

RESPONSES TO "HOW CAN THIS ONLINE RESOURCE BE IMPROVED?"
More interactive, less reading
Maybe less intimidating amounts of text for less competent users.
Keep thriving
By having more breaks within the information
Maybe an app version ?
I think a last page with the links to all the apps recommended would be nice
I was wary about uploading the app. Is there a way one can get assurance that this is not a scam, or been hacked...
I think the videos chats are perhaps better than lots of words
Some clearer signposting to specific answers to the questions.
Establish authorship and credibility earlier. Propaganda appears from the social media companies in feeds fairly regularly about privacy issues and how seriously they take it, and there are occasional scare stories. My first question when looking at a resource like this is who has produced it and why. A resource arising from a university research project has credibility, and it's worth highlighting that.
I accidentally skipped 'take control' because i saw the link to survey 2

Table 30 Responses to "How can this online resource be improved?"

6.3 Discussion

This study aimed to understand the needs for and impacts of a privacy literacy resource for people living with IBD through an intervention study. It paid particular attention to understanding whether people living with IBD perceive more or less social and information privacy concerns and what are the perceived barriers to learning more about the digital economy. The following section explores key findings and discusses them in the wider context of the IBD OHCs and privacy literature.

Previous research that has explored online privacy amongst people living with health conditions have conflicting conclusions over whether this population has an increased sensitivity to privacy over a ‘healthy’ population. Two papers (Bansal et al, 2010; Tisnado et al, 2006) suggest that people with health conditions have an increased sensitivity to privacy concerning their health. Meanwhile a later study by Zang (2017) indicated that people with health conditions are more willing to self-disclose and risk their privacy because of higher values for information and emotional support. In this empirical study, a sample of people living with IBD (n=98) and people who consider themselves to be healthy (n=26) were studied to understand whether people with this particular condition have an increased sensitivity to privacy through the dual lens of social and information privacy (**RQ3a**). Conducting statistical tests to answer this research question, this study found that while there was concern amongst the IBD sample, yet on average they were less concerned about both their social and information privacy than the control sample.

This study explored whether there were any antecedents to help explain why people with IBD express lower information and social privacy concerns. Independent variables of perceived control (collection and use) had a significant relationship with information privacy concern ($-.254\ \rho < 0.05$; $-.285\ \rho < 0.01$, respectively). Participants with IBD however who had lower concerns were more likely to believe that they had more control over what information about them was collected and how it was used by social media platforms. This relationship supports the risk calculus theory that takes mitigating behaviours into account, when assessing a 'net' privacy concern (Li, 2012).

Previous research indicates that when people have the ability to take some control over their personal information, they can mitigate perceived privacy risks (Li, 2012; Zhang, 2017; Brady et al, 2016). In this study however, there was no significant relationship between privacy behaviours and their perception of control. Those who perceived higher levels of control and lower levels of information privacy concern, were also less likely to be aware of privacy issues in society (-.220 $\rho < 0.05$). Furthermore, for participants who did not continue to the Health Privacy Toolkit and perceived higher levels of control in Survey 1 were more likely to believe that they knew enough about how their information is collected and used (.303 $\rho < 0.05$). Therefore, while on the surface it seems that the risk calculus exists for information privacy, with poor awareness and lack of privacy enabling behaviours, people’s perceptions of control may be misguided, leading to a false sense of security.

In terms of demographics, in this study, older age groups correlated with higher privacy concern (.234 $\rho = .031$) and expressed lower perceived control (-.223 $\rho = .035$) amongst the IBD group. This supports previous OHC and privacy research (Zhang et al, 2017; Frost et al, 2014) that observed similar findings. Conversely, the control group of healthy participants yielded the opposite effect, finding a significant negative correlation between age and health-related information privacy concern. In a study by Frost et al (2014), they reported that younger people living with cancer were more aware of their life after cancer and how self-disclosing about their health might impact on their future opportunities. While this study did not support this hypothesis in the IBD group, younger healthy participants were more concerned about assumptions being made about their health by social media platforms, despite not living with a chronic illness.

While Zhang et al (2018) explored the relationship between health-status and health disclosure, the role of privacy concern was unclear. This current study found that health-related self-disclosure and privacy enhancing behaviours did not have a statistically significant relationship with information privacy concern and perceived information control variables. However, both self-disclosure and privacy enhancing behaviours did strongly correlate with social privacy concerns. This finding suggests that self-disclosure is a poor indicator of information privacy concern (Taddicken, 2014), but a strong indication of social privacy concern.

The study's findings suggest that unless a person experiences or perceived a privacy violation by social media platforms, the length of time they have used social media will not increase their concern. To elaborate, similar to previous research (Lankton & Tripp, 2013), this study found that the length of time a person has used social media platforms for did not correlate with information privacy concern. However, had someone previously experienced or perceived an information privacy violation in the past, then they were significantly more likely to report higher concerns.

Under GDPR information about health is considered a 'sensitive' data category (EU, 2016). In this study participants with IBD recognised that the information they share about their health is more sensitive than information they would otherwise share on social media. Despite this, participants with IBD expressed slightly lower information and social privacy concerns than healthy individuals. It is possible that the observation of others' sharing health information as well as not personally experiencing harm normalises sensitive information sharing (Chang et al, 2016).

From this study people with IBD were no more likely to engage with an online learning resource than the control sample (**RQ3c)**. However, in response to **RQ3b,** the most persistent barrier to engaging with conversations and materials around personal data was insufficient time and not necessarily because they did not believe that their information was important. Comparing responses in the surveys before and after the interventions, participants reported to perceive an increased amount of importance for their personal information. This indicates that an exposure to awareness raising content through social media posts may encourage individuals to think about their personal information. A potential solution that can help raise awareness of privacy-related news and behaviours is to share information through social media, that does not require the reader to dedicate a significant amount of time in one sitting.

In this study participants who engaged with the online resource were found to report an increase in information privacy concerns and decrease in their perceptions of control (**RQ3d)**. While previous research indicates that with more education people experience increased agency over personal information (Sideri et al, 2019; Vanderhoven, 2015), this was not found in this study. It highlights how social media platforms need to be more transparent about their practices to reduce the cause for concern and, failing that, privacy tools need to be accessible and easy to use.

A final point for discussion in this study is the extent to which PPI influenced the study. While there is no certainty over how the study and resources would have taken shape without PPI input, there is confidence that the process improved the appropriateness of the resource to ensure that the content provided was thought provoking in a balanced way. A critical aim of this resource was to reduce the risk of voluntary withdrawal from online support as a result of an increased awareness, particularly as there is significant evidence indicating the therapeutic benefits of OHCs (Szigethy et al, 2009; Coulson, 2013; Coulson, 2015; Summers, 2018). There have not been any known reports in the months following the study that participants have withdrawn from OHCs; participants were given the researcher's email address should they feel concerned and there was not any email correspondence with the researcher. Similarly the qualitative feedback in Surveys 2a and 2b did not suggest that anyone felt significantly worried about their information privacy.

While there were benefits from working with the PPI group in the design stages, user feedback also provided more useful feedback for further improving the resources. Finally, despite the positive outcomes, there were limitations with the PPI method in this study. With PPI members being distributed over the UK and their involvement subject to a voluntary basis, asynchronous communications were the only feasible way to get feedback. A design process that has more active involvement, such as doing iterative design workshops and synchronous group feedback may have yielded better designs.

6.4 Limitations

A challenge that is commonly faced in online surveys is self-selection bias (Khazaal et al, 2014). While the study was shared broadly on Facebook, Twitter and Instagram, participants' motives for engaging are unclear. They may have an interest in privacy, or represent particularly active users, for instance.

Furthermore, as previously stated, the control group for this study represented 21% of respondents which will not give a precise estimation of the true population's perceptions. Efforts were made to increase the control group, including an extension for recruitment. However, the timing of this study coincided with the novel coronavirus pandemic COVID-19 (World Health Organisation, 2020). To reduce bias caused by the coronavirus and people's peaked interest in public health, the recruitment ended. Furthermore, while participants declared not to have IBD, it is possible that they live with other heath conditions.

Similar to interviews, while participants were made anonymous, social desirability bias remains a limitation of this study. Graeff (2005) remarks "people naturally want others to view them favorably with respect to socially acceptable values, behaviors, beliefs, and opinions" (p. 412). In areas of the study, such as being asked about their awareness of online privacy and their privacy enabling behaviours may have led to participants responding in a way to make their answers more appealing to the researcher.

As a privacy-preserving measure to reduce data collection from non-consenting individuals, this study was conducted in a controlled setting. Individuals were presented with a hypothetical social media scenario, where their attention was being directed. An 'in the wild' study could be conducted to understand how an awareness campaign would be responded to in a less controlled setting; however, privacy measures would indeed need to be taken into careful consideration. Furthermore, to test how far Survey 1 itself influenced people's behaviours, 38.5% (n=10) of participants from Survey 2b reported that their primary reason for looking at the toolkit was "the previous survey made me question what I think social media platforms do with my data". While this indicates how the survey itself could be considered to be an intervention, it emphasises a need for future studies to yield better insights into how far a social media campaign can raise awareness to people.

The surveys were adapted from Xu et al (2010) to differentiate between social and information privacy and to include variables pertaining to activity to learn. However, this meant that survey 1 was long to complete and participants averaged around 15 minutes to complete it. While the variables of social and information privacy were all valid, to reduce the burden on repeating the same survey after participants had engaged with learning materials, some variables were removed. This meant that there was a limitation on how far some variables could be tracked between survey 1a and 2a/2b.

The biggest methodological challenge that this study faced was participant retention. In particular, there were challenges to encourage participants who proceeded to engage with the Health Privacy Toolkit to complete the second survey. In the study design, to mitigate this, email addresses were collected to identify participant completion and to send two follow-up reminders of the study. In the early stages of recruitment it was clear that despite email reminders participants were not engaging with Survey 2b. To mitigate this issue, an additional question was inserted into Survey 1 to give people who did not have time in that moment to visit the resource to go straight to Survey 1a, instead to improve the retention rate of post-intervention survey responses. Indeed, as previously reported there was a retention rate of 51%.

6.5 Conclusions

The findings in this chapter demonstrated how people who engage with OHCs do not necessarily have a greater concern for their social and information privacy than healthy individuals. Indeed, regardless of health status, there was an interest in learning more about online privacy, however, time was a significant barrier.

This study underlined how perceptions of privacy, control and trust play important roles in online communications, but do not necessarily influence platform usage.

Having the opportunity to access information about online privacy was welcomed by participants. Recommendations to improve the resource centred around text-management; providing visual aids to explain concepts and issues. Other recommendations included credibility and making the author of the resource clearer, establishing the University as a reputable source. In the future, to accommodate for individuals with limited time, the management of a long-term campaign that embeds information into their social media experience could be implemented.

DISCUSSION AND CONCLUSION

CHAPTER 7: DISCUSSION CHAPTER

7.0 Introduction

The main purpose of this thesis was to get a clearer understanding of the privacy beliefs, attitudes, and behaviours demonstrated by people using social media platforms to engage with IBD online communities. The literature review (Chapters 2 and 3) presented how online health communities are needed by people living with IBD and provide a space for social support. However, while social media presents people living with chronic illnesses with opportunities to access support, the role of online privacy in IBD OHCs had not been scientifically examined.

The three empirical studies presented in the previous section of this thesis comprehensively explored the attitudes and understanding of online privacy through a dual lens of social and information privacy. In order to understand the complexities of how privacy is considered within this online health community spread over different social media platforms, one objective of this thesis was to examine how people with IBD engage with Facebook, Twitter, and Instagram.

The findings of this thesis draw on a multi-stakeholder and a multi-disciplinary approach to the research, with the inclusion of both patients and community leaders in responding to research calls. In support of responsible research and innovation (RRI), the findings from study participants also helped shape the direction of the research. Together, these different perspectives captured over three studies have provided new insights on how the IBD OHCs use social media and their attitudes to privacy.

In this chapter, the main findings presented in this doctoral thesis will be critically discussed, drawing on relevant literature when appropriate. The implications of the research follow; firstly, what future research should be considered, before how the findings and practical outputs of this thesis, by means of the Health Privacy Toolkit, can be applied to support OHCs. Consideration is then given to the methodological approach of this thesis. This section reflects on the responsible research and innovation approach, how the research was executed, and what limitations there were. The chapter, and thesis, is concluded with some closing remarks which summarises the contributions of the research.

7.1 Summary of Main Findings

In this section the main findings from this research will be discussed. First, findings pertaining to the uses of contemporary social media platforms are reviewed, followed by an extensive discussion of how social and information privacy are perceived by the IBD communities.

7.1.1 How are Contemporary Social Media Platforms used by People with Inflammatory Bowel Disease Engaging in Online Health Communities?

It was recognised in the literature review that in order to understand the contextual construction of privacy, there was a need to get a clearer understanding of how social media platforms are used by people living with IBD. The following discussion brings together previous literature as well as new findings born from the studies undertaken in this thesis.

Social media platforms are used by people all over the world, with global statistics indicating that over half the world's population is connected online (Internet World Stats, 2020). For people living with chronic health conditions, having access to online health communities, as demonstrated in the literature review, can provide benefits to quality of life and coping abilities for people living with IBD (Coulson, 2013; Coulson, 2015; Summers, 2018). While online health community research has been conducted over the past two decades, the rapid growth of social media platforms has meant that there are new opportunities to understand the interactions between people using the platforms, as well as the interactions people have with the software itself.

As previous reports indicate that the average person uses more than one social media platform (Chaffey, 2020) and Guo et al (2016) observed that Facebook, Twitter and Instagram were the most used platforms for support amongst people with IBD, this thesis selected these three contemporary platforms for enquiry.

7.1.1.1 Platforms Yield the Same Affordances

In accordance with the literature review, the observations from this thesis validates previous findings that people report positive outcomes as a result of accessing support through social media platforms. Participants in Study 1 and Study 2 described the positive outcomes that they had experienced from interacting with other people and other stakeholders. Furthermore, in Study 3, 95.4% participants with IBD agreed that using social media to connect with others was important to them. Such benefits included having access to new information, other people's experiences, and mitigating feelings of loneliness. This thesis agrees with the previous literature that indicates how online social support can benefit individuals with IBD (Coulson, 2015; Britt, 2017). Given previous IBD OHC literature has explored web-based forums, Facebook and YouTube; this thesis contributes to the knowledge that Twitter and Instagram too provide people with social support benefits.

To understand how contemporary social media platforms are used, Study 1 adopted an adapted version of the SCENA model (Merolli et al, 2014) to identify what therapeutic affordances were experienced through people's interaction with different features. The first overall finding observed in this thesis, is that while people with IBD are likely to use more than one social media platform for health-related support (Study 1 and Study 3), Facebook, Twitter, and Instagram's technical features are homogenous and yield the same therapeutic affordances. The only arguable 'exclusive' feature between the platforms is the ability to create 'groups' on Facebook that provides additional social privacy protection. However, the similarities between the platform features and the affordances described indicates that people living with IBD can access support on any of the platforms to suit their preferences.

Through Study 1, Facebook, Twitter and Instagram were observed to have similar functionality including sharing posts through an account, commenting on posts, liking, direct messaging, and privacy settings. Each of these features are characteristics of how previous scholars have separated social media platforms from other web-based social networking such as web-based forums (Ellison & boyd, 2008; Obar & Wildman, 2015; Hayes et al, 2015). While the features of social media platforms have intrinsic affordances built into their design, participants in Study 1 reported how the features have different limitations between the platforms, such as Instagram's requirement for a picture and Twitter's 240-character limit. The limits and restrictions of seemingly homogenous features were recognised to have broader impacts on people's overall experiences of engaging with OHCs on social media.

This means that while many participants across Study 1 and 3 reported to use several platforms to engage in IBD OHCs, the therapeutic affordances from each will be similar. The use of several platforms therefore is unlikely to be as a result that the outcomes afforded by technical features are different, but for other reasons such as to meet a wider variety of people. This therefore reminds the academic community that the examination of social media platforms needs to consider both the computer interactions as well as the social ones.

7.1.1.2 Imagined Affordances

The concept of imagined affordances that “incorporates the material, the mediated, and the emotional aspects of human–technology interaction” (Nagy & Neff, 2015: p.2) helps to explain how features and their affordances contribute towards broader emotional and attitudinal perceptions.

In this thesis, in particular, feelings of safety and privacy were identified to have some bearing on people’s comfort with self-disclosing health information. This supports O’Hara’s (2016) theory of phenomenology, which presents the notion that platforms may elicit feelings of “privacy” while simultaneously collecting and processing vast sums of personal data.

The ways in which social media platforms are designed contribute towards people’s feelings of safety. For instance, in contrast to Twitter’s public facing profiles and restricted posting, which contributed to lower self-disclosure, participants in Study 1 described Facebook Groups as a ‘safe’ place to share “graphic” (p/13: see p. 124) health-related experiences.

In Study 1 the expectation of social privacy associated with Facebook Groups, perpetuated to some participants’ expectations of information privacy; believing that Facebook should not be using that information because it’s in a private group. There was not any evidence in Study 3 however to statistically support whether individuals believed that the use of Facebook Groups provided a sense of control over their information privacy. Regardless, while some participants did remark that Facebook Groups felt like a safe space, this was not widespread, with some participants reporting that Twitter felt safer for them because no-one from their real life follows them on that platform. This indicates that while the ways in which features are presented to users can nudge feelings of safety, users will adapt their behaviours to create what feels like a safe space for them.

People's social experiences on social media platforms were shown to impact on people's perceived experiences. For some participants in Study 1, reports of confrontation and hostility in large Facebook Groups influenced their decision to withdraw participation and exclusively use Twitter (P/5) for IBD support. Indeed, this finding also supports Hayes et al (2016) study that concluded how both technical design and social interactions influenced people's experiences.

Imagined affordances also levers on people's personal motivations. Indeed, supporting Basarova and Choi's (2014) theory that motivations shape [healthy] people's online behaviours, and self-disclosure intention, participants in this study were influenced by their motivations and preferences. For individuals who are motivated to advocate for IBD and raise awareness, they described high degrees of self-disclosure in a public setting, whereas other participants were much more deliberate about their posting behaviours in relation to their social privacy concerns (Study 1 & Study 3). This also corresponds with Merolli et al's therapeutic affordance category of *adaptation* (2014), whereby social media platforms have different features to support people's personal needs.

While social privacy concerns were observed to shape health-related online behaviours (See 7.1.2.1 for further discussion), health status was also shown to be a factor which influences people's involvement in IBD OHCs on social media. As such, some participants reported that when they are in periods of remission, and do not require social support, they become less active but may still contribute their experiences to help others. What this suggests, however, is that people who are actively seeking information or posting about their health may be experiencing periods of unwellness with their condition. This supports previous research by Merolli et al (2014) that demonstrated how patients appropriate their social media use depending on their health needs.

While therapeutic affordances remain the same across Facebook, Twitter, and Instagram, the ways in which people use the platforms depends on their motivations, health status, privacy preferences, as well as the platform design itself. Ultimately, this thesis concludes that although there are certainly common motivations, behaviours and feature affordances, people each have different experiences of these platforms (Bucher and Helmond, 2017).

7.1.2 What are the Attitudes and Approaches to Online Privacy by Members of the IBD OHCs?

The main focus of this thesis is to explore the perceptions of online privacy from an OHC perspective. Through the literature review, it was made clear that the notion of privacy on the internet is complex. Dividing online privacy into two counterparts, social privacy and information privacy (Lutz & Strathoff, 2011; Gürses & Diaz, 2013), provided a dual lens to examine how each is understood by the IBD OHCs. To recapitulate, social privacy covers the information flows between people, while information privacy pays attention to the information flows between individuals, platforms and other parties (Gürses & Diaz, 2013). This section discusses how people living with IBD manage their social and information privacy and the observations indicating that attitudes towards information privacy are changing.

7.1.2.1 Social Privacy

A notable finding from Study 1 was that information privacy and social privacy were thought about and acted upon differently by people living with IBD. Study 3 also recognised that between the IBD group and the healthy group, people living without IBD reported to have higher social privacy concerns around their health on social media. This could be because people living with IBD have expressed more social privacy enabling behaviours around their health information and feel that that they have more mastery self-efficacy (Bandura, 2008), which supports the risk calculus (Li, 2012). It is also possible that the term 'health' to an individual without a chronic illness could be interpreted in many different ways from the common cold, having an acute terminal illness or, indeed, living with poor mental health, which is still somewhat stigmatising (Bharadwaj et al, 2017).

The findings from this thesis also identified differences in how people with IBD viewed and responded to social privacy and information privacy. In terms of social privacy, the findings from Study 1 demonstrated how participants would feel uncomfortable having access to self-disclosed health information; these included family members, friends, current and potential colleagues, and employers. This supports previous literature that observed similar findings in other health communities, including myalgic encephalomyelitis, chronic fatigue syndrome, and type 1 and type 2 diabetes (Brady et al, 2016), as well as weight-loss (Patterson, 2013). Participants in Study 1 and 3 indicated that their online behaviours are a reflection of their privacy preferences, with people being able to articulate their concerns and actions, which is reminiscent of the risk calculus (Li, 2012). Platform features were leveraged to afford self-presentation (Merolli et al, 2014), enabling people to take control over the context their information is shared in and how they are perceived by others. While some features such as privacy settings, Instagram Stories (limited to 24 hours), and direct messages inherently increase social privacy boundaries, participants also described other techniques such as using multiple platforms and accounts.

As described in the literature review, self-disclosure has often been used as a measure of low privacy concern, when privacy is considered to be something to trade-off (Taddicken, 2014; Barth & de Jong, 2017). This research does not support that increased self-disclosure is indicative of a lower privacy concern, because information is shared contextually, with different boundaries in place

(Nissembaum, 2004). Indeed instead, this research builds on the Functional Model of Self-Disclosure (Basarova & Choi, 2014) which contends that disclosure behaviours are goal orientated; whereby different expectations of intimacy and norms encompass different communication modes. In this research, participants reported that they would expect to share and see more graphic and sensitive information in closed Facebook Groups than on Twitter, for example. However, it should be stressed that for individuals whose goal is to raise awareness of their illness to others, they are more likely to disclose more intimate information in a more public setting.

However, self-censorship was recognised as an important privacy mechanism in Study 1 and 3. In Study 1 participants were mindful about what they self-disclosed in particular contexts, carefully considering impression management methods so that they could both access support without potentially portraying themselves as “whinging” about their illness to non-empathetic friends and family. Meanwhile in Study 3 there was a correlation between low health-related self-disclosure on social media, social privacy concern (.309, $\rho < 0.01$) and their privacy related behaviours (-.265, $\rho < 0.05$). This supports how self-disclosure is an important behaviour to observe; but it should be remembered that it is not the only privacy-enhancing behaviour taken. Although this thesis recognises that individuals may disclose more health information with the IBD community than with their family and friends, it is evidenced throughout this thesis that individuals have their own personal boundaries of what they feel comfortable sharing. An example of this is in Study 2 community leaders of a Facebook Group reported how individuals private message them to post a question to the group on their behalf, if they feel too uncomfortable to post through their own profile.

The clear articulation of social privacy risks and mitigating actions by people in the IBD OHCs strongly suggests that people have a good understanding of the context in which they share information, and also have the digital literacy skills to minimise the likelihood of context collapse. This ability to rationally process the risks, benefits and mitigations is indicative of the risk calculus. With previous research indicating that increased self-efficacy reduces privacy concern (Lee et al, 2017), this thesis posits that as a result of poor self-efficacy over information privacy management, the net concern is higher.

7.1.2.2 Information Privacy

Although social privacy was observed to play an important role in how people conducted themselves on social media platforms, the ways in which participants considered their information privacy were comparably different.

In Study 1 many of the participants reported that they had not given much, if any, prior thought about how information about them is collected and used by social media platforms, despite sharing information about their health. It should be noted at this point that there is evidence to suggest a change in attitudes by Study 3, which will be discussed later in this chapter. In Study 1 and Study 2, it was clear that there were few individuals who could articulate specific ways in which personal data is collected by online platforms. Coupled with a lack of prior consideration and not reading the privacy policies, Study 1 evidenced how participants struggled to demonstrate a clear understanding of how their information is collected and what it is used for.

While risks were difficult to identify for participants in Study 1, there were concerns shared between Study 1 and Study 3 for information privacy. Findings from Study 1 indicated that individuals with IBD typically did not articulate information privacy enhancing behaviours, which is possibly as a result of their inexplicit understandings of the ways different personal data is collected. This supports Lutz and Strathoff (2012) who suggested that one reason why individuals appear to behave in ways that contradict their beliefs (the privacy paradox) is poor self-efficacy. Indeed, the awareness of information privacy and privacy enabling techniques through the Health Privacy Toolkit did not demonstrate an increased sense of self-efficacy in Study 3; further discussion can be found in Section 7.1.2.5.

In Study 3, people living with IBD appeared much more concerned about their information privacy than their social privacy. However, when compared to the control group, people living without IBD demonstrated slightly increased levels of information privacy concerns around their health. Indeed, while both groups were in agreement that information privacy is concerning around health, perhaps to a person living with IBD, they may be less surprised if a social media platform collects information about their health when they are engaged in health-related communities. However, to an individual who is not involved in the communities, this kind of tracking could be particularly discomforting. Nevertheless, further studies should explore the true nature of why this result indicates a higher concern amongst health individuals.

While a lack of knowledge acts as one possible explanation, this thesis supports previous work that indicates how cognitive bias impacts on the way people think about information privacy concerns. Previous literary commentary has noted how people do not seem to care about their privacy and it is viewed as an asset to be traded for services (Waldman, 2020). The findings from Study 1 suggests that participants recognised that there was a trade-off; they described that they would accept the potential negative consequences in the future, in favour of connecting with others. This is reminiscent of temporal discounting of risk (Hallam & Zanella, 2017).

This thesis has supporting evidence to suggest that people with IBD are similarly subject to cognitive bias when weighing up the positives and negatives of participating in OHCs on social media. Firstly, this thesis highlights how people with IBD are subject to hyperbolic (temporal) discounting, whereby the short-term consequences are weighted more than those that might anticipated in the longer term (Hallam & Zanella, 2017; Waldman, 2020); which impacts on the way people perceive information privacy concerns. Indeed, participants in Study 1 talked about the need to access support online and community leaders in Study

2 remarked on how some people are desperate for support that it is unlikely they would stop to think about the bigger picture. These findings support Kordzadeh and Warren (2017) who found that the perceived positive outcomes of support positively affected people's willingness to self-disclose online over privacy concerns.

Secondly, participants across all the studies described a relationship between privacy concern and previous negative experiences. For instance, Participant 16 in Study 1 referred to their experience of context collapse between their social media profiles when their IBD-related account was recommended to people in her personal life. This amounted to them describing a distrust in the platforms and their ability to define their privacy boundaries online. Indeed, participants in Study 1 and Study 2 remarked on how it is difficult to understand the severity of what a privacy invasion feels like until it has happened. Finally, in Study 3 there were significant correlations between perceived information privacy concerns and previous privacy violations (-.357, $\rho = 0.01$). Indeed, this finding supports previous research that suggests previous perceived privacy invasion moderates people's privacy concern (Li et al, 2012).

Furthermore, even as the Cambridge Analytica scandal broke during the recruitment phase for Study 1, which raised people's attention to information privacy, some participants still felt that they would not be negatively impacted by data handling practices. This underweighting of personal risk indicates how people are subject to comparative optimism bias, believing that negative impacts will happen to someone else and not themselves (Debatin et al, 2009; Cho et al, 2010; Min Baek et al, 2013; Kokolakis, 2017).

A final comment to make about cognitive bias is how the disclosure behaviours of others might impact on an individual's risk perception. The culture of self-disclosing health information normalises the sharing of sensitive information online. Self-disclosure cultural norms have been reported to influence willingness to self-disclose through the Theory of Planned Behaviour (Ajzen, 1991). Study 1 reported how the sharing culture in Facebook Groups is particularly graphic and detailed in comparison with other platforms. This supports Chang et al's study (2016) that observed how individuals were more likely to self-disclose when they have seen others share sensitive information with minimal or no immediate negative outcome on information privacy. Indeed, as previously discussed in terms of the Functional Model of Self-disclosure (Basarova & Choi, 2014), the presence of social privacy-enabling functionality in Facebook Groups and Direct Message offer increased boundaries that provides a safe and comfortable space to share.

Significantly, there is a danger that social privacy measures are conflated with information privacy protections. While functionality can satisfy social privacy concerns, some participants in Study 1 were uncomfortable with the idea that social media platforms, such as Facebook, will still collect and process the information shared in private and closed Facebook Groups. It is important that when individuals exercise control over their online privacy, it needs to be clear which privacy they're managing.

7.1.2.3 People with IBD demonstrate altruistic attitude towards information sharing

Although some participants in Study 1 and Study 3 reported having a discomfort with third parties having access to their self-disclosed health information, people with IBD in Study 1 were accepting that secondary data uses could serve as a societal benefit. Participants interviewed in Study 1, as well as community leaders from Study 2, reported how the collection of data is not only useful to patients, but can give valuable insights into the illness for other stakeholders who provide healthcare and support. From the literature review, O'Hara (2016) described the constant negotiation between personal and societal preferences, which in the case of self-disclosed health information, is the decision making between protecting one's privacy and contributing their data to society. This thesis provides supporting evidence of how people living with IBD recognise how their information could be useful to third parties in research and development but would like to have a clear awareness of when this occurs, giving consent.

Many Study 1 participants were uncomfortable when they discussed a hypothetical situation that their self-disclosed health information is shared with other companies. However, others believed that information sharing can lead to better research, healthcare and products, and they were more comfortable with this idea. In both cases, participants reported that they would like to see more consent processes to ensure that they understood the secondary uses of their personal information. Contextualising this in the literature, the requirement for consent is particularly important at different stages of life, for a person living with a chronic illness as their privacy preferences and willingness to consent will change over time (O'Kane et al, 2013). Indeed, some participants also recognised the logistical shortcomings of seeking consent from thousands of people, some of whom may be dormant in the community.

Community leaders from Study 2 reiterated the societal benefits online networks can have on making positive change to regulation and approaches to illness management, but recognised the importance of consent. In Study 3, a comparison was made between the IBD group and the healthy control group to distil whether people with an illness were more concerned about third-party sharing of self-disclosed health information. The results revealed that there was not a clear agreement amongst the IBD group, whereas the healthy group were typically concerned with third-party sharing (Figure 22). The variability in concern by the IBD group vs the agreement of concern by the healthy group may indicate that people with a chronic illness may be more accepting of secondary data use because they recognise the societal benefits. Given that there is an awareness of how self-disclosed health information can be used to support research (Study 1 and Study 2) coupled with more mixed concerns with third-party data sharing (Study 3), there is some evidence to indicate that people living with IBD indicate more altruistic attitudes towards their health information on social media, particularly when consent is given.

7.1.2.4 Attitudes Towards Information Privacy are Changing amongst People with IBD

An unexpected and unintended finding from this thesis is that over the 2 years of data collection, people's attitudes towards information privacy and how their information is used by online platforms may be changing. This sub-section will discuss how findings from the studies together suggest this to be the case.

Information privacy is being thought about more

While Study 1 and 2 indicated that little consideration is given to how information is collected and processed, Study 3 presented some surprising findings. In a survey that yielded over 100 respondents living with IBD, participants were asked whether they had thought about how social media platforms handle their information in the past, 78.5% (n=77) participants with IBD agreed with the statement. It is possible that in the two years between Study 1 and Study 3, there had been a shift in attitudes that has increased people's attention to information privacy. It is also possible, however, that this overarching observation is due to sampling differences; for example, participants recruited for Study 3 may have been more interested in privacy.

Previous research and market reports indicated a low engagement rate with terms and conditions documents of online services (Debatin & Lovejoy, 2009; Patterson, 2013; Rao et al, 2016; Obar & Oeldorf-Hirsch, 2019). The observations in this thesis do not dispute these findings but suggest that there may be an increased interest in people returning to the policies. Study 1 was conducted in early 2018 before the implementation of the GDPR, and during the Facebook Cambridge Analytica scandal revelations. The majority of the participants (n=31) in the interview study reported to not have read the terms and conditions of the social media platforms that they used.

Two years later when Study 3 was conducted, survey participants with IBD were asked whether they had read the terms and conditions of the social platforms they use in the past 12 months. A third (n=30) of participants reported that they had not, while 56.8% (n=50) answered that they had 'skim-read' the policies. Comparing to the sample of health participants, people with IBD were proportionally more likely to report on skim reading policies. While online surveys are subject to social desirability bias (Lavrakas, 2012), it is possible that in the months following the Facebook-Cambridge Analytica scandal as well as new regulations, coming into effect in 2018 and 2020[21] respectively, has had an impact on people's engagement with privacy policies. Despite a reported positive engagement with the policies laid out by social media platforms, 57.5%

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[21] GDPR in May 2018; and the California Consumer Privacy Act in January 2020.

participants with IBD (Study 3) disagreed that these documents are an effective way to demonstrate their commitments to privacy. However, to put ‘skim reading’ into context, a 2018 study by Obar & Oeldorf-Hirsch found that policies that would take a person around 30 minutes to read, were engaged with for an average of 73 seconds before accepting a privacy policy. This raises questions around how much people can understand what is in the policies from a limited time spent ‘skim reading’ and should be explored more thoroughly.

Taking this into consideration, it was important to understand other ways in which people might have learned more about their information privacy online. In Study 3 90.6% (n=78) of participants with IBD agreed that they were aware of privacy issues in society. Furthermore, 86.2% (n=75) of participants had been made aware of at least one data misuse by tech companies through the media; however, only 3.4% (n=3) reported to actively seek out news around privacy breaches. This indicates that while there is a general awareness of how personal information is used and misused by tech companies, it is still only a small proportion of people who reported to take an active interest. This demonstrates how people are exposed to examples of privacy breaches in their everyday life through news consumption.

From these findings there is evidence to suggest that concurrent with people with IBD having thought more about their information privacy, that they may also have been made aware of how information is collected and processed; both through engaging with terms and conditions as well as reports from the media. A report by Dot Everyone published in May 2020 similarly indicated that people have a better understanding of data collection and processing practises than they did in 2018.

However, it should also be considered that social desirability bias may have factored into participants' responses to their reported awareness. It is possible that participants believe that they ought to be thinking more about information privacy. However, due to the limitations of survey design, it is not possible to qualify how participants had thought more about privacy in the past few years.

Changes in information privacy behaviours

For people living with IBD, they expressed clear social privacy preferences and mitigating actions in Study 1. Through the risk calculus perspective (Li, 2012), the calculation of threats, benefits, and the capacity to mitigate risk means that social privacy can be maintained through different techniques and people can still benefit from the OHCs. Although some people in Study 1 were uncomfortable with the idea that their information might be used for other purposes by social media platforms, a lack of understanding and consideration of information privacy in turn meant that mitigating actions were not taken. This indeed follows previous literature that supports how information privacy is less understood and therefore not acted upon (Lutz & Strathoff, 2011; Brady et al, 2016; O'Hara, 2016). In Study 1, only two participants reporting on using information privacy tools to reduce and obfuscate the data collected by online services. It appears that people do not actively behave in ways that contradict their information privacy preferences; more that they have a low awareness and understanding to make informed judgement; which ultimately means that people make decisions subject to cognitive bias, as previously discussed.

In Study 3, participants were asked whether they believe that their online behaviours reflect their privacy concerns. There was a moderate correlation indicating that for people who expressed they had thought about their information privacy, were more likely to report that their online behaviours reflected their privacy concerns. A weak correlation was also made between an awareness of privacy issues in society and privacy behaviours. Taken together, the findings from Study 1 and 3 suggests that people who have thought more about how information is collected and used are more likely to have an awareness of information privacy issues.

While more actions might be taken to mitigate information privacy concerns, this thesis also addressed perceptions of control. In Study 1 and 2, participants discussed power asymmetries between social media platforms and individual users. While community leaders recognised that more can be done to improve individual's digital literacy skills, significant changes to individual freedoms and privacy can only come from regulation and the platform providers themselves. Participants in Study 1 echoed feelings of powerlessness, stating that platforms 'own' them and 'can do what they want'. This supports findings from a previous study by Hargittai and Marwick (2016), where young people felt a sense of apathy with regards to their personal information, feeling that they do not have much self-efficacy beyond self-censorship. Yet, in Study 3, participants were divided over their perceptions of control over what information is collected and how it is used: 37.8% believed they had some control over what is collected while 42.2% did not.

An explanation for this split can be the motivating factors behind their perceived self-efficacy: Bandura (2008) presents 4 ways that self-efficacy can be influenced. Bandura (2008) argues that through *mastery,* having previous positive outcomes from past behaviours, is the most significant way of building self-efficacy. Meanwhile a persons' physiological state can negatively impact on a person's perception of self-efficacy, such as low mood (Bandura, 2008). Corroborating evidence from the three studies in this thesis, there is a between previous negative experiences on perceived control; which supports the challenges to people's self-efficacy (Bandura, 2008) if they have failed attempts to control their information flows. However, it should also be noted that while harms may not have been perceived, it may not be as a direct result of the individual's previous behaviours, given that algorithmic decision making is complex (Crawford & Schultz, 2014).

Comparing these findings on the relationship between information privacy and behaviours, there were stronger and more significant correlations between social privacy concerns and mitigating behaviours. Collectively these findings offer insights into understanding the dichotomy between concerns and behaviours when considered through the dual lens of information and social privacy of OHCs. In summary, people living with IBD who have stronger social privacy concerns are more likely to take privacy enabling action, such as audience management techniques and self-censorship.

With evidence from Study 1 suggesting that people do not take as many mitigating actions, if any, in accordance with their information privacy, Study 3 aimed to provide an opportunity for participants to learn about available tools and services. While the resource did not have a significant impact on perceived self-efficacy and control, it is possible that a lack of experience applying any of the tools contributes to a lower sense of *mastery*. Furthermore, currently with opaque data processing practices (Hargittai & Ellison, 2016), it will always be difficult to understand the causal relationship between mitigating action and future privacy risks for people living with a chronic illness (Brady et al, 2016). What this highlights is that although attention should be made to educate individuals about information privacy, as discussed in Study 2, governments and social media platforms should be working towards improving people's information privacy so that there is more transparency to support people's understanding.

People want to learn more

This thesis suggests there may be a growing appetite for learning about online privacy within the IBD community and a shift in attitudes towards information privacy. Though there is the indication that people are thinking more about their information privacy and might be taking some mitigating steps to take more control, there was an appetite for people to learn, suggesting not only that attitudes might be changing, but that people want to have more knowledge. Just as participants in Study 1 asked questions to the researcher about what happens and how they can protect themselves, community leaders in Study 2 believed that it is important for people engaging with social media platforms to self-disclose health information, to be more aware of the risks involved.

It has been routinely concluded that with more understanding of how data is collected and processed, individuals have a better capacity to identify risks and how they can be mitigated (Sideri et al, 2019; Vanderhoven et al, 2014). Having more knowledge moves people away from irrationally applying the privacy calculus, that suggests privacy is a trade-off based on cognitive bias, and towards a dual risk privacy calculus.

It is optimistic to believe, however, that people will ever act rationally when making decisions, particularly around social media platform use (Barth et al, 2017). Indeed, people act on their emotions and in the case of people living with a chronic health condition, the need to seek information and support from others is a more pressing priority over the consideration of their long-term privacy preferences as discussed in Study 2. Again, this supports the Functional Model of Self-Disclosure which contends that the motivations will shape the methods users' self-disclosure on social media. Furthermore, it also supports previous research by Acquisti (2004) who found that short term gratifications are strong influencers of disclosure. It also supports the temporal discounting of long-term risks as discussed by Hallam and Zanella (2016).

One proposed intervention to support people's privacy, from Study 2, was an awareness raising campaign and resource, giving people the information that they need in order to take more control of their personal information flows. While an educational intervention could have been used to measure data literacy proficiencies, it was deemed more useful to the community to understand whether people with a chronic health condition, using social media platforms, would be willing to actively learn more about their online privacy. There was evidence to suggest from Study 1 that there was a desire to learn more about what information is collected and how individuals can take more control. For instance, throughout one interview, a participant was browsing through their device's privacy settings discovering controls and permissions that they were otherwise unaware of. With the agreement by community leaders to proceed with an intervention study (Study 3), in which they supported its design through PPI methods.

Results from Study 3 demonstrated that 74.4% of people with IBD reported that they wanted to learn more; 65.6% of these individuals then continued to engage with the Health Privacy Toolkit resource. The proportion of people from the IBD and Healthy groups, accessing the Health Privacy Toolkit was similar at 49% and 50%, respectively. Firstly, this suggests that given the opportunity, there is a significant amount of people who wants to actively learn more, regardless of their health status. This study also indicated that perception of time was the most significant factor in preventing people from learning more in this particular study.

With half of the study respondents actively choosing to engage with the online resource, there is clear justification to conclude that given the opportunity, people do want to gain new knowledge about the context they share information in. However, the findings from this thesis suggests that regardless of health status, there is a general desire to learn more about online privacy, given the opportunity.

7.1.2.5 Awareness Raising Impact on Concern and Perceived Control

This thesis shows that amongst the sample of people living with IBD in Study 3 (n=98), there is a willingness and interest in learning more about the digital economy. Analysing pre and post intervention surveys in Study 3, a key finding suggests that with more awareness comes increased concern, decreased perceptions of self-efficacy, and trust. For people who reported to have more exposure to media stories pertaining to data misuse, they also demonstrated a higher concern and lower sense of control over their information. The pattern was observed again comparing people's perceptions after their interaction with the Health Privacy Toolkit.

A key design challenge for the online resource was to ensure that visitors had access to privacy enabling technologies that they could use. Despite 65.2% (n=15) of IBD participants in Study 3 having reportedly engaged with the tools page, there was little effect on people's self-efficacy. Indeed, there are a number of factors that could contribute to this; firstly, accessing the resource, which was perceived by participants to be rich with information, could be an information overload. Indeed, longitudinal access to the resource may be worthwhile, which supports Vanderhoven's study (2014) that identified how a longer-term intervention may yield 'stronger' results to self-efficacy, which was confirmed by Sideri et al (2019). Bandura (2008) argues that the characteristic of mastery is practiced over time through experiencing successes as well as failure. Therefore, after having one or two interactions with a resource to support people's knowledge in different ways to protect information privacy, participants did not have the time to practice any new skills before the exit survey. In addition, given that few participants across the studies could identify information privacy breaches, it may be difficult for participants to identify whether their actions have been successful or not against their personal information privacy concerns.

Secondly, there are methodological implications such as time constraints that would limit a person's ability to process information and explore the tools available; having too much information to effectively process subject individuals to bounded rationality, which can have an irrational impact on information making, relying on heuristics (Barth et al, 2017). While there were participant retention challenges in Study 3, the interview data from Study 1 further qualifies people's feelings of low control and the powers held by social media platforms (Hargittai & Ellsion, 2016). A more detailed methodological discussion can be found in Section 7.3 of this chapter.

In addition to the characteristic of mastery, self-efficacy is also improved with social modelling and persuasion (Bandura, 2008). This means that if there is a more normative culture of information privacy behaviour and individuals can observe the benefits others have experienced, then this will have a positive influence on their personal beliefs of control. Again, to examine this in future works a much more longitudinal study would need to be conducted.

7.2 Implications and Impacts

The overall findings of this thesis and their position within the current literature around online privacy and online health communities present opportunities for future research and practical application. The following subsections will discuss the implications for future work.

7.2.1 Academic Contribution

This thesis presents new findings for the social psychology discipline with new insights into how privacy impacts on social media behaviours in the health communities' context.

In particular, this thesis presents new insights into how people living with a chronic health condition consider both their information and social privacy concerns. Throughout the studies, participants demonstrated how social privacy is often considered as part of engaging in health discourse on social media. Participants consider their online identity and impression management when deciding which context they wish to self-disclose and to what extent. This research highlights that people living with IBD carefully consider their audience management which builds on Basarova & Choi's Functional Model of Self-Disclosure (2014). While Basarova and Choi's research (2014) explores general use of Facebook communications, this thesis examined three social media platforms through a chronic health lens. Motivations around social privacy controls indeed centre around identity management and self-presentation, however people's motivations play a vital role to understand why some people are much more public about sharing intimate information than others.

The methods individuals apply when managing their contextual integrity is nuanced and individual, based on their personal preferences, previous experiences and their motivations. While non-disclosure is one way an individual can retain their contextual integrity, this thesis' exploration of how social privacy can be maintained with health self-disclosures rejects the theory that self-disclosure is a predictor for privacy concern. This thesis presents how the privacy paradox (Acquisti, 2004; Barth & Jong, 2017) is not clearly evident through a social privacy lens in online health communities.

This thesis presents how people living with IBD, a chronic health condition, also perceive information privacy. Previous literature in IBD communities have paid little focus to the influence of privacy in health discourse online. This thesis presents new insights into how information privacy is difficult for individuals to understand, with some participants using simplistic mental models to explain that social media platforms collect everything. For some there is a misconception that social privacy controls, such as privacy settings and closed Facebook Groups, will have an impact on the extent social media platforms will collect information.

Knowledge and self-efficacy have been identified as key factors to support participants being able to better understand the risks and their ability to take control over their contextual integrity. In the first and second study, participants reported on the power imbalances between individuals and large social media corporations, understanding that to have a service for free, there is a trade-off. The thesis presents how while people living with IBD use social media to share health information, they present information privacy concerns and a low sense of self-efficacy. While a knowledge awareness intervention was tested, this thesis concludes that longer term solutions are required to support people's mastery and provide encouragement to act on their privacy concerns.

Finally, this thesis explored the relationship between social media platform features and affordances through an adapted SCENA model (Merolli et al, 2014). This thesis identified that while social media platforms share homogenous features, and to some extent the same affordances, the ways in which the features interact with one another and are presented to users impacts on their uses and outcomes. One example of this is the encouragement of direct messaging on Instagram as the default reply to Instagram Stories. The encouragement of direct messaging, and the social privacy boundaries that encompass one-to-one conversations, again provides a sense of safety in self-disclosing more intimate health information than perhaps in a more public setting such as a post or story. This thesis therefore contributes to the knowledge of how technological affordances and social affordances intersect and impact on a user's overall experiences and imagined affordances. While the technologies mediate online health communities and health discourse, social factors such as group dynamics will inevitably play a vital role in how far a person interprets the beneficial outcomes of using a technology.

7.2.2 Future Academic Work

Researchers who employ netnography and content analysis techniques in public online settings should be considerate of the nature of people's self-presentation behaviours. In addition to reviewing what is publicly available, researchers should consider what is also hidden in restricted communities and in direct messages.

IBD was identified as a condition that has associated stigma associated, including embarrassing stigmatising symptoms, such as diarrhoea and incontinence. However, over the past few years with different awareness efforts from the media, celebrities and charities, there is an argument that IBD carries less stigma than other conditions, such as mental health. Therefore, while the findings about how individuals living with IBD perceive their social and information privacy may be generalisable across other conditions, the author would urge researchers to explore this exploration of privacy with other groups.

The Health Privacy Toolkit serves as a practical output that can be shared with OHCs more widely. Participants reported that with more awareness, the lower self-efficacy they feel; however, future studies should explore whether over time, and with increased exposure to privacy enhancing tools, if individuals become more actively involved in behaving according to their information privacy concerns and improve their mastery (Bandura, 2008). Indeed, previous research by Sideri et al (2019) that explored long term privacy literacy found that students reporting more behaviour change in a formal learning environment; however, future research should explore the long-term impact of informal learning experiences.

While the focus of this thesis has been on the IBD OHCs, the Health Privacy Toolkit can be used or adapted (with creative commons licensing) for other health conditions. Although the literature indicates that some people with IBD can feel stigmatised, there are arguably other illnesses that hold greater stigma including HIV and mental health conditions. Future research can explore whether there are differences in social and information privacy concerns between different chronic and acute conditions.

As Study 3 indicated that after people were exposed to the social media post, they were likely to revisit privacy settings, future research can focus on how a social media campaign impacts on people's privacy preferences over time. A study could include a pre-survey, asking them to follow a specific account that would share short extracts from the Health Privacy Toolkit over a period of time.

A mixed methods approach could be used to assess the post’s engagement as well as seeing whether participants felt that having exposure through their social media experience was useful, engaging and impactful. Having more distance between the pre-survey and viewing the awareness raising content may help mitigate response bias.

One focus group in Study 2 represented staff from a children’s IBD charity. While this thesis focused on adults accessing social media for health-related support, the quality of life and coping mechanisms for young people coming to terms with managing their illness is extremely important. Future studies can explore a multi-stakeholder approach, that includes the perspectives of young patients, their carers, and charity staff to understand their concerns using the internet for support and how to safely encourage peer-to-peer support.

While this research has contributed a rich account of how people with IBD use social media platforms, new research opportunities have been identified; online support for young people has yielded low research output (Szeto et al, 2018). Secondly, as a result of a recurring observation through recruitment as well as verbally articulated by participants in Studies 1 and 2, future studies should further explore the distribution of men in OHCs, in comparison to the incident rates of the disease across gender.

Indeed, it is worth mentioning that the write up of this thesis has taken place during the Covid-19 pandemic. With countries entering different degrees of lockdown, millions of people all over the world were given the strong message to ‘stay at home’. This meant that technology use and screen time increased as it has been used as a means for people to connect with colleagues, teachers, family and friends. Beyond this, technologies were developed to understand the spread of the virus and provide more data so that the general public can act safely and accordingly. Urgent research of how people’s attitudes towards self-disclosed health information should be conducted to see if under a global crisis, people’s attitudes towards their personal information are more altruistic. Furthermore, longitudinal studies should compare the attitudes during the pandemic and years after the virus is contained to understand whether any changes are long term.

With countries going into different degrees of lockdown and searching for ways in which technology can support the testing, tracing, and reporting of the virus, in the interest of public health, there is an abundance of scope for how findings from this thesis ask new questions.

While it was not explored specifically in this thesis, there is an opportunity for further research to explore how the social norms of sharing intimate health information online establishes a sense of safety. And therefore examining the extent to which the Theory of Planning Behaviour / Reasoned Action can help impacts on how the social context and the exposure to health disclosures shape attitudes of perceived safety (Fishbein & Ajzen 1975).

7.2.3 Individual and Organisational Impacts

In terms of the broader impacts as a result of this PhD exploration; the researcher engaged with different stakeholders throughout the process, engaging with community leaders and charities. While they did not contribute to the research, the author was invited to share research findings with Crohn's and Colitis UK, the UK's largest charity for IBD. In addition, CICRA, the children's IBD charity invited the author to continue the research in the context of children and parents. This therefore demonstrates that this area of research can have impact on strategic decisions by charitable organisations about how they support people living with IBD.

On an individual basis, the practical output from this research is publicly available to those living with IBD. Individuals who participated in Study 3 have direct access to this resource should they wish to build their knowledge further. It should be remarked that a key finding from this thesis is the requirement for a long-term strategy to increase exposure to social and information privacy literacy. Indeed, the process of recruitment and participation in all of the studies has in and of itself enabled more exposure and discussion around privacy, arguably making the research an intervention.

7.2.4 Practical Output

The most immediate practical outcome of this thesis is the Health Privacy Toolkit resource, that was inspired by and adapted from the LSE myprivacy.uk

(Livingstone, 2019). Its purpose is to bring a balanced view of how information is collected and processed by online services; case studies of data misuses; and, available tools that people can use to take more control over their personal information flows, while still being able to access health-related online support. Designed in response to Study 2 with Patient and Public Involvement, participants in Study 3 made useful suggestions to increase user engagement in the future. With complex subject matter, it is critical that the information presented is clear and understandable. While some of the requests are actionable in the short term, other comments require more resources the create visual elements. When the Health Privacy Toolkit satisfies the needs of people in the community, it can be promoted widely across online health communities of different illnesses.

There is an opportunity to further develop the service through a UX (user experience) lens. As part of this approach, the website would be iteratively tested with users with different accessibility needs (motor, cognitive, sight and deafness) as well as those with particularly low digital skills (Putnam et al, 2012). This would make great leaps towards making the Health Privacy Toolkit more accessible. In addition to ensuring better accessibility, moderated usability testing would enable us to understand how users interact with the website and what areas are particularly unclear (Marsh, 2018). While navigation was not brought up as an area of focus from study 3, a card sorting exercise could be employed to redesign the navigation and content in a more user centred way (Marsh, 2018).

Indeed, while this thesis focused on bringing learning opportunities to individuals to take more responsibility over their information privacy, it is important to recognise that online privacy should go beyond a rational actor approach. The digital economy is multi-stakeholder and while improving self-efficacy is important, discussions in Study 2 recognised the need for widespread privacy enhancing changes. GDPR, California Privacy and the response to the Cambridge Analytica scandal have made positive steps forward, however, there are still questions over how data is processed and effectively communicating that with end users. A suggestion by community leaders in Study 2 was the gatekeeping of data in Facebook Groups, satisfying protections from non-members as well as Facebook being unable to use the information that is shared within them. Indeed, this raises issues around Facebook's responsibility for detecting hate-speech, suicide risks, terrorism and other crimes. However, with participants in Study 1 unhappy with Facebook processing Group data, when it is in seemingly private space, there is potential for this area to be explored.

An important point echoed by community leaders is that the lack of transparency by online companies and the challenges in finding causal links between online behaviours and impacts, raises challenges to communicate risks to the general public. While it might be the case that there are few risks to people living with chronic illnesses, with a lack of transparency, there are still uncertainties. Further still, attitudes towards privacy are not fixed, but are constantly evolving in response to new technologies and the contexts in which they impact.

Previous research has demonstrated a digital divide, indicating that some demographics are less privacy literate, including those who are not as educated, female, older people, and minorities (specifically Black people) are negatively associated with privacy literacy (Epstein and Quinn, 2020; van Deursen and van Dijk, 2015). Epstein and Quinn (2020) challenge inequalities of privacy literacy and its impacts on privacy behaviours, reporting that “doing without understanding may reify existing power structures, likely reinforcing the relatively powerless status of already marginalized groups,” (p. 9). Since 2013, children in the UK follow a computing curriculum that explores identity management and privacy[22] (Department for Education, 2013), however as online services, regulation, and technologies change there is need for lifelong learning resources to support people to ‘do with understanding’. To help close the digital divide, it is important that people who are not at school, and are particularly vulnerable, should have the opportunity to learn about online privacy.

Indeed, understanding the complexities of the digital economy is not straight forward and privacy enhancing technologies such as VPNs, cookie blockers and email encryption are inconvenient, sometimes difficult to use, and not always free. Although privacy enhancing technologies are designed to help empower

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[22] Though it is not clear what is meant by ‘privacy’

individuals, they can be burdensome and can further contribute to the digital divide with unequitable opportunities to learn and access such tools (Matzner et al, 2016).

7.3 Methodological Reflections

While this thesis focused on online communities, the empirical research took place in face-to-face as well as in online settings. In Study 1, semi-structured interviews were conducted through VoIP and phone calls; Study 2, focus groups were conducted in physical locations; and, online surveys were used in Study 3. This section will reflect on the methodological decisions made throughout this research, drawing on the challenges and implications.

This thesis has adopted a responsible research innovation approach, as set out by the European Union and supported by EPSRC. It embodies the objective of 'science with and for society' where it has involved community stakeholders throughout the research process. Findings from each study shaped the design and research focus of the subsequent studies. Taken together, the three studies have presented a rich account for how privacy is perceived and acted upon in the IBD online health communities using social media. This thesis took a methodologically pragmatic approach to gain new insights into OHCs whilst maintaining ethical standards to limit any anticipated adverse impacts.

Taking the position that participants should be active contributors, making a conscious choice to take part and give consent, there were particular challenges around recruitment. With the online communities geographically distributed over the world and across different platforms, the ability to employ random sampling techniques would have been extremely inefficient and encroaching on people's privacy.

In this thesis, three social media platforms were investigated, each with different architectures and protocols that impacts on the exposure of recruitment posts. While Twitter's hashtags and retweeting components meant that 42.1% (n=16) were recruited for Study 1 and 51% (n=50) for Study 3, recruitment on Facebook was particularly slow with 23.7% (n=9) and 6.1% (n=6), respectfully. One reason for this is that thousands of people use Facebook Groups to access support and while the researcher herself legitimately can join these groups because of her shared experience with IBD, Group Admins operated as gate keepers. Each group has its own established set of rules and etiquette, which community leaders referred to in Study 2, that controls the amount of advertising posts shared in a community. Of course, it is welcoming to have responsible volunteers to ensure that Facebook Groups are a safe space for support. In this thesis two Groups in Study 1 approved the study to be shared, while in Study 3 there were three. Although it might be as a result of the algorithm that determines the ordering of posts on groups, the recruitment rate for Facebook was lowest across these studies. Careful consideration should be given to the recruitment of participants through Facebook Groups, with future researchers being respectful of the community guidelines created by the admins (Coulson, 2015). In this research, advertising research posts were only shared in Facebook Groups with consent from the admins, providing them with access to the information sheets to determine the appropriateness of the study's exposure to their members. It should be noted that although the researcher herself has a diagnosis of IBD, these ethical procedures were still followed and respected; five admins declined Study 3 to be shared in their groups.

Another challenge, with regards to open recruitment for interviews and online surveys is that convenience sampling of self-selecting participants might not be representative of the population (Coulson, 2015). Participants in Study 1 disproportionately represented people living with Crohn's disease over UC; current literature estimates that there are more people living with UC than Crohn's disease (Loftus et al, 2007; Ng et al, 2017). In Study 3, the demographic information similarly shown an imbalance between gender, with 74.2% respondents representing people identifying as women; yet, gender was more evenly distributed in Study 1. Participants in Study 1 and Study 2 discussed their own observations of how they perceive fewer men actively participating online, regardless.

The Code of Human Research Ethics (2010) argues that the observations of public behaviour should only take place in settings whereby the participant expects to "be observed by strangers" (p.25). While there is a multitude of Twitter-based social media research, due to its 'public' nature, this thesis had a broader enquiry, exploring platforms that are perceived more private, thus immediately encroaching issues of observing behaviours. Secondly, participants in Study 1 who used Twitter, understood that they tweet publicly and cannot be in control of who sees and uses that information. However, the point that privacy preferences change over time is significantly important. The persistent nature of asynchronous technologies means that self-disclosed information is available indefinitely, unless an account has been closed or tweets deleted. People forget what they have shared in the past and might feel uncomfortable with that information being used for purposes without their consent. Furthermore, the recruitment of active participants enables a dialogue between researcher and participants which means that withdrawal of participation was possible.

While online behaviours could have been observed, this research enquiry focused on perceptions and experiences, rather than online disclosure. Taking the position that people disclose information in specific contexts, for a clear purpose, the collection of behavioural information was considered to jeopardise contextual integrity of these communities.

Following the guidance in the Responsible Research and Innovation, the researcher engaged with key stakeholders in the community to create a tool that served to benefit it. After having had critical and involved discussions throughout Study 2, PPI was adopted to ensure that the Health Privacy Toolkit was informative, balanced, and ethical. The PPI group was made up of participants from Study 2 and were liaised with through email. The aim was to raise awareness of data collection and processing practices, and privacy enhancing tools. The PPI group were instrumental in making sure that the message communicated to participants in Study 3 (and people more widely) is clear, balanced, and does not intentionally engender fear that might prevent people from seeking support online in the future. Furthermore, the resources that were approved for Study 3 were also critiqued by respondents participating in the study. This collective feedback provides clear instruction to make the resource more accommodating and supportive for its use by the communities more widely.

7.4 Lived Experience

As mentioned in the introductory chapter of this thesis, the author has a lived experience of IBD.

There were certainly some benefits of having a shared experience; having some knowledge of the prevalent Facebook communities and the hashtags commonly used, meant that recruitment was not particularly challenging. Secondly, while there is no comparison, having a shared experience was useful in being able to justify the researcher's intentions for this research in the community. It helped to level the power dynamic between researcher and participant by having some shared experience and understanding.

Ethically speaking, while it is a researcher's responsibility to do no harm on their participants, having a shared lived experience as the participants brought some unexpected challenges for the researcher. Particularly during Study 1, as a means to allow the participants to relax into speaking in a research setting, people shared their experiences living with IBD. As the researcher has not had any personal experience of having surgery and therefore no experience of living with a temporary or permanent stoma, some people's stories were particularly challenging for the researcher to process on a personal level. Recognising that the researcher was carrying an additional emotional burden, she was fortunate enough to have a strong personal and professional network through which she was able to decompress how the stories were making her feel.

While there were some challenges during the analysis process of Study 1, overall, the researcher still felt independent from the IBD communities from being a lurker themselves and not an active contributor. On balance, having the lived experience positively impacted this PhD and its impact on the community, having access to two national charities.

7.5 Concluding Remarks

In summary, this thesis presents an in-depth view of the role of privacy in online health communities using social media. Specifically focusing on Inflammatory Bowel Disease as an exemplary group, this research explored privacy through a dual lens of social and information privacy. The results have shown that social and information privacy are thought about and responded to differently. However, over the course of this research enquiry there is evidence to indicate that people living with IBD may be paying more attention to how their data is used by platforms.

The mixed methods approach to this thesis presented new insights into how people use contemporary social media platforms to engage with the IBD communities distributed over Facebook, Twitter and Instagram. The findings from the studies taken together indicate that people IBD often use multiple platforms which yield different experiences but similar affordances. People consciously negotiate their social privacy, recognising who they want to share information about their health and demonstrating digital literacy skills in the use of different functionality to retain contextual integrity.

With regards to information privacy, there remains the challenge to improve people's self-efficacy, so that they feel empowered to take meaningful control over their data by mastering their skills. This PhD focused on supporting individual agency as a short-term solution to safeguard people's information privacy from context collapse and data misuse. Although there was evidence to indicate that people demonstrate more of an awareness of privacy issues in society, even with access to privacy enhancing tools, individuals express feelings of disempowerment. It is clear that although more measures can and should be taken to improve lifelong learning data literacy campaigns, that there are still widespread changes that could significantly improve people's information privacy in a convenient way.

It is hoped that the findings from this thesis encourages future privacy perception research to explore the phenomenon through a dual lens: it is clear that there are still disparities in how they are understood and responded to by people, even those who are sharing more sensitive information. It also contributes new knowledge around information privacy awareness and the impact on self-efficacy, indicating that there are more opportunities in this field to support individuals and understand the connection between awareness, behaviours, and perceived control. Finally, beyond providing the basis for future studies, this research has created a learning asset which is open for use by online communities and reuse with other illnesses.

BIBLIOGRAPHY

Abildgaard, J. S., Saksvik, P., & Nielsen, K. (2016). How to measure the intervention process? An assessment of qualitative and quantitative approaches to data collection in the process evaluation of organizational interventions. Frontiers in Psychology. https://doi.org/10.3389/fpsyg.2016.01380

Acquisti, A. (2004). Privacy in Electronic Commerce and the Economics of Immediate Gratification, 21–29.

Acquisti, A., & Grossklags, J. (n.d.). Privacy and Rationality in Individual Decision Making.

Acquisti, A., Brandimarte, L., & Loewenstein, G. (2015). Privacy and human behavior in the age of information. Science. https://doi.org/10.1126/science.aaa1465

Ajzen, I. (1991). Theory of Planned Behavior. ORGANIZATIONAL BEHAVIOR AND HUMAN DECISION PROCESSES, 50(1), 179–211.

Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2016). Long-term condition self-management support in online communities: A meta-synthesis of qualitative papers. Journal of Medical Internet Research, 18(3), 1–17. https://doi.org/10.2196/jmir.5260

Anderson, C. L., & Agarwal, R. (2011). The digitization of healthcare: Boundary risks, emotion, and consumer willingness to disclose personal health information. Information Systems Research, 22(3), 469–490. https://doi.org/10.1287/isre.1100.0335

Angwin, J. (2014). Dragnet Nation: A Quest for Privacy, Security, and Freedom in a World of Relentless Surveillance. Colorado Technology Law Journal.

Angwin, J., & Stecklow, S. (2010). “Scrapers\” Dig Deep for Data on Web. Wall Street Journal.

Angwin, J., Larson, J., Mattu, S., & Kirchner, L. (2016, May 23). Machine Bias — ProPublica. Retrieved September 4, 2020, from https://www.propublica.org/article/machine-bias-risk-assessments-in-criminal-sentencing

Arnold, A. (2018, July 29). Consumer Trust In Social Media Is Declining: Here’s How Brands Should Change Their Strategies. Forbes. Retrieved from https://www.forbes.com/sites/andrewarnold/2018/07/29/consumer-trust-in-social-media-is-declining-heres-how-brands-should-change-their-strategies/

Ashley, D., & Orenstein, D. M. (2005). Sociological Theory: Classical Statements, 6th edition. Pearson.

Ashworth, L., & Free, C. (2006). Marketing dataveillance and digital privacy: Using theories of justice to understand consumers’ online privacy concerns. Journal of Business Ethics. https://doi.org/10.1007/s10551-006-9007-7

Bai, W., Kim, D., Namara, M., Qian, Y., Kelley, P. G., & Mazurek, M. L. (2016). An inconvenient trust: User attitudes toward security and usability tradeoffs for key-directory encryption systems. In SOUPS 2016 - 12th Symposium on Usable Privacy and Security.

Bandura, A., & Lopez, S. J. (2008). An agentic perspective on positive psychology. Positive Psychology: Exploring the Best in People, Vol 1: Discovering Human Strengths.

Bansal, G., Zahedi, F. M., & Gefen, D. (2010). The impact of personal dispositions on information sensitivity, privacy concern and trust in disclosing health information online. Decision Support Systems, 49(2), 138–150. https://doi.org/10.1016/j.dss.2010.01.010

Barth, S., & de Jong, M. D. T. (2017). The privacy paradox – Investigating discrepancies between expressed privacy concerns and actual online behavior – A systematic literature review. Telematics and Informatics, 34(7), 1038–1058. https://doi.org/10.1016/j.tele.2017.04.013

Baumgart, D. C., & Carding, S. R. (2007). Inflammatory bowel disease: Cause and immunobiology. The Lancet, 369, 1627–1640.

Bazarova, N. N. (2012). Contents and contexts: Disclosure perceptions on facebook. In Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW (pp. 369–372). https://doi.org/10.1145/2145204.2145262

Bazarova, N. N., & Choi, Y. H. (2014). Self-Disclosure in Social Media : Extending the Functional Approach to Disclosure. Journal of Comunication. https://doi.org/10.1111/jcom.12106

BBC - BBC launches Own It app - providing a helping hand to young people, online - Media Centre. (2019, September 18). Retrieved July 9, 2020, from https://www.bbc.co.uk/mediacentre/latestnews/2019/own-it

BBC. (2017). The selfie campaign urging you to “Get Your Belly Out.”

Bellis, M. (2020, February 6). The History of Facebook and How It Was Invented. Retrieved June 27, 2020, from https://www.thoughtco.com/who-invented-facebook-1991791

Bernardi, R. (2016). How Do Online Communities of Patients Aggregate on Twitter ? An Affordance Perspective, (Tempini 2015), 1–19.

Bernklev, T., Jahnsen, J., Henriksen, M., Lygren, I., Aadland, E., Sauar, J., … Moum, B. (2006). Relationship between sick leave, unemployment, disability, and health-related quality of life in patients with inflammatory bowel disease. Inflammatory Bowel Diseases. https://doi.org/10.1097/01.MIB.0000218762.61217.4a

Bharadwaj, P., Pai, M. M., & Suziedelyte, A. (2017). Mental health stigma. Economics Letters, 159, 57–60.

Bhattacherjee, A. (2002). Individual Trust in Online Firms: Scale Development and Initial Test. Journal of Management Information Systems, 19(1), 211–241. https://doi.org/10.1080/07421222.2002.11045715

Blank, G., & Dutton, W. H. (2012). Age and trust in the internet: The centrality of experience and attitudes toward technology in britain. Social Science Computer Review. https://doi.org/10.1177/0894439310396186

Bone, J., Emele, C. D., Abdul, A., Coghill, G., & Pang, W. (2016). The social sciences and the web: From 'Lurking' to interdisciplinary 'Big Data' research. Methodological Innovations, 9, 205979911663066. https://doi.org/10.1177/2059799116630665

Boyd, D. (2008). Taken Out of Context: American Teen Sociality in Networked Publics. SSRN Electronic Journal. https://doi.org/10.2139/ssrn.1344756

Boyd, D. (2012). Networked privacy. Surveillance and Society, 10(3–4), 348–350.

Boyd, D. (2014). It's complicated: The social lives of networked teens. It's Complicated: The Social Lives of Networked Teens. https://doi.org/10.1080/08838151.2014.935944

Boyles, J. L., Smith, A., & Madden, M. (2012, September 5). Privacy and Data Management on Mobile Devices | Pew Research Center. Retrieved June 27, 2020, from https://www.pewresearch.org/internet/2012/09/05/privacy-and-data-management-on-mobile-devices/

Brady, E., Segar, J., & Sanders, C. (2016). "I always vet things": Navigating privacy and the presentation of self on health discussion boards among individuals with long-term conditions. Journal of Medical Internet Research, 18(10). https://doi.org/10.2196/jmir.6019

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. Health Communication, 11(2), 123–151. https://doi.org/10.1207/s15327027hc1102_2

Britt, R. K. (2017). Online Social Support for Participants of Crohn's and Ulcerative Colitis Groups. Health Communication, 32(12), 1529–1538. https://doi.org/10.1080/10410236.2016.1234539

Burke, S. (2000). Delos: Investigating the notion of privacy within the ancient Greek house. In Leicester, School of Archaeology and.

Burr, N. E., Lord, R., Hull, M. A., & Subramanian, V. (2019). Decreasing Risk of First and Subsequent Surgeries in Patients With Crohn's Disease in England From 1994 through 2013. Clinical Gastroenterology and Hepatology. https://doi.org/10.1016/j.cgh.2018.12.022

Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. Psychological Bulletin. https://doi.org/10.1037/h0046016

Carroll-Meehan, C. (2020, August 19). A levels: government's U-turn has left universities in the lurch. Retrieved September 4, 2020, from https://theconversation.com/a-levels-governments-u-turn-has-left-universities-in-the-lurch-144763

Carter, B., Qualter, P., & Dix, J. (2015). Social relationships , loneliness and adolescence : The potential for disruption by chronic illness. Journal of Child Health Care, 19(4), 421–422. https://doi.org/10.1177/1367493515618477

Chaffey, D. (2020). Global social media research summary 2020. Retrieved June 14, 2020, from https://www.smartinsights.com/social-media-marketing/social-media-strategy/new-global-social-media-research/

Chalklen, C., & Anderson, H. (2017). Mothering on facebook: Exploring the privacy/openness paradox. Social Media and Society, 3(2). https://doi.org/10.1177/2056305117707187

Chang, D., Krupka, E. L., Adar, E., & Acquisti, A. (2016). Engineering information disclosure: Norm shaping designs. Conference on Human Factors in Computing Systems - Proceedings, 587–597. https://doi.org/10.1145/2858036.2858346

Cheung, W. Y., Garratt, A. M., Russell, I. T., & Williams, J. G. (2000). The UK IBDQ-A British version of the inflammatory bowel disease questionnaire: Development and validation. Journal of Clinical Epidemiology. https://doi.org/10.1016/S0895-4356(99)00152-3

Choi, H., Park, J., & Jung, Y. (2018). The role of privacy fatigue in online privacy behavior. Computers in Human Behavior. https://doi.org/10.1016/j.chb.2017.12.001

Choi, M. J., Kim, S. H., Lee, S., Kwon, B. C., Yi, J. S., Choo, J., & Huh, J. (2017). Toward predicting social support needs in online health social networks. Journal of Medical Internet Research, 19(8), 1–10. https://doi.org/10.2196/jmir.7660

Cinnamon, J. (2017). Social injustice in surveillance capitalism. Surveillance and Society. https://doi.org/10.24908/ss.v15i5.6433

Cinnamon, J. (2017). Social injustice in surveillance capitalism. Surveillance and Society. https://doi.org/10.24908/ss.v15i5.6433

Clarke, R. (1988). Information technology and dataveillance. Communications of the ACM. https://doi.org/10.1145/42411.42413

Clarke, R. (2003). Dataveillance – 15 Years On. Privacy Issues Forum.

Cohen, C. (2014). The most inspiring bikini photos you'll see this summer. Telegraph.

Coulson, N. (2015). Patterns of engagement with inflammatory bowel disease online support groups: Comparing posters and lurkers. Gastroenterology Nursing, 38(5), 348–353. https://doi.org/10.1097/SGA.0000000000000131

Coulson, N. S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. JRSM Short Reports, 4(8), 2042533313478004. https://doi.org/10.1177/2042533313478004

Coulson, N. S. (2015). Exploring patients' engagement with web-based peer support for Inflammatory Bowel Disease: forums or Facebook? Health Psychology Update, 24(2), 3–9. Retrieved from http://www.healthpsychologyconsultancy.co.uk/documents/Healthbaselinecomparisontheory-Adjustmenttorheumatoidarthritis.pdf

Coulson, N. S. (2015). Online Research Methods for Psychologists. London: Palgrave.

Coulson, N. S. (2017). Affordance theory can help understanding of individuals' use of online support communities. British Journal of Health Psychology, 22(3), 379–382. https://doi.org/10.1111/bjhp.12247

Coulson, N. S., Buchanan, H., & Aubeeluck, A. (2007). Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. Patient Education and Counseling, 68(2), 173–178. https://doi.org/10.1016/j.pec.2007.06.002

Crawford, K., & Schultz, J. (2014). Big data and due processes: Toward a framework to redress predictive privacy harms. Public Law & Legal Theory Research Paper Series. Retrieved from http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2325784

Crohn's & Colitis Foundation of America. (2014). The Facts About Inflammatory Bowel Diseases. Inflammatory Bowel Diseases. https://doi.org/10.1097/00054725-199606000-00001

Crohn's and Colitis UK. (2017, June). What are the symptoms? | Crohn's & Colitis UK. Retrieved June 29, 2020, from https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/what-are-the-symptoms

Crohn's and Colitis UK. (2017, May). Employment & IBD: a guide for employees | Crohn's & Colitis UK. Retrieved June 29, 2020, from https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/employment-ibd-a-guide-for-employees

Culnan, M. J., & Armstrong, P. K. (1999). Information Privacy Concerns, Procedural Fairness, and Impersonal Trust: An Empirical Investigation. Organization Science, 10(1), 104–115. https://doi.org/10.1287/orsc.10.1.104

Curran, D. (2018). Are you ready? {This} is all the data {Facebook} and {Google} have on you. The Guardian, p. Curran, Dylan. Retrieved from https://www.theguardian.com/commentisfree/2018/mar/28/all-the-data-facebook-google-has-on-you-privacy

Cutrona, C. E., & Suhr, J. A. (1992). Controllability of Stressful Events and Satisfaction With Spouse Support Behaviors. Communication Research. https://doi.org/10.1177/009365092019002002

D'Ignazio, C., & Bhargava, R. (2015). Approaches to Building Big Data Literacy. In Bloomberg Data for Good Exchange Conference.

D'Ignazio, C., & Bhargava, R. (2015). Approaches to Building Big Data Literacy. In Bloomberg Data for Good Exchange Conference.

Daniel, J. (2001). Young adults' perceptions of living with chronic inflammatory bowel disease. Gastroenterology Nursing, 25(3), 83–94.

Data Protection Authority. (2015, November 10). The judgment in the Facebook case | Data Protection Authority. Retrieved June 27, 2020, from https://www.dataprotectionauthority.be/news/judgment-facebook-case

Debatin, B., Lovejoy, J. P., Horn, A. K., & Hughes, B. N. (2009). Facebook and online privacy: Attitudes, behaviors, and unintended consequences. Journal of Computer-Mediated Communication, 15(1), 83–108. https://doi.org/10.1111/j.1083-6101.2009.01494.x

Denzin, N. K. (1978). The Research Act: A theoretical orientation to sociological methods. In Symbolic Interaction: A Reader in Social Psychology. https://doi.org/10.2307/2092290

Department for Education. (2013). Computing programmes of study: key stages 3 and 4 National curriculum in England Purpose of study. Retrieved from www.nationalarchives.gov.uk/doc/open-

Dewey, C. (2016). 98 personal data points that Facebook uses to target ads to you. Washington Post.

Dominelli, A. (2003). Web Surveys—Benefits and Considerations. Clinical Research and Regulatory Affairs, 20(4), 409–416.

Dwork, C. (2006). Differential Privacy BT - Automata, Languages and Programming. In Automata, Languages and Programming.

Edelmann, N. (2013). Reviewing the definitions of "lurkers" and some implications for online research. Cyberpsychology, Behavior, and Social Networking. https://doi.org/10.1089/cyber.2012.0362

Ellison, N. B., Steinfield, C., & Lampe, C. (2010). Connection strategies: Social capital implications of Facebook-enabled communication practices. New Media and Society, 13(6), 873–892. https://doi.org/10.1177/1461444810385389

Ellison, N., Heino, R., & Gibbs, J. (2006). Managing impressions online: Self-presentation processes in the online dating environment. Journal of Computer-Mediated Communication. https://doi.org/10.1111/j.1083-6101.2006.00020.x

Employment & IBD: a guide for employers | Crohn's & Colitis UK. (2017). Retrieved June 27, 2020, from https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/employment-ibd-a-guide-for-employers

Engineering and Physical Sciences Research Council. (n.d.). Framework for Responsible Innovation - EPSRC website. Retrieved June 18, 2020, from https://epsrc.ukri.org/index.cfm/research/framework/

Epstein, D., & Quinn, K. (2020). Markers of Online Privacy Marginalization: Empirical Examination of Socioeconomic Disparities in Social Media Privacy Attitudes, Literacy, and Behavior. Social Media and Society. https://doi.org/10.1177/2056305120916853

EU. (2016). Home Page of EU GDPR. EU GDPR Terminal.

European Commission. (2017, May 18). Mergers: Facebook fined for providing misleading information. Retrieved from https://ec.europa.eu/commission/presscorner/detail/en/IP_17_1369

Evans, J. R., & Mathur, A. (2005). The value of online surveys. Internet Research. https://doi.org/10.1108/10662240510590360

Evans, J. R., & Mathur, A. (2018). The value of online surveys: a look back and a look ahead. Internet Research. https://doi.org/10.1108/IntR-03-2018-0089

Facebook. (2017). Our First Communities Summit and New Tools For Group Admins - About Facebook. Retrieved June 27, 2020, from https://about.fb.com/news/2017/06/our-first-communities-summit-and-new-tools-for-group-admins/

Facebook. (2019). Facebook Reports Third Quarter 2019 Results.

Facebook. (2020). What Names are Allowed on Facebook?

Fahimi, M., Barlas, F. M., Thomas, R. K., & Buttermore, N. (2015). Scientific Surveys Based on Incomplete Sampling Frames and High Rates of Nonresponse. Survey Practice. https://doi.org/10.29115/sp-2015-0031

Fan, H., & Lederman, R. (2018). Online health communities: how do community members build the trust required to adopt information and form close relationships? European Journal of Information Systems, 27(1), 62–89.

Fan, H., Lederman, R., Smith, S. P., & Chang, S. (2014). How trust is formed in online health communities: A process perspective. Communications of the Association for Information Systems, 34(1), 28.

Fan, H., Smith, S. P., Lederman, R., & Chang, S. (2010). Why people trust in online health communities: An integrated approach. In 21st Australasian Conference on Information Systems.

Ferenstein, G. (2015). The Birth And Death Of Privacy: 3,000 Years of History Told Through 46 Images.

Ferguson, T. (1997). Health care in cyberspace: Patients lead a revolution. Futurist.

Fernandes, T., & Castro, A. (2020). Understanding drivers and outcomes of lurking vs. posting engagement behaviours in social media-based brand communities. Journal of Marketing Management. https://doi.org/10.1080/0267257X.2020.1724179

Fink, A. (2013). The survey form: Questions, scales, and appearance. How to Conduct Surveys: A Step-by-Step Guide.

Finstad, K. (2010). Response Interpolation and Scale Sensitivity: Evidence Against 5-Point Scales. Journal of Usability Studies, 5(3), 104–110.

Fishbein, M., & Ajzen, I. (1975). Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research. Contemporary Sociology, 6, 244.

Fox, S. (2014). The social life of health information | Pew Research Center. Retrieved July 21, 2020, from https://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/

Frohlich, D. O. (2016). The Social Construction of Inflammatory Bowel Disease Using Social Media Technologies. Health Communication, 31(11), 1412–1420. https://doi.org/10.1080/10410236.2015.1077690

Frohlich, D. O., & Zmyslinski-Seelig, A. (2012). The Presence of Social Support Messages on YouTube Videos About Inflammatory Bowel Disease and Ostomies. Health Communication, 27(5), 421–428. https://doi.org/10.1080/10410236.2011.606524

Frost, J. H., & Massagli, M. P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another’s data. Journal of Medical Internet Research, 10(3), 1–14. https://doi.org/10.2196/jmir.1053

Frost, J., Vermeulen, I. E., & Beekers, N. (2014). Anonymity versus privacy: Selective information sharing in online cancer communities. Journal of Medical Internet Research, 16(5), 1–16. https://doi.org/10.2196/jmir.2684

Fullwood, C., Chadwick, D., Keep, M., Attrill-Smith, A., Asbury, T., & Kirwan, G. (2019). Lurking towards empowerment: Explaining propensity to engage with online health support groups and its association with positive outcomes. Computers in Human Behavior. https://doi.org/10.1016/j.chb.2018.08.037

Gavison, R. (1980). Privacy and the Limits of Law. The Yale Law Journal, 89(3), 421. https://doi.org/10.2307/795891

Gaylor, B. (2015). Do Not Track Documentary.

Gibson, J. J. (1977). The Theory of Affordance. In Perceiving Acting and Knowing.

Gillmor, D. (2010). Mediactive.

Gov.uk. (2018, September 12). Essential digital skills framework - GOV.UK. Retrieved June 27, 2020, from https://www.gov.uk/government/publications/essential-digital-skills-framework#history

Granovetter, M. (2012). the Strength of Weak Ties : a Network Theory Revisited. Socialogical Theory, 1(1983), 201–233. Retrieved from http://www.jstor.org/stable/202051

Granovetter, M. S. (1973). The Strength of Weak Ties. American Journal of Sociology. https://doi.org/10.1086/225469

Greenley, R. N., Hommel, K. A., Nebel, J., Raboin, T., Li, S. H., Simpson, P., & MacKner, L. (2010). A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. Journal of Pediatric Psychology, 35(8), 857–869. https://doi.org/10.1093/jpepsy/jsp120

Greenwald, G. (2014). No Place To Hide. Edward Snowden, The NSA and The Surveillance State. Penguin Books.

Grundy, Q., Chiu, K., Held, F., Continella, A., Bero, L., & Holz, R. (2019). Data sharing practices of medicines related apps and the mobile ecosystem: Traffic, content, and network analysis. BMJ (Online). https://doi.org/10.1136/bmj.l920

Gurses, S., & Diaz, C. (2013). Two tales of privacy in online social networks. IEEE Security and Privacy, 11(3), 29–37. https://doi.org/10.1109/MSP.2013.47

Guthrie, E., Jackson, J., Shaffer, J., Thompson, D., Tomenson, B., & Creed, F. (2002). Psychological disorder and severity of inflammatory bowel disease predict health-related quality of life in ulcerative colitis and Crohn’s disease. American Journal of Gastroenterology. https://doi.org/10.1016/S0002-9270(02)04198-9

Hall, N. J., Rubin, G. P., Dougall, A., Hungin, A. P. S., & Neely, J. (2005). The Fight for ‘Health-related Normality’: A Qualitative Study of the Experiences of Individuals Living with Established Inflammatory Bowel Disease (IBD). Journal of Health Psychology, 10(3), 443–455. https://doi.org/10.1177/1359105305051433

Hallam, C., & Zanella, G. (2017). Online self-disclosure: The privacy paradox explained as a temporally discounted balance between concerns and rewards. Computers in Human Behavior. https://doi.org/10.1016/j.chb.2016.11.033

Hanauer, S. B. (2006). Inflammatory Bowel Disease : Epidemiology , Pathogenesis , and Therapeutic Opportunities. Inflammatory Bowel Diseases, 12(January), 3–9. https://doi.org/https://doi.org/10.1097/01.MIB.0000195385.19268.68

Hargittai, E., & Marwick, A. (2016). “What can i really do?” Explaining the privacy paradox with online apathy. International Journal of Communication. https://doi.org/10.5167/uzh-148157

Hargittai, E., & Marwick, A. (2016). “What can i really do?” Explaining the privacy paradox with online apathy. International Journal of Communication. https://doi.org/10.5167/uzh-148157

Head, K. A., Jurenka, J. S., & Ascp, M. T. (2003). Inflammatory Bowel Disease Part I: Pathophysiology and Conventional and Alternative Treatment Options - 247.pdf. Alternative Medicine Review, 8(3). Retrieved from http://www.altmedrev.com/publications/8/3/247.pdf

Huckvale, K., Torous, J., & Larsen, M. E. (2019). Assessment of the Data Sharing and Privacy Practices of Smartphone Apps for Depression and Smoking Cessation. JAMA Network Open. https://doi.org/10.1001/jamanetworkopen.2019.2542

Huesch, M., Chetlen, A., Segel, J., & Schetter, S. (2017). Frequencies of private mentions and sharing of mammography and breast cancer terms on facebook: A pilot study. Journal of Medical Internet Research, 19(6). https://doi.org/10.2196/jmir.7508

IBD Relief. (n.d.). What is indeterminate colitis | IBD Relief. Retrieved August 31, 2020, from https://www.ibdrelief.com/learn/what-is-ibd/what-is-indeterminate-colitis

IBDUK. (n.d.). IBD Standards | IBD UK. Retrieved August 31, 2020, from https://www.ibduk.org/ibd-standards

Internet World Stats. (2020). World Internet Users Statistics and 2020 World Population Stats. Retrieved June 27, 2020, from https://www.internetworldstats.com/stats.htm

Iryna, P., Lixuan, Z., & Oksana, B. (2013). Antecedents and consequences of trust in a social media brand: A cross-cultural study of Twitter. Computers in Human Behavior, 29(4), 1546–1555. Retrieved from http://linkinghub.elsevier.com/retrieve/pii/S0747563213000484http://api.elsevier.com/content/article/PII:S0747563213000484?httpAccept=text/xml

Isika, N. U., Mendoza, A., & Bosua, R. (2015). Appropriation of social media by patients with chronic illness to share knowledge. ACIS 2015 Proceedings - 26th Australasian Conference on Information Systems, 1–14.

Ismail, N. (2018). ‘FAKE DATA is creeping up on companies worldwide.’

ITO, M., TOGARI, T., JEONG PARK, M., & YAMAZAKI, Y. (2008). Difficulties at work experienced by patients with inflammatory bowel disease (IBD) and factors relevant to work motivation and depression. Japanese Journal of Health and Human Ecology, 74(6), 290–310. https://doi.org/10.3861/jshhe.74.290

Jagdish, D. (Massachusetts I. of T. (2014). IMMERSION : a platform forvisualization and temporal analysis of email data.

Jenkins, H., Ford, S., & Green, J. (2013). Spreadable media: Creating value and meaning in a networked culture. Spreadable Media: Creating Value and Meaning in a Networked Culture. https://doi.org/10.3983/twc.2014.0633

Jia, H., Wisniewski, P., Xu, H., Rosson, M. B., & Carroll, J. M. (2015). Risk-Taking as a learning process for shaping teen's online information privacy behaviors. CSCW 2015 - Proceedings of the 2015 ACM International Conference on Computer-Supported Cooperative Work and Social Computing, (January), 583–599. https://doi.org/10.1145/2675133.2675287

Joachim, G. (1998). The Birth and Dissolution of an Inflammatory Bowel Disease Support Group: Lessons in Providing Support. Gastroenterology Nursing, 21(3), 119–124. https://doi.org/10.1097/00001610-199805000-00004

Joinson, A. N., Paine, C., Reips, U.-D., & Buchanan, T. (2006). Privacy and Trust: The role of situational and dispositional variables in online disclosure. Workshop on Privacy Trust and Identity Issues for Ambient Intelligence, 1–6.

Jones, R., Sailaja, N., & Kerlin, L. (2017). Probing the design space of usable privacy policies: A qualitative exploration of a reimagined privacy policy. In HCI 2017: Digital Make Believe - Proceedings of the 31st International BCS Human Computer Interaction Conference, HCI 2017. https://doi.org/10.14236/ewic/HCI2017.50

Joshi, A., Kale, S., Chandel, S., & Pal, K. (2015). Likert Scale: Explored and Explained. British Journal of Applied Science & Technology, 7(4), 396–403.

Jozani, M., Ayaburi, E., Ko, M., & Choo, K. K. R. (2020). Privacy concerns and benefits of engagement with social media-enabled apps: A privacy calculus perspective. Computers in Human Behavior. https://doi.org/10.1016/j.chb.2020.106260

Jung, Y., & Rader, E. (2016). The Imagined Audience and Privacy Concern on Facebook: Differences Between Producers and Consumers. Social Media and Society, 2(2). https://doi.org/10.1177/2056305116644615

Kalz, M. (2015). Lifelong Learning and Its Support with New Technologies. In International Encyclopedia of the Social & Behavioral Sciences: Second Edition. https://doi.org/10.1016/B978-0-08-097086-8.92006-3

Kehr, F., Kowatsch, T., Wentzel, D., & Fleisch, E. (2015). Blissfully ignorant: The effects of general privacy concerns, general institutional trust, and affect in the privacy calculus. Information Systems Journal, 25(6), 607–635. https://doi.org/10.1111/isj.12062

Kehr, F., Kowatsch, T., Wentzel, D., & Fleisch, E. (2015). Thinking Styles and Privacy Decisions: Need for Cognition, Faith into Intuition, and the Privacy Calculus. In 2th International Conference on Wirtschaftsinformatik. Retrieved from https://www.alexandria.unisg.ch/242199/1/WI2015-S-14-00075.pdf

Khazaal, Y., Van Singer, M., Chatton, A., Achab, S., Zullino, D., Rothen, S., … Thorens, G. (2014). Does self-selection affect samples'representativeness in online surveys an investigation in online video game research. Journal of Medical Internet Research. https://doi.org/10.2196/jmir.2759

Kilroy, S., Nolan, E., & Sarma, K. M. (2011). Quality of life and level of anxiety in youths with inflammatory bowel disease in Ireland. Journal of Pediatric Gastroenterology and Nutrition, 53(3), 275–279. https://doi.org/10.1097/MPG.0b013e318214c131

Kokolakis, S. (2015). Privacy attitudes and privacy behaviour: A review of current research on the privacy paradox phenomenon. Computers and Security, 64(2013), 122–134. https://doi.org/10.1016/j.cose.2015.07.002

Kordzadeh, N., & Warren, J. (2017). Communicating personal health information in virtual health communities: An integration of privacy calculus model and affective commitment. Journal of the Association for Information Systems, 18(1), 45–81. https://doi.org/10.17705/1jais.00446

Kosyfaki, C., Angelova, N. P., Tsohou, A., & Magkos, E. (2017). The Privacy Paradox in the Context of Online Health Data Disclosure by Users. In M. Themistocleous & V. Morabito (Eds.), Information Systems (pp. 421–428). Cham: Springer International Publishing.

Kraemer, K. L. (1991). Introduction. Paper presented at the Information Systems Research Challenge: Survey Research Methods.

Kramer, A. D. I. (2012). The spread of emotion via Facebook. In Conference on Human Factors in Computing Systems - Proceedings. https://doi.org/10.1145/2207676.2207787

Lahat, A., Neuman, S., Eliakim, R., & Ben-Horin, S. (2014). Partners of patients with inflammatory bowel disease: How important is their support? Clinical and Experimental Gastroenterology, 7(1), 255–259. https://doi.org/10.2147/CEG.S62173

Lanier, J. (2014). Who Owns the Future? Simon and Schuster.

Lankton, N., & Tripp, J. (2013). A quantitative and qualitative study of Facebook privacy using the Antecedent-Privacy Concern-Outcome Macro Model. In 19th Americas Conference on Information Systems, AMCIS 2013 - Hyperconnected World: Anything, Anywhere, Anytime.

Larson, D. W., & Pemberton, J. H. (2004). Current concepts and controversies in surgery for IBD. Gastroenterology, 126(6), 1611–1619. https://doi.org/10.1053/j.gastro.2004.03.063

Lave, J., & Wenger, E. (1991). Situated Learning Legitimate Peripheral Participation | Developmental psychology |. Cambridge University Press.

Lavrakas, P. (2012). Encyclopedia of Survey Research Methods. Encyclopedia of Survey Research Methods. https://doi.org/10.4135/9781412963947

Lebanoff, L., & Liu, F. (2018). Automatic detection of vague words and sentences in privacy policies. In Proceedings of the 2018 Conference on Empirical Methods in Natural Language Processing, EMNLP 2018. https://doi.org/10.18653/v1/d18-1387

Lee, W. Y., Tan, C.-S., & Siah, P. C. (2017). The Role of Online Privacy Concern as a Mediator between Internet Self-Efficacy and Online Technical Protection Privacy Behavior. Sains Humanika, 9(3–2), 37–43. https://doi.org/10.11113/sh.v9n3-2.1271

Leon, P. G., Ur, B., Balebako, R., Cranor, L. F., Shay, R., & Wang, Y. (2012). Why Johnny can't opt out: A usability evaluation of tools to limit online behavioral advertising. In Conference on Human Factors in Computing Systems - Proceedings. https://doi.org/10.1145/2207676.2207759

Leung, L. (2007). Stressful Life Events, Motives for Internet Use, and Social Support Among Digital Kids, 10(2), 204–215. https://doi.org/10.1089/cpb.2006.9967

Lewinski, A. A., Vorderstrasse, A. A., Anderson, R. A., Pan, W., Fisher, E. B., & Johnson, C. M. (2017). Analyzing Unstructured Communication in a Computer-Mediated Environment for Adults With Type 2 Diabetes: A Research Protocol. JMIR Research Protocols, 6(4), e65. https://doi.org/10.2196/resprot.7442

Lewis Andrew. (2010). If you are not paying for it, you're not the customer; you're the product being sold. Retrieved June 28, 2020, from https://www.metafilter.com/user.mefi/15556

Li, H., Gupta, A., Zhang, J., & Sarathy, R. (2014). Examining the decision to use standalone personal health record systems as a trust-enabled fair social contract. Decision Support Systems, 57(1), 376–386. https://doi.org/10.1016/j.dss.2012.10.043

Li, Y. (2012). Theories in online information privacy research: A critical review and an integrated framework. Decision Support Systems, 54(1), 471–481. https://doi.org/10.1016/j.dss.2012.06.010

Liao, Y. (2019). Sharing Personal Health Information o n Social Media : Balancing Self - presentation and Privacy. In International Conference on Social Media & Society. https://doi.org/1145/3328529.3328560

Lightfoot, G., & Wisniewski, T. P. (2014). Information asymmetry and power in a surveillance society. Information and Organization, 24(4), 214–235. https://doi.org/https://doi.org/10.1016/j.infoandorg.2014.09.001

Litt, E., & Hargittai, E. (2016). The Imagined Audience on Social Network Sites. Social Media and Society, 2(1). https://doi.org/10.1177/2056305116633482

Loftus, C. G., Loftus, E. V., Harmsen, W. S., Zinsmeister, A. R., Tremaine, W. J., Melton, L. J., & Sandborn, W. J. (2007). Update on the incidence and prevalence of Crohn's disease and ulcerative colitis in Olmsted County, Minnesota, 1940-2000. Inflammatory Bowel Diseases. https://doi.org/10.1002/ibd.20029

Loftus, E. V. (2004). Clinical Epidemiology of Inflammatory Bowel Disease : Incidence , Prevalence , and Environmental Influences. GASTROENTEROLOGY, 126(6), 1504–1517. https://doi.org/10.1053/j.gastro.2004.01.063

Lomas, N. (2018, April 10). A brief history of Facebook's privacy hostility ahead of Zuckerberg's testimony | TechCrunch. Retrieved June 27, 2020, from https://techcrunch.com/2018/04/10/a-brief-history-of-facebooks-privacy-hostility-ahead-of-zuckerbergs-testimony/?guccounter=1

Lönnfors, S., Vermeire, S., Greco, M., Hommes, D., Bell, C., & Avedano, L. (2014). IBD and health-related quality of life — Discovering the true impact. European Crohn's and Colitis Organisation, (October), 1281–1286.

Lutz, C., & Strathoff, P. (2011). Privacy concerns and online behavior – Not so paradoxical after all? Multinationale Unternehmen Und Institutionen Im Wandel – Herausforderungen Für Wirtschaft, Recht Und Gesellschaft, 81–99. https://doi.org/10.2139/ssrn.2425132

Lutz, C., & Tamó-Larrieux, A. (2020). The Robot Privacy Paradox: Understanding How Privacy Concerns Shape Intentions to Use Social Robots. Human-Machine Communication, 1, 87–111. https://doi.org/10.30658/hmc.1.6

Mackay, H., & Gillespie, G. (1992). Extending the Social Shaping of Technology Approach: Ideology and Appropriation. Social Studies of Science. https://doi.org/10.1177/030631292022004006

Malik, S., & Coulson, N. S. (2011). The Therapeutic Potential of the Internet: Exploring Self-help Processes in an Internet Forum for Young People With Inflammatory Bowel Disease. Gastroenterology Nursing, 34(6), 439–448. https://doi.org/10.1097/SGA.0b013e318237a9ba

Maloney-Krichmar, D., & Preece, J. (2003). The meaning of an online health community in the lives of its members: roles, relationships and group dynamics, 20–27. https://doi.org/10.1109/istas.2002.1013791

Mander, J. (2015). Internet Users Have Average of 5.54 Social Media Accounts. Retrieved April 1, 2020, from https://blog.globalwebindex.com/chart-of-the-day/internet-users-have-average-of-5-54-social-media- accounts/

Marsh, S. (2018). User Research: A Practical Guide to Designing Better Products and Services. Kogan Page.

Martens, H. (2010). Evaluating Media Literacy Education: Concepts, Theories and Future Directions. Journal of Media Literacy Education, 2(1), 1.

Marwick, a. E., & Boyd, D. (2010). I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. New Media & Society, 13(1), 114–133. https://doi.org/10.1177/1461444810365313

Matini, L., & Ogden, J. (2015). A qualitative study of patients' experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation. Journal of Health Psychology, 21(11), 2493–2502. https://doi.org/10.1177/1359105315580463

Matzner, T., Masur, P. K., Ochs, C., & von Pape, T. (2016). Do-It-Yourself Data Protection—Empowerment or Burden? https://doi.org/10.1007/978-94-017-7376-8_11

Mayer, R. C., Davis, J. H., & Schoorman, F. D. (1995). AN INTEGRATIVE MODEL OF ORGANIZATIONAL TRUST. Academy of Management Review. https://doi.org/10.5465/amr.1995.9508080335

Meade, A. W., & Craig, S. B. (2012). Identifying careless responses in survey data. Psychological Methods. https://doi.org/10.1037/a0028085

Mendelson, A. L., & Papacharissi, Z. (2010). Look at us: Collective Narcissism in College Student Facebook Photo Galleries. The Networked Self: Identity, Community and Culture on Social Network Sites.

Merolli, M., Gray, K., & Martin-sanchez, F. (2013). Health outcomes and related effects of using social media in chronic disease management : A literature review and analysis of affordances. Journal of Biomedical Informatics, 46(6), 957–969. https://doi.org/10.1016/j.jbi.2013.04.010

Merolli, M., Gray, K., & Martin-Sanchez, F. (2014). Therapeutic affordances of social media: Emergent themes from a global online survey of people with Chronic Pain. Journal of Medical Internet Research, 16(12), 1–16. https://doi.org/10.2196/jmir.3494

Mesch, G. S. (2012). Is online trust and trust in social institutions associated with online disclosure of identifiable information online? Computers in Human Behavior. https://doi.org/10.1016/j.chb.2012.03.010

Montgomery, S. (2019, February 25). What's in an Algorithm? The Problem of the Black Box | Tufts Observer. Retrieved September 4, 2020, from https://tuftsobserver.org/whats-in-an-algorithm-the-problem-of-the-black-box/

Moody, G. A., Bhakta, P., & Mayberry, J. F. (1993). Disinterest in local self-help groups amongst patients with inflammatory bowel disease in Leicester. International Journal of Colorectal Disease, 8(4), 181–183. https://doi.org/10.1007/BF00290301

Moore, D., Ayers, S., & Drey, N. (2016). A Thematic Analysis of Stigma and Disclosure for Perinatal Depression on an Online Forum. JMIR Mental Health, 3(2), e18. https://doi.org/10.2196/mental.5611

Moreno, M. A., & D'Angelo, J. (2018). Applying an affordances framework to social media intervention approaches (Preprint). Journal of Medical Internet Research, 21, 1–9. https://doi.org/10.2196/11014

Mountifield, R., Bampton, P., Prosser, R., Muller, K., & Andrews, J. M. (2009). Fear and fertility in inflammatory bowel disease: A mismatch of perception and reality affects family planning decisions. Inflammatory Bowel Diseases. https://doi.org/10.1002/ibd.20839

Mozilla. (2019). Lightbeam extension for Firefox is no longer supported. Retrieved from https://www.mozilla.org/en-US/lightbeam/

Munson, S. A., Resnick, P., Newman, M. W., Morris, M. E., & Lauterbach, D. (2011). It's not that i don't have problems, i'm just not putting them on facebook. In CSCW (p. 341). Hangzhou. https://doi.org/10.1145/1958824.1958876

Naslund, J. A., & Aschbrenner, K. A. (2019). Risks to privacy with use of social media: Understanding the views of social media users with serious mental illness. Psychiatric Services. https://doi.org/10.1176/appi.ps.201800520

Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: Peer-To-peer support and social media. Epidemiology and Psychiatric Sciences. https://doi.org/10.1017/S2045796015001067

Ng, S. C., Shi, H. Y., Hamidi, N., Underwood, F. E., Tang, W., Benchimol, E. I., … Kaplan, G. G. (2017). Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. The Lancet, 390(10114), 2769–2778. https://doi.org/https://doi.org/10.1016/S0140-6736(17)32448-0

Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: A qualitative examination. Health and Quality of Life Outcomes. https://doi.org/10.1186/1477-7525-5-28

Nissembaum, H. (New Y. U. (2004). Privacy as Contextual Integrity. Washington Law Review, 101–139. Retrieved from http://www.kentlaw.edu/faculty/rwarner/classes/internetlaw/2011/materials/nissenbaum_norms.pdf

Nonnecke, B., & Preece, J. (1999). Shedding Light on Lurkers in Online Communities. In Ethnographic Studies in Real and Virtual Environments: Inhabited Information Spaces and Connected Communities.

Nonnecke, B., & Preece, J. (2000). Lurker demographics: Counting the silent. In Conference on Human Factors in Computing Systems - Proceedings (pp. 73–80). New York, New York, USA: ACM Press. https://doi.org/10.1145/332040.332409

Nonnecke, B., & Preece, J. (2003). Lurker demographics: Counting the silent. Association for Computing Machinery, 2(1), 73–80. https://doi.org/10.1145/332040.332409

Norman, D. (2013). The Design of Everyday Things. The Design of Everyday Things: Revised and Expanded Edition. https://doi.org/10.15358/9783800648108

Norman, D. (2016). The Design of Everyday Things. The Design of Everyday Things. https://doi.org/10.15358/9783800648108

O'Kane, A. A., Mentis, H. M., & Thereska, E. (2013). Non-static nature of patient consent: Shifting Privacy Perspectives in Health Information Sharing. In Proceedings of the 2013 conference on Computer supported cooperative work - CSCW '13 (pp. 553–562). New York, New York, USA: ACM Press. https://doi.org/10.1145/2441776.2441838

O’Leary, K., Coulson, N., Perez-Vallejos, E., & McAuley, D. (2020). Towards understanding how individuals with inflammatory bowel disease use contemporary social media platforms for health-related discourse. Computers in Human Behavior, 112, 106463. https://doi.org/https://doi.org/10.1016/j.chb.2020.106463

Obar, J. A., & Oeldorf-Hirsch, A. (2020). The biggest lie on the Internet: ignoring the privacy policies and terms of service policies of social networking services. Information Communication and Society. https://doi.org/10.1080/1369118X.2018.1486870

Ohara, K. (2016). The Seven Veils of Privacy. IEEE Internet Computing, 20(2), 86–91. https://doi.org/10.1109/MIC.2016.34

Oliveira, S., Zaltman, C., Elia, C., Vargens, R., Leal, A., Barros, R., & Fogac, H. (2006). Quality-of-Life Measurement in Patients with Inflammatory Bowel Disease Receiving Social Support. Crohn’s & Colitis Foundation of America, Inc. DOI 10.1002/Ibd.2007, 13(4), 470–474. https://doi.org/10.1002/ibd.20071

Orsatti, J., & Riemer, K. (2012). Identity and self-presentation: From a representational to a performative lens in studying social media engagement in organisations. ACIS 2012 : Proceedings of the 23rd Australasian Conference on Information Systems, 1–12.

Orwell, G. (1949). Nineteen Eighty-Four; A Novel. London: Secker & Warburg.

Ostherr, K., Borodina, S., Bracken, R. C., Lotterman, C., Storer, E., & Williams, B. (2017). Trust and privacy in the context of user-generated health data. Big Data and Society, 1(11). https://doi.org/10.1177/2053951717704673

Papacharissi, Z., & Mendelson, A. (2011). Toward a new(er) sociability: Uses, gratifications and social capital on facebook. In Media Perspectives for the 21st Century. https://doi.org/10.4324/9780203834077

Papathanassopoulos, S. (2015). Privacy 2.0. Social Media and Society, 1(1), 1–2. https://doi.org/10.1177/2056305115578141

Park, Y. J. (2011). Digital Literacy and Privacy Behavior Online. Communication Research, 40(2), 215 –236. https://doi.org/10.1177/0093650211418338

Patil, V. T., & Shyamasundar, R. K. (2017). Privacy as a currency: Un-regulated? ICETE 2017 - Proceedings of the 14th International Joint Conference on e-Business and Telecommunications, 4(Icete), 586–595. https://doi.org/10.5220/0006478705860595

Patterson, H. (2013). Contextual Expectations of Privacy in Self-Generated Health Information Flows. In TPRC 41: The 41st Research Conference on Communication, Information and Internet Policy (pp. 1–48). https://doi.org/http://dx.doi.org/10.2139/ssrn.2242144

People, Power and Technology: The 2020 Digital Attitudes Report | doteveryone. (2020). Retrieved from https://www.doteveryone.org.uk/report/peoplepowertech2020/

Pithadia, A. B., & Jain, S. (2011). Treatment of inflammatory bowel disease (IBD). Pharmacological Reports. https://doi.org/10.1016/S1734-1140(11)70575-8

Postmes, T., & Spears, R. (1998). Deindividuation and Antinormative Behavior: A Meta-Analysis. Psychological Bulletin. https://doi.org/10.1037/0033-2909.123.3.238

Pozzi, G., Pigni, F., & Vitari, C. (2014). Affordance theory in the IS discipline: A review and synthesis of the literature. In 20th Americas Conference on Information Systems, AMCIS 2014.

Prescott, J., Hanley, T., & Ujhelyi, K. (2017). Peer Communication in Online Mental Health Forums for Young People: Directional and Nondirectional Support. JMIR Mental Health, 4(3), e29. https://doi.org/10.2196/mental.6921

Putnam, C., Wozniak, K., Zefeldt, M. J., Cheng, J., Caputo, M., & Duffield, C. (2012). How do professionals who create computing technologies consider accessibility? ASSETS'12 - Proceedings of the 14th International ACM SIGACCESS Conference on Computers and Accessibility, 87–94. https://doi.org/10.1145/2384916.2384932

Putnam, R. D. (2000). Bowling Alone: The Collapse and Revival of American Community: New York: Simon und Schuster, 2001. ISBN. Policy Analysis. https://doi.org/10.2307/3089235

Rad Campaign., & Lincoln Park Strategies. (2018). The State of Social Media and Online Privacy. Retrieved from http://onlineprivacydata.com/

Rao, A., Schaub, F., Sadeh, N., Acquisti, A., & Kang, R. (2016). Expecting the Unexpected: Understanding Mismatched Privacy Expectations Online. In the Proceedings of the Twelfth Symposium on Usable Privacy and Security (SOUPS 2016) (pp. 77–96). Retrieved from https://www.usenix.org/conference/soups2016/technical-sessions/presentation/rao

Raynes-Goldie, K. S. (2012). Privacy in the Age of Facebook: Discourse, Architecture, Consequences. Curtin University.

Reidenberg, J. R., Breaux, T., Cranor, L. F., French, B., Grannis, A., Graves, J., … Schaub, F. (2018). Disagreeable Privacy Policies: Mismatches between Meaning and Users Understanding. SSRN Electronic Journal, 30(1). https://doi.org/10.2139/ssrn.2418297

Reidenberg, J. R., Breaux, T., Cranor, L. F., French, B., Grannis, A., Graves, J. T., … Schaub, F. (2015). Disagreeable Privacy Policies. Berkeley Technology Law Journal, 30(1), 39–88.

Revilla, M. A., Saris, W. E., & Krosnick, J. A. (2014). Choosing the Number of Categories in Agree-Disagree Scales. Sociological Methods and Research. https://doi.org/10.1177/0049124113509605

Roccetti, M., Casari, A., & Marfia, G. (2015). Inside Chronic Autoimmune Disease Communities: A Social Networks Perspective to Crohn's Patient Behavior and Medical Information. (pp. 1089–1096). https://doi.org/10.1145/2808797.2808813

Roccetti, M., Prandi, C., Salomoni, P., & Marfia, G. (2016). Unleashing the true potential of social networks : confirming infliximab medical trials through Facebook posts. Network Modeling Analysis in Health Informatics and Bioinformatics, 5(1), 1–13. https://doi.org/10.1007/s13721-016-0122-9

Roccetti, M., Salomoni, P., Prandi, C., Marfia, G., Montagnani, M., & Gningaye, L. (2016). Understanding Crohn’s disease patients reaction to infliximab from facebook: A medical perspective. Proceedings of the 2016 IEEE/ACM International Conference on Advances in Social Networks Analysis and Mining, ASONAM 2016, (Cd), 1007–1010. https://doi.org/10.1109/ASONAM.2016.7752364

Rodríguez-De-Dios, I., & Igartua, J. J. (2016). Skills of digital literacy to address the risks of interactive communication. Journal of Information Technology Research. https://doi.org/10.4018/JITR.2016010104

Rogala, L., Miller, N., Graff, L. A., Rawsthorne, P., Clara, I., Walker, J. R., … Bernstein, C. N. (2008). Population-based controlled study of social support, self-perceived stress, activity and work issues, and access to health care in inflammatory bowel disease. Inflammatory Bowel Diseases, 14(4), 526–535. https://doi.org/10.1002/ibd.20353

Roter, D. L., & Hall, J. A. (1992). Improving talk through interventions. In Doctors talking to Patients / Patients talking to Doctors: Improving communication in medical visits.

Ruckenstein, M., & Granroth, J. (2019). Algorithms, advertising and the intimacy of surveillance. Journal of Cultural Economy. https://doi.org/10.1080/17530350.2019.1574866

Ruckenstein, M., & Granroth, J. (2019). Algorithms, advertising and the intimacy of surveillance. Journal of Cultural Economy. https://doi.org/10.1080/17530350.2019.1574866

Sale, J. E. M., Lohfeld, L. H., & Brazil, K. (2002). Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. Quality and Quantity. https://doi.org/10.1023/A:1014301607592

Sandstrom, G. M., & Dunn, E. W. (2014). Social interactions and well-being: The surprising power of weak ties. Personality and Social Psychology Bulletin, 40(7), 910–922. https://doi.org/10.1177/0146167214529799

Saunders, B. (2014). Stigma, deviance and morality in young adults’ accounts of inflammatory bowel disease. Sociology of Health & Illness. https://doi.org/10.1111/1467-9566.12148

Schippinger, M., Liebmann, P., Ruckenstuhl, P., Leithner, A., & Bernhardt, G. (2016). Like or Dislike? Impact of Facebook on Ewing Sarcoma Treatment. JMIR Cancer, 2(2), e11. https://doi.org/10.2196/cancer.5367

Schneider, M. A., & Fletcher, P. C. (2008). I feel as if my IBS is keeping me hostage!’ exploring the negative impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) upon university-aged women. International Journal of Nursing Practice, 14(2), 135–148. https://doi.org/10.1111/j.1440-172X.2008.00677.x

Schneier, B. (2015). Data and Goliath. Data and Goliath. https://doi.org/10.1007/s13398-014-0173-7.2

Scism, L. (2019, January 20). New York Insurers Can Evaluate Your Social Media Use—If They Can Prove Why It's Needed. The Wall Street Journal.

Setoyama, Y., Yamazaki, Y., & Namayama, K. (2011). Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. Journal of Medical Internet Research, 13(4), 1–10. https://doi.org/10.2196/jmir.1696

Shah, R., Abraham, B., Hou, J., & Sellin, J. (2015). Frequency and associated factors of hair loss among patients with inflammatory bowel disease. World Journal of Gastroenterology, 21(1), 229–232. https://doi.org/10.3748/wjg.v21.i1.229

Sideri, M., Kitsiou, A., Tzortzaki, E., Kalloniatis, C., & Gritzalis, S. (2019). Enhancing university students' privacy literacy through an educational intervention: A Greek case-study. In International Journal of Electronic Governance. https://doi.org/10.1504/IJEG.2019.103719

Sideri, M., Kitsiou, A., Tzortzaki, E., Kalloniatis, C., & Gritzalis, S. (2019). Enhancing university students' privacy literacy through an educational intervention: A Greek case-study. In International Journal of Electronic Governance. https://doi.org/10.1504/IJEG.2019.103719

Sillence, E. (2010). Seeking out very like-minded others: exploring trust and advice issues in an online health support group. International Journal of Web Based Communities, 6(4), 376–394.

Sillence, E., Hardy, C., & Briggs, P. (2013). Why don't we trust health websites that help us help each other? An analysis of online peer-to-peer healthcare. Proceedings of the 5th Annual ACM Web Science Conference, WebSci'13, volume(May), 396–404. https://doi.org/10.1145/2464464.2464488

Sillence, E., Hardy, C., Harris, P. R., & Briggs, P. (2016). Modeling patient engagement in peer-to-peer healthcare, (April), 481–486. https://doi.org/10.1145/2567948.2576937

Solove, D. (2007). "I've Got Nothing to Hide" and Other Misunderstandings of Privacy. San Diego Law Review.

Song, J., & Zahedi, F. M. (2007). Trust in health infomediaries. Decision Support Systems. https://doi.org/10.1016/j.dss.2006.11.011

Spratt, T. J. R. (2019). Passing Strategies and Performative Identities: Coping with (In)Visible Chronic Diseases. Journal of Medical Humanities. https://doi.org/10.1007/s10912-019-09600-x

Stewart Loane, S., & D'Alessandro, S. (2014). Empowered and knowledgeable health consumers: The impact of online support groups on the doctor-patient relationship. Australasian Marketing Journal, 22(3), 238–245. https://doi.org/10.1016/j.ausmj.2014.08.007

Strahilevitz, L. J., & Kugler, M. B. (2016). Is privacy policy language irrelevant to consumers? Journal of Legal Studies. https://doi.org/10.1086/689933

Sue, V. M., & Ritter, L. A. (2012). Conducting online surveys. Sage.

Summers, M. C. (2018). The Effect of Ostomate-to-Ostomate Support on Psychosocial Adaptation to Stoma. Doctor of Nursing Practice Capstone Projects, 28.

Swanson, J. A. (1994). Aristotle on Liberality: Its Relation to Justice and Its Public and Private Practice. Polity. https://doi.org/10.2307/3235084

Szeto, W., Van Der Bent, A., Petty, C. R., Reich, J., Farraye, F., & Fishman, L. N. (2018). Use of Social Media for Health-Related Tasks by Adolescents with Inflammatory Bowel Disease: A Step in the Pathway of Transition. Inflammatory Bowel Diseases, 24(6), 1114–1122. https://doi.org/10.1093/ibd/izy021

Szigethy, E., Hardy, D., Craig, A. E., Low, C., & Kukic, S. (2009). Girls connect: Effects of a support group for teenage girls with inflammatory bowel disease and their mothers. Inflammatory Bowel Diseases, 15(8), 1127–1128. https://doi.org/10.1002/ibd.20775

Tactical Tech. (2012). Me and My Shadow.

Taddicken, M. (2014). The "Privacy Paradox" in the Social Web: The Impact of Privacy Concerns, Individual Characteristics, and the Perceived Social Relevance on Different Forms of Self-Disclosure. Journal of Computer-Mediated Communication, 19(2), 248–273. https://doi.org/10.1111/jcc4.12052

Takacs, L. F., & Kollman, C. E. (1994). An inflammatory bowel disease support group for teens and their parents. Gastroenterology Nursing. https://doi.org/10.1097/00001610-199408000-00004

Tanis, M. (2008). Health-related on-line forums: What's the big attraction? Journal of Health Communication, 13(7), 698–714. https://doi.org/10.1080/10810730802415316

Tanner, A. (2017). Our Bodies, Our Data. How Companies make Billions Selling our Medical Records. Beacpn Press.

Taşkın, D., & Taşkın, Ç. (2019). Measuring the impact of privacy concerns, perceived risk and trust on the continuance intention of facebook users by means of PLS-SEM. In CEUR Workshop Proceedings.

Tavernier, N., Fumery, M., Peyrin-Biroulet, L., Colombel, J. F., & Gower-Rousseau, C. (2013). Systematic review: Fertility in non-surgically treated inflammatory bowel disease. Alimentary Pharmacology and Therapeutics, 38(8), 847–853. https://doi.org/10.1111/apt.12478

Terry, N. P. (2012). Protecting Patient Privacy in the Age of Big Data. SSRN Electronic Journal. https://doi.org/10.2139/ssrn.2153269

Thode, W., Griesbaum, J., & Mandl, T. (n.d.). “ I would have never allowed it ”: User Perception of Third-party Tracking and Implications for Display Advertising, (May 2015), 445–456.

Toch, E., Wisniewski, P. J., Wilkinson, D., Namara, M., Badillo-Urquiola, K., Knijnenburg, B. P., … Romano-Bergstrom, J. (2018). Moving beyond a “one-size fits all” approach: Exploring Individual Differences in Privacy. In Conference on Human Factors in Computing Systems - Proceedings. https://doi.org/10.1145/3170427.3170617

Trepte, S., Teutsch, D., Masur, P. K., Eicher, C., Fischer, M., Hennhöfer, A., & Lind, F. (2015). Reforming European Data Protection Law. In Reforming European Data Protection Law (Vol. 20, pp. 333–365). Springer. https://doi.org/10.1007/978-94-017-9385-8

Tsuei, C. (2010). How Advertisers Use Internet Cookies to Track You. Retrieved August 31, 2020, from https://www.wsj.com/video/how-advertisers-use-internet-cookies-to-track-you/92E525EB-9E4A-4399-817D-8C4E6EF68F93.html

Twitter. (2019). Investor Fact Sheet.

Twitter. (n.d.). How to create a thread on Twitter. Retrieved June 21, 2020, from https://help.twitter.com/en/using-twitter/create-a-thread

UK, C. & C. (n.d.). About us. Retrieved June 10, 2020, from https://www.crohnsandcolitis.org.uk/about-us

Ur, B., Leon, P. G., Cranor, L. F., Shay, R., & Wang, Y. (2012). Smart, useful, scary, creepy: Perceptions of online behavioral advertising. In SOUPS 2012 - Proceedings of the 8th Symposium on Usable Privacy and Security. https://doi.org/10.1145/2335356.2335362

van Deursen, A. J. A. M., & Helsper, E. J. (2015). The Third-Level Digital Divide: Who Benefits Most from Being Online? https://doi.org/10.1108/s2050-206020150000010002

van Dijck, J. (2014). Datafication, dataism and dataveillance: Big data between scientific paradigm and ideology. Surveillance and Society. https://doi.org/10.24908/ss.v12i2.4776

van Uden-Kraan, C. F., Seydel, E. R., Drossaert, C. H. C., Taal, E., van de Laar, M. A. F. J., & Shaw, B. R. (2008). Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia. Qualitative Health Research, 18(3), 405–417. https://doi.org/10.1177/1049732307313429

Vanderhoven, E., Schellens, T., & Valcke, M. (2014). Educating teens about the risks on social network sites. An intervention study in secondary education. Comunicar. https://doi.org/10.3916/C43-2014-12

Vanderhoven, E., Schellens, T., Vanderlinde, R., & Valcke, M. (2016). Developing educational materials about risks on social network sites: a design based research approach. Educational Technology Research and Development. https://doi.org/10.1007/s11423-015-9415-4

Vervier, L., Zeissig, E. M., Lidynia, C., & Ziefle, M. (2017). Perceptions of digital footprints and the value of privacy. In IoTBDS 2017 - Proceedings of the 2nd International Conference on Internet of Things, Big Data and Security. https://doi.org/10.5220/0006301000800091

Waldman, A. E. (2020). Cognitive biases, dark patterns, and the 'privacy paradox.' Current Opinion in Psychology, 31, 105–109. https://doi.org/10.1016/j.copsyc.2019.08.025

Walker, A. M., Yao, Y., Geeng, C., Hoyle, R., & Wisniewski, P. (2019). Moving beyond "one size fits all." Interactions. https://doi.org/10.1145/3358904

Wang, X., Zhao, K., & Street, N. (2017). Analyzing and predicting user participations in online health communities: A social support perspective. Journal of Medical Internet Research, 19(4). https://doi.org/10.2196/jmir.6834

Warren, S. D., & Brandeis, L. D. (1890). The right to privacy. Harvard Law Review, 5(5).

Weinberger, M., Zhitomirsky-Geffet, M., & Bouhnik, D. (2017). Factors affecting users' online privacy literacy among students in Israel. Online Information Review. https://doi.org/10.1108/OIR-05-2016-0127

Welbourne, J. L., Blanchard, A. L., & Wadsworth, M. B. (2013). Motivations in virtual health communities and their relationship to community, connectedness and stress. Computers in Human Behavior, 29(1), 129–139. https://doi.org/10.1016/j.chb.2012.07.024

Westin, A. F. (1967). Privacy and Freedom (Vol. 25). New York: Athenum.

Williams, P., Jenkins, J., Valacich, J., & Byrd, M. (2017). Measuring Actual Behaviors in HCI Research – A call to Action and an Example. AIS Transactions on Human-Computer Interaction. https://doi.org/10.17705/1thci.00101

Wilton, R. (2017). Trust and ethical data handling in the healthcare context. Health and Technology, 7(4), 569–578. https://doi.org/10.1007/s12553-017-0206-2

Woodward, A. (University of S. (2019). Health apps pose "unprecedented" privacy risks. BBC.

World Health Organisation. (2020). WHO Coronavirus Disease (COVID-19) Dashboard | WHO Coronavirus Disease (COVID-19) Dashboard. Retrieved June 29, 2020, from https://covid19.who.int/

Wright, K. (2002). Social support within an on-line cancer community: An assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. Journal of Applied Communication Research, 30(3), 195–209. https://doi.org/10.1080/00909880216586

Xu, H., Dinev, T., Smith, J., & Hart, P. (2011). Journal of the Association for Information Systems Information Privacy Concerns : Linking Individual Perceptions with Institutional Privacy Assurances Information Privacy Concerns : Linking Individual Perceptions with Institutional Privacy Assurances. Journal of the Association for Information Systems, 12(12), 798–824.

Zafarani, R., Abbasi, M. A., & Liu, H. (2014). Social media mining: An introduction. Social Media Mining: An Introduction. https://doi.org/10.1017/CBO9781139088510

Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B., & Zhu, Q. (2018). Health information privacy concerns, antecedents, and information disclosure intention in online health communities. Information and Management, 55(4), 482–493. https://doi.org/10.1016/j.im.2017.11.003

Zhao, L., Lu, Y., Wang, B., Chau, P. Y. K., & Zhang, L. (2012). Cultivating the sense of belonging and motivating user participation in virtual communities: A social capital perspective. International Journal of Information Management, 32(6), 574–588. https://doi.org/10.1016/j.ijinfomgt.2012.02.006

Zuboff, S. (2015). Big other: Surveillance Capitalism and the Prospects of an Information Civilization. Journal of Information Technology, 30(1), 75–89. https://doi.org/10.1057/jit.2015.5

Zuboff, S. (2019). The Age of Surveillance Capitalism. Profile Books.

APPENDICES

Appendix 1: Study 1 Supporting Materials

Appendix 1a: Study 1 Ethics Application Form

School of Computer Science
Research Ethics Checklist

for PGR students & staff

- This checklist must be completed for every research project that involves human participants, use of personal data and/or biological material, b*efore* potential participants are approached to take part in any research.
- Any significant change in the design or implementation of the research should be notified to cs-ethicsadmin@cs.nott.ac.uk and may require a new application for ethics approval.
- It is the applicant's responsibility to follow the University of Nottingham Code of Research Conduct and Research Ethics and any relevant academic or professional guidelines in the conduct of the study. **This includes providing appropriate information sheets, consent forms and recruitment materials, and ensuring confidentiality in the storage and use of personal data.**
- Completion of this form confirms that you have read and understood the guidelines at www.cs.nott.ac.uk/ethics regarding:
    - what is defined as *personal data;*
    - what is required for *valid consent;*
    - the key requirements of the Data Protection Act
- The supervisor/principal investigator is responsible for exercising appropriate professional judgement when completing Section VI of this form.

- **Sections I to V should be completed by the student or researcher undertaking the study. Section VI should be completed by the supervisor/principal investigator.**
- The **supervisor/principal investigator** is responsible for emailing the completed form to cs-ethicsadmin@cs.nott.ac.uk, and for providing feedback to the student/researcher.

SECTION I: Applicant Details	
1. Applicant's name	Kate Green
2. UoN Email address	Psxkg1@nottingham.ac.uk
3. Status	**PGR Student**
4. Student ID (PGR students only)	**4288178**
5. Supervisor/PI's name	Dr Elvira Perez
6. Supervisor/PI's email address	**Elvira.Perez@notingham.ac.uk**

SECTION II: Project Details	
1. Project title	Understanding the online Inflammatory Bowel Disease Community across forums, Facebook, Twitter and Instagram.
2. Proposed start date and latest end date of study	February 2018 – 31st August 2018
3. Date and version of this submission	**29th January 2018, V3**
4. Type of submission?	**Revision** *Some of the questions have been altered so that they are more guided by the literature.*
5. Application ID (if known[23])	CS-2017-R5

6. Description of Project, including aims/objectives and procedures. *Please include any information which may affect the consideration of the ethics involved, e.g. how participants will be recruited and rewarded, data to be collected/used (see also II.7), location of study, unusual circumstances, age range of participants:*

This study is situated in the wider scope of a multi-disciplinary PhD that explores how patients living with chronic illnesses come to share sensitive health information in and with platform providers. It will draw particular attention to how users trust platform providers and what they identify as perceived risks of sharing such information. This PhD will pay particular attention to Inflammatory Bowel Disease as an example of a chronic illness. While there is evidence to suggest why and how patients use the internet, there is a gap in the literature that addresses the uses of different platforms by patients.

The aim of this study is to better understand the Inflammatory Bowel Disease (IBD) community across different online platforms. It will explore disparities between demographics, user motivations and user behaviours across forums and social media platforms Facebook, Twitter and Instagram. It also will begin to discern user perceptions of sharing information about their health on the Internet.

During this study, semi-structured interviews will be conducted to provide rich descriptions of how the communities operate in different platforms. I will be interviewing representatives with expert-experiential knowledge of the communities in which they reside and participate in. They will share their perceptions of the demographics (age, sex, countries); motivations for using the platform; the platform features and what they afford; and, what behaviours to community members exhibit. They will also discuss how they perceive their online privacy when discussing their health. Since the online community is distributed all over the world, the interviews will take place through video or voice call through Skype/telephone. The data collected will be made into text form (transcriptions) and will be analysed with manual thematic analysis.

I will be approaching participants through the platforms they use. They will be Facebook Group administrators and frequent users, Twitter users with a significant presence in IBD conversations, Instagram users with significant presence in IBD community, as well as forum administrators and users. They will receive an information sheet about the project and will only participate if they give informed consent. Each participant will receive a compensation for their time in the form of a £10 voucher (or equivalent for participants overseas).

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[23] Normally each ethics application will be allocated an ID by the University *after* its initial submission

Some participants may use a pseudonym to disguise their real identity online. As part of the consent process, they will have to confirm that they are over 18 years old, self-report they feel well enough to participate, and sign their real name. However, all names (including pseudonyms) will be removed from the publicly available data to preserve anonymity.

7a. What is the source of funding for the project?	EPSRC (Horizon CDT PhD)
7b. Does the funder expect research data to be made available to others? *See SHERPA/JULIET* *http://www.sherpa.ac.uk/juliet/index.php*	**Yes**
7c. Will data from the project potentially support an academic publication? *(Not just a dissertation or assessment.)*	**Yes**

8. Will personal data (including photos, video or audio) or biological materials be collected, recorded or used?

Yes

If Yes, please give details below.
The interviews will be audio recorded. The recordings will be transcribed and these transcriptions will be used for analysis. The transcriptions will remove personal identifying information such as their name. The data will be saved securely at the University of Nottingham and only will the anonymised transcriptions be made publicly available.

What data *(or materials) will be collected or used*	Audio recordings from interviews will be collected for transcription and analysis.
*What if any **constraints** apply to use of this data (or materials)*	Participant consent.

How *will this data (or materials) be:*

collected or obtained	Phone/Skype interviews will be audio recorded
processed before analysis	Audio recordings will be transcribed. Transcripts will be de-identified, removing names and other personally identifying information.
stored and secured	Securely on University of Nottingham servers with password protection.
analysed	Thematic analysis of text will be conducted.
reported in publications	Participants will be referred to by their role (e.g. Facebook admin/user)
archived	Data that is published in a journal may be archived for 7 years, should participants consent.
***How** and **when** (if ever) will this data (or materials) be:*	
reused	Given the data (with consent) is publicly available after publication for 7 years, it cannot be predicted how it might be reused.
published or made available to others	Data sets will be anonymised before publication of any papers and the PhD thesis.
deleted or destroyed	Data will be deleted 7 years after PhD thesis has been submitted; however some data may be made public for journals with participants consent.

*If human subjects are involved then at what point(s) can they **withdraw** and what will happen in each case? (if no human subjects are involved enter "Not Applicable")*

Participants can withdraw from the study at any time. If they have already participated in the interview their data will be destroyed and thus discounted from analysis.

*What will happen to this data if/when you **leave** the University?*

The data will be destroyed when I leave the university.

SECTION III: Research Ethics Checklist (Part 1)

Please answer all questions:	**Yes/ No**
1. Does the study involve participants who are unable to give informed consent (e.g., children, people with learning disabilities or dementia[24], prisoners, your own students)?	No

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[24] If participants are adults who lack the mental capacity to give informed consent then you must obtain approval from an "appropriate body" approved by the Secretary of State (instead of this committee).

2. Will the study involve participants who are particularly vulnerable[25]?	Yes
3. Will it be necessary for participants to take part in the study without their knowledge and consent at the time (e.g., covert observation of people in non-public places)?	No
4. Will it be necessary for participants to be kept in ignorance, misled or deceived at any point in the study (e.g., if revealing the full aims of the project during the consent process would undermine the research)?	No
5. Will the study involve the discussion of sensitive topics (e.g., sexual activity, drug use)?	No
6. Will participants be asked to discuss anything or partake in any activity that they may find embarrassing or traumatic?	No
7. Is it likely that the study will cause offence to participants for reasons of ethnicity, religion, gender, sexual orientation or culture?	No
8. Are drugs, placebos or other substances (e.g., food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
9. Will body fluids or biological material samples be obtained from participants? (e.g., blood, tissue etc)	No
10. Is pain or more than mild discomfort likely to result from the study?	No
11. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	No
12. Will the study involve prolonged or repetitive testing for each participant?	No
13. Will financial inducement (other than reasonable expenses and compensation for time) be offered to participants?	No
14. Will the study involve the recruitment of patients, staff, tissue sample, records or other data through the NHS or involve NHS sites and other property?[26]	No
15. Will the study involve the use of animals?[27]	No

SECTION III: Research Ethics Checklist (Part 2)

Please answer all questions:	**Yes/No/NA**
1. For research conducted in public, non-governmental and private organisations and institutions (such as schools, charities, companies and offices), will approval be gained in advance from the appropriate authorities?	NA

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[25] "who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation" (Department of Health (2000): *No Secrets: guidance on protecting vulnerable adults in care)*

[26] If Yes then you must obtain NHS REC and R&D approvals from the relevant Trusts (instead of this committee).

[27] For work with animals always seek advice from the University's Animal Welfare and Ethical Review Body (AWERB). If the animal(s) are vertebrates or cephalopods then you must obtain approval from AWERB (instead of this committee).

2.	If the research uses human participants, personal data or the use of biological material, will explicit consent be gained?	Yes
3.	Will participants be informed of their right to withdraw from the study at any time, without giving explanation?	Yes
4.	If data is being collected, will this data be anonymised before publication or sharing?	Yes
5.	Will participants be assured of the confidentiality of any data?	Yes
6.	Will all data be stored in accordance with the Data Protection Act 1998?	Yes
7.	Will participants be informed about who will have access to the data?	Yes
8.	If quotations from participants will be used, will participants be asked for consent?	Yes
9.	If audio-visual media (voice recording, video, photographs etc) will be used, will participants be asked for consent?	Yes
10.	If digital media (e.g. computer records, http traffic, location logs etc) will be used, will participants be asked for consent?	NA
11.	If the research involves contact with children, will appropriate safeguards be in place (e.g. supervision, DBS checks if required)?	NA
12.	If research data itself is to be published, shared or reused (e.g. alongside a publication or in an archive) will participants be asked for consent?	Yes

- If you have answered ‘No’ to all questions in SECTION III Part 1 and ‘Yes’ to all relevant questions in SECTION III Part 2 the project is deemed to involve **minimal risk** - go to the signature page.

- If you have answered ‘Yes’ to any of the questions in Part 1 or ‘No’ to any of the questions in Part 2 the project is deemed to involve **more than minimal risk**. Please explain in SECTION IV why this is necessary and how you plan to deal with the ethical issues raised.

SECTION IV: If the project involves more than minimal risk, please explain why this is necessary and how you plan to deal with the ethical issues raised

I am aware that participants may be perceived as vulnerable given that the reason that I am approaching them is their involvement with a health community about their illness. Some patients that use online social platforms may not consider themselves as vulnerable, but might feel empowered to speak about their illness.

Sensitive to their health status, I decided to check ‘yes’ to give an opportunity to discuss how I will involve participants in an ethical way.

This study primarily focuses on the Inflammatory Bowel Disease online community, a health-support community where patients seek emotional and informational support. This study will be specifically asking community administrators and users for their personal uses and observations of the community. I will not view or collect any social media data from the communities. Participants will be asked to describe their observations without revealing identifiable information of any of the other community members, if they do, this information will be anonymised during transcription.

Some participants may be identified as ‘vulnerable’ given that they are likely to have Inflammatory Bowel Disease. It is a lifelong, incurable illness whereby patients go through unpredictable gastro-intestinal flare-ups that cause symptoms such as diarrhoea, fatigue and weight-loss.

Participants for this study will be recruited through open-calls on public platforms as well as being specifically invited because they have been identified as active online users, advocating for IBD and/or IBD support.

As part of the consent process, I will ask patients to self-declare that they feel well enough to participate in the study. If at any point they do not feel like participating, they may withdraw.

Participants will have the choice of how they wish to participate in the interview – with or without video. While email interviews are possible, there may be limitations in the data since there is not an opportunity to prompt or ask the participant to further explain a point.

After the ethics board approval, I will ask the first four participants for their feedback with regards to the clarity of the information and consent process. Should any revisions be made, they will be resubmitted to the ethics board. This is to ensure that patients are fully informed and have had the opportunity to comment on the study design.

RESEARCH ETHICS CHECKLIST – SIGNATURE PAGE

SECTION V: Applicant Declaration	
Please confirm each of the following statements:	**Yes/No**
The project is deemed to involve **minimal risk** as defined in SECTION III	**No**

I confirm that I have read the University of Nottingham Code of Research Conduct and Research Ethics		Yes
I confirm that I have read the guidance documents listed on page 1		Yes
I confirm that the information provided in this application is correct		Yes
Signature of applicant*	K Green	
Date	29th January 2018	

SECTION VI: Supervisor/PI Declaration

Please confirm each of the following statements:	**Yes/ No**
The participant information sheet or leaflet is appropriate for this research project**	**Yes**
The procedures for recruiting participants and obtaining informed consent are appropriate**	Yes
The collection and handling of data is appropriate and in accordance with the Data Protection Act	Yes
Signature of supervisor/PI*	
Date	23rd November 2017

** For email submission, please type your name in place of a signature.*

***All applications for projects involving human participants (or their tissue) must be accompanied by an information sheet, consent form and recruitment materials (e.g. posters, flyers, text for emails) where relevant.*

- The **supervisor/principal investigator** is responsible for emailing the completed form, together with any information sheets and consent forms, to cs-ethicsadmin@cs.nott.ac.uk.
- The **supervisor/principal investigator** is also responsible for providing feedback to the student/researcher following Ethics Committee consideration.

Appendix 1b: Study 1 Information Sheet

Study Title: Understanding the online Inflammatory Bowel Disease Community across forums, Facebook, Twitter and Instagram.

What is the study about?
As part of her PhD thesis, Kate is interested in learning more about how we use different social platforms to talk about Inflammatory Bowel Disease. This study is looking at patient motivations for joining social platforms and how they are used. She is also interested in sharing information about IBD on these platforms. The social platforms are forums, Facebook, Twitter and Instagram.

Why have you been asked to participate in the study?
You have been invited to join the study because you have been identified as someone who might have a lot of experience with using one or many social platforms to talk about IBD.

What does your participation entail?
Your participation includes one interview that can take place over Skype (with or without video) or phone call.

What data will be collected and how will it be used?
You will be asked to sign a consent agreement which will ask for some personal information. The interviews themselves will be audio-recorded.
The audio recordings will be transcribed into text that will be used for analysis. Personally identifying information (such as your name) will be removed from the transcriptions to make them anonymous. The anonymous transcripts will be used to support research publication (including PhD thesis) and presentations. You will only be identified in any resulting publications or presentations if you request this. This anonymous data may also be made available to other researchers.

How will your data be stored?
Your data will be stored securely on password-protected University-approved research storage in accordance with the Data Protection Act (1998). Only Kate Green and her supervisory research team will have authorised access to the full collected data. However, note that no computer system is completely secure, so it is always possible that a third-party could obtain copies of your data.
Your data will be destroyed up to 7 years after the PhD is submitted. Anonymous data sets may be publicly available during this time should you give consent.

Can you withdraw from the study?
Your participation is entirely voluntary and you may withdraw from the study at any time. If you withdraw after the interview has taken place, then your data will be removed from the analysis and deleted.
If you wish to withdraw then please inform Kate Green (kate.green@nottingham.ac.uk).

How will your time be compensated?
Your participation in the study is greatly appreciated and your time will be reimbursed with a £10 (or equivalent) shopping voucher.

Who is doing the study?

This research is being conducted by PhD candidate and IBD patient Kate Green from Horizon Digital Economy Research at the University of Nottingham. This research project is supported by the EPSRC funding body and Open Lab at Newcastle University. It has been reviewed and approved by the University of Nottingham, School of Computer Science Research Ethics Committee.

Who do you ask if you have further questions?

If you have **questions** please talk to a member of the research team, or after the event contact: Kate Green, Horizon Digital Economy Research, School of Computer Science, The University of Nottingham, Jubilee Campus, Nottingham NG8 1BB; email: kate.green@nottingham.ac.uk

Appendix 1c Study 1 Consent Form

Consent Form for: Understanding the online Inflammatory Bowel Disease Community across forums, Facebook, Twitter and Instagram.

Please tick the appropriate boxes	**Yes**	**No**
Taking Part		
I have read and understood the project information sheet dated [29/01/2018].	○	○
I have been given the opportunity to ask questions about the project.	○	○
I agree to take part in the project. Taking part in the project will include being interviewed either over voice/video call or text.	○	○
I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part.	○	○
I confirm that I feel well enough to be involved with this study	○	○
Use of the information I provide for this project only		
I understand my personal details such as phone number and Skype ID will not be revealed to people outside the project.	○	○
I understand that my words may be quoted in publications, reports, web pages, and other research outputs.	○	○
I understand that data that **cannot** identify me may be published on web pages or in databases to support such research outputs.	○	○
Please choose ***one*** *of the following two options:*		
I would like my real name used in the above	○	
I would **not** like my real name to be used in the above.	○	
Use of the information I provide beyond this project		
I agree for anonymised transcripts of my interview to be archived at the University of Nottingham for up to 7 years after PhD thesis publication.	○	○
I understand that other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
I understand that other authenticated researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	○	○
So we can use the information you provide legally		
I grant Kate Green a worldwide, non-exclusive, royalty-free, sub-licensable license to use, copy, distribute, display, excerpt and annotate any collected materials related to this project for which I hold the copyright (e.g. written and spoken responses) *only* for the purposes for which I have given consent.	○	○

____________________	____________________	__________
Name of participant	[printed] Signature	Date

Researcher [printed] Signature Date

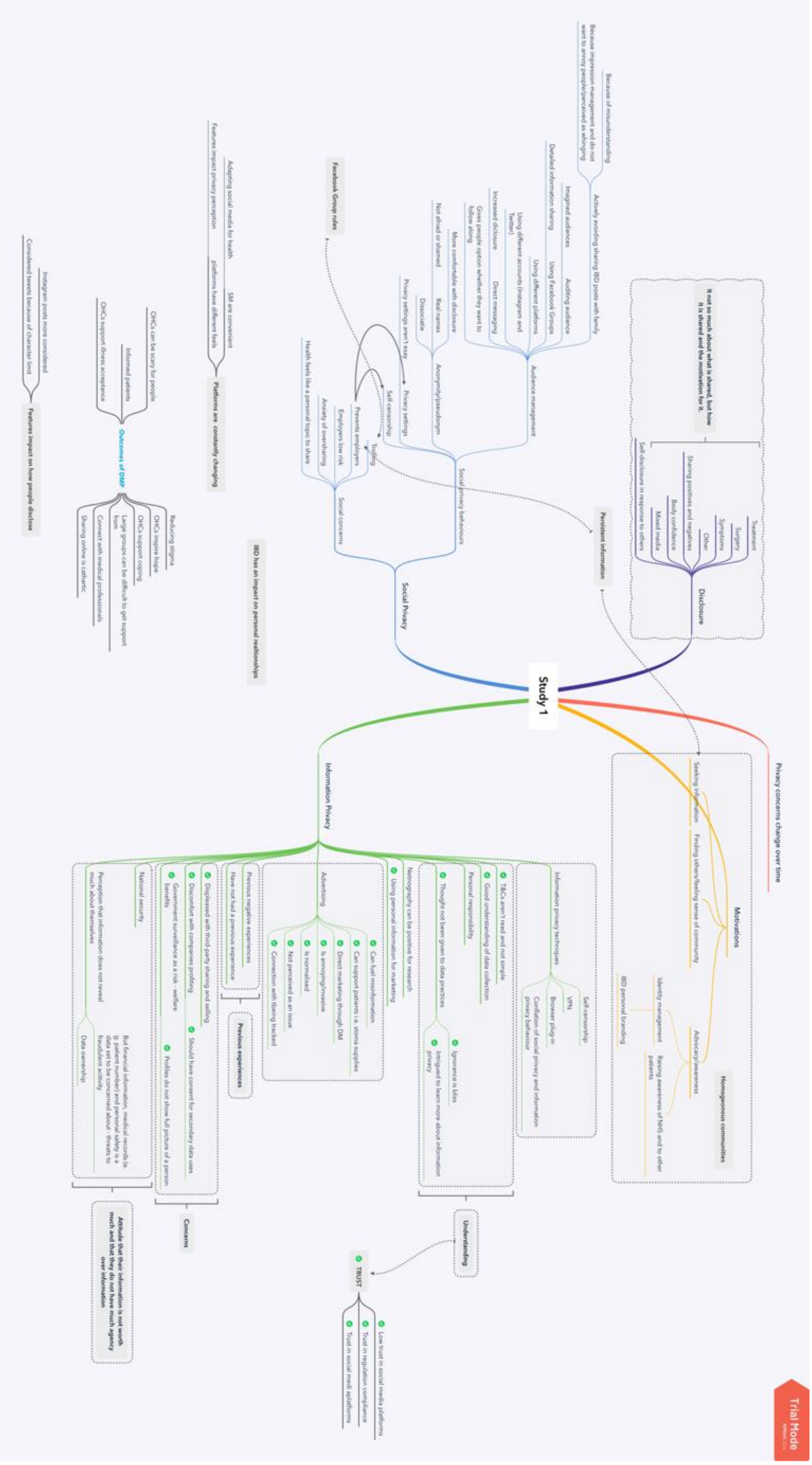
Project contact details for further information: Kate Green, kate.green@nottingham.ac.uk

Appendix 1d: Study 1 Interview Schedule

1. Semi-structured interview question schedule (and prompts)
    a. Please can you tell me about your journey with IBD?
    b. When were you diagnosed?
    c. How old were you at the time?
2. Can you tell me about how you have used the internet with regards to your IBD?
    a. When did you first go online?
    b. What did you want to do?
    c. Why did you want to do that?
3. Can you tell me about how you have used the Internet so speak to others with IBD?
    a. When did you first do this?
    b. What were you hoping would come out of it?
    c. How often do you go to the online community? (more than once a day/daily/weekly etc)
4. Do you find that you go online at any particular time of day?
5. Do you post about your IBD? What sorts of things do you share?
6. Do you share different elements about your IBD in different ways?
7. Do you post differently depending on how you are feeling?
8. Have you ever shared any pictures about your IBD?
9. Have you used different platforms over time? Can you tell me about how you have used them?
10. Do you currently use different platforms? Why is this?
11. What features do you like or find useful in each one?
12. What features do you not like or find limiting?
13. When you are on these different platforms, do you see any differences in what and how people post?
    a. Has this changed at all over time?
    b. What do other people share on the Internet?
    c. So do people ask questions? What kind of things do people ask about?
    d. Do people share information about their symptoms/surgery/medication?
14. Do you speak with anyone on private channels? What kinds of things are talked about in a private message.
15. Do you use your real name with your profiles?
    a. If not, then why not?
    b. Do other people use their real names?
16. How do you feel about sharing your health information on the Internet?
17. What are the benefits of sharing information about your IBD on the Internet?
18. Do you see any risks in sharing health information online?
19. Do you do anything to minimise these risks?
20. Do you have a preference over who can see information you post about your health?
21. How do you feel about friends/family/employers/co-workers/insurance companies/medical research/ commercial research/marketing companies/ advertising companies?
    a. Why is this?
22. What do you do to control who sees information you post about your health?
23. Do you know if the platforms you use have ‘privacy’ settings that you can change?
    a. (If yes) Have you changed your privacy settings?
    b. If yes, describe the changes you have made and why. If no, why not?
24. Have you read the privacy policy of the platform you are using?

25. Do you trust that this platform will protect information about your health? Why?
26. Do you know what data [the platform] collects about you?
27. What do you expect they do with this information?
    a. How does this make you feel?
28. Do you do anything to try and control what information [platform] collects about you?
    a. Why do you do this?
29. Is there a reason why you don’t control information what [platform] collects about you?
30. Do you have anything else you would like to add that you might think will contribute towards us better understanding the IBD online community?

Appendix 1e: Study 1 Thematic Map



Digital version available: https://kateoleary.net/supporting-mind-maps

Appendix 2: Study 2

Appendix 2a: Study 2 Ethics Application

School of Computer Science
Research Ethics Checklist

for PGR students & staff

- This checklist must be completed for every research project that involves human participants, use of personal data and/or biological material, b*efore* potential participants are approached to take part in any research.
- Any significant change in the design or implementation of the research should be notified to cs-ethicsadmin@cs.nott.ac.uk and may require a new application for ethics approval.
- It is the applicant's responsibility to follow the University of Nottingham Code of Research Conduct and Research Ethics and any relevant academic or professional guidelines in the conduct of the study. **This includes providing appropriate information sheets, consent forms and recruitment materials, and ensuring confidentiality in the storage and use of personal data.**
- Completion of this form confirms that you have read and understood the guidelines at www.cs.nott.ac.uk/ethics regarding:
  - what is defined as *personal data;*
  - what is required for *valid consent;*
  - the key requirements of the Data Protection Act
- The supervisor/principal investigator is responsible for exercising appropriate professional judgement when completing Section VI of this form.

- **Sections I to V should be completed by the student or researcher undertaking the study. Section VI should be completed by the supervisor/principal investigator.**
- The **supervisor/principal investigator** is responsible for emailing the completed form to cs-ethicsadmin@cs.nott.ac.uk, and for providing feedback to the student/researcher.

SECTION I: Applicant Details	
1. Applicant's name	Kate Green
2. UoN Email address	Psxkg1@nottingham.ac.uk
3. Status	**PGR Student**
4. Student ID (PGR students only)	**4288178**
5. Supervisor/PI's name	Dr Elvira Perez-Vallejos
6. Supervisor/PI's email address	**Elvira.Perez@notingham.ac.uk**

SECTION II: Project Details	
1. Project title	Benefits and concerns of using social media platforms from organisational perspectives.
2. Proposed start date and latest end date of study	1st May 2019 – 1st September 2019
3. Date and version of this submission	**29th April 2019, V2**
4. Type of submission?	**Re-submission with changes**
5. Application ID (if known[28])	CS-2018-R46

6. Description of Project, including aims/objectives and procedures. *Please include any information which may affect the consideration of the ethics involved, e.g. how participants will be recruited and rewarded, data to be collected/used (see also II.7), location of study, unusual circumstances, age range of participants:*

In my previous PhD study, I interviewed patients with Crohn's and Ulcerative Colitis who use social media as a means for engaging with the Inflammatory Bowel Disease (IBD) online health communities (OHC). The findings indicate that patients have a good grasp of social privacy concerns and mitigating actions to reduce risks. Patients demonstrated a low and varied understanding of how social media platforms collected and process their data, including self-disclosed health information. This low understanding of the digital economy precludes patients from perceiving potential risks around sharing information on commercial platforms not specifically designed for health-related communications.

This study aims to understand the perspective of the charitable organisations and community leaders around institutional privacy concerns. A group of participants from the organisation will be invited to take part in a focus group which will be split into three parts. The first part, Kate Green will present findings from study 1 to share knowledge. The second part, Kate will host a discussion with the participants around the findings, learning the perspectives from the organisation and further discussing key issues raised from study 1. The final part of the focus group will entail the discussion of future actions that can be taken to help improve the welfare of patients using social media to discuss their health.

I will be inviting organisations to be involved in this study through email and building rapport through subsequent phone calls. Prospective participants will be given an information sheet, privacy notice and consent form prior to participation.

The focus group will not take place without a consent form being received. Participants will be invited to join the focus group at their offices. It will be recorded through two voice recorders as well as notes taken during the process. The recordings will be transcribed and analysed through a coding structure previously used in the last study, identifying understanding, benefits and concerns around social media platforms. To preserve anonymity, names and job roles will be removed from the data set; participants will be referred to as a participant number.

7a. What is the source of funding for the project?	EPSRC (Horizon CDT PhD)

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[28] Normally each ethics application will be allocated an ID by the University *after* its initial submission

7b. Does the funder expect research data to be made available to others? *See SHERPA/JULIET* *http://www.sherpa.ac.uk/juliet/index.php*	**Yes**
7c. Will data from the project potentially support an academic publication? *(Not just a dissertation or assessment.)*	**Yes**

8. Will personal data (including photos, video or audio) or biological materials be collected, recorded or used?

Yes

If Yes, please give details below.
The focus group will be audio recorded. The recordings will be transcribed and these transcriptions will be used for analysis. The transcriptions will remove personal identifying information such as their name. The data will be saved securely at the University of Nottingham and only will the anonymised transcriptions be made publicly available.

What data *(or materials) will be collected or used*	Audio recordings from interviews will be collected for transcription and analysis. Any field notes taken on paper throughout the interviews.
What if any ***constraints*** *apply to use of this data (or materials)*	Participant consent.

How *will this data (or materials) be:*

collected or obtained	Face to face and will be audio recorded
processed before analysis	Audio recordings will be transcribed. Transcripts will be de-identified, removing names and other personally identifying information.
stored and secured	Securely on University of Nottingham servers with password protection.
analysed	Thematic analysis of text will be conducted.
reported in publications	Participants will be reported by their participant number to retain anonymity
archived	Data will be archived for 7 years after PhD submission. It will be archived on UoN servers until the 7 year period ends or when Kate leaves the university. In that case a downloaded copy of the anonymised data set will be stored on an encrypted hard drive by Kate Green.

How *and* ***when*** *(if ever) will this data (or materials) be:*

reused	Data may only be re-used by Kate Green in the 7 years following PhD thesis submission, the data set will not be publicly available.
published or made available to others	The data set will not be publicly available to others.
deleted or destroyed	Data will be deleted 7 years after PhD thesis has been submitted.

If human subjects are involved then at what point(s) can they ***withdraw*** *and what will happen in each case? (if no human subjects are involved enter "Not Applicable")*

Participants can withdraw from the study at any time. If they have already participated in the interview their data will be destroyed and thus discounted from analysis.

What will happen to this data if/when you ***leave*** *the University?*

The data will be deleted from University of Nottingham servers. A downloaded copy will be stored on an encrypted hard drive and kept in a secure location by Kate Green until 7 years after PhD submission, when it will be deleted.

SECTION III: Research Ethics Checklist (Part 1)

Please answer all questions:	**Yes/No**
16. Does the study involve participants who are unable to give informed consent (e.g., children, people with learning disabilities or dementia[29], prisoners, your own students)?	No
17. Will the study involve participants who are particularly vulnerable[30]?	No
18. Will it be necessary for participants to take part in the study without their knowledge and consent at the time (e.g., covert observation of people in non-public places)?	No
19. Will it be necessary for participants to be kept in ignorance, misled or deceived at any point in the study (e.g., if revealing the full aims of the project during the consent process would undermine the research)?	No
20. Will the study involve the discussion of sensitive topics (e.g., sexual activity, drug use)?	No
21. Will participants be asked to discuss anything or partake in any activity that they may find embarrassing or traumatic?	No
22. Is it likely that the study will cause offence to participants for reasons of ethnicity, religion, gender, sexual orientation or culture?	No
23. Are drugs, placebos or other substances (e.g., food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
24. Will body fluids or biological material samples be obtained from participants? (e.g., blood, tissue etc)	No
25. Is pain or more than mild discomfort likely to result from the study?	No
26. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	No

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[29] If participants are adults who lack the mental capacity to give informed consent then you must obtain approval from an "appropriate body" approved by the Secretary of State (instead of this committee).

[30] "who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation" (Department of Health (2000): *No Secrets: guidance on protecting vulnerable adults in care)*

27. Will the study involve prolonged or repetitive testing for each participant?	No
28. Will financial inducement (other than reasonable expenses and compensation for time) be offered to participants?	No
29. Will the study involve the recruitment of patients, staff, tissue sample, records or other data through the NHS or involve NHS sites and other property?[31]	No
30. Will the study involve the use of animals?[32]	No

SECTION III: Research Ethics Checklist (Part 2)

Please answer all questions:	**Yes/No/NA**
31. For research conducted in public, non-governmental and private organisations and institutions (such as schools, charities, companies and offices), will approval be gained in advance from the appropriate authorities?	Yes
32. If the research uses human participants, personal data or the use of biological material, will explicit consent be gained?	Yes
33. Will participants be informed of their right to withdraw from the study at any time, without giving explanation?	Yes
34. If data is being collected, will this data be anonymised before publication or sharing?	Yes
35. Will participants be assured of the confidentiality of any data?	Yes
36. Will all data be stored in accordance with the General Data Protection Regulation 2018?	Yes
37. Will participants be informed about who will have access to the data?	Yes
38. If quotations from participants will be used, will participants be asked for consent?	Yes
39. If audio-visual media (voice recording, video, photographs etc) will be used, will participants be asked for consent?	Yes
40. If digital media (e.g. computer records, http traffic, location logs etc) will be used, will participants be asked for consent?	NA
41. If the research involves contact with children, will appropriate safeguards be in place (e.g. supervision, DBS checks if required)?	NA
42. If research data itself is to be published, shared or reused (e.g. alongside a publication or in an archive) will participants be asked for consent?	Yes

- If you have answered ‘No’ to all questions in SECTION III Part 1 and ‘Yes’ to all relevant questions in SECTION III Part 2 the project is deemed to involve **minimal risk** - go to the signature page.

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[31] If Yes then you must obtain NHS REC and R&D approvals from the relevant Trusts (instead of this committee).

[32] For work with animals always seek advice from the University’s Animal Welfare and Ethical Review Body (AWERB). If the animal(s) are vertebrates or cephalopods then you must obtain approval from AWERB (instead of this committee).

- If you have answered 'Yes' to any of the questions in Part 1 or 'No' to any of the questions in Part 2 the project is deemed to involve **more than minimal risk**. Please explain in SECTION IV why this is necessary and how you plan to deal with the ethical issues raised.

SECTION IV: If the project involves more than minimal risk, please explain why this is necessary and how you plan to deal with the ethical issues raised

RESEARCH ETHICS CHECKLIST – SIGNATURE PAGE

SECTION V: Applicant Declaration		
Please confirm each of the following statements:		**Yes/No**
The project is deemed to involve **minimal risk** as defined in SECTION III		**No**
I confirm that I have read the University of Nottingham Code of Research Conduct and Research Ethics		Yes
I confirm that I have read the guidance documents listed on page 1		Yes
I confirm that the information provided in this application is correct		Yes
Signature of applicant*	K Green	
Date	22nd March 2019	

SECTION VI: Supervisor/PI Declaration		
Please confirm each of the following statements:		**Yes/No**
The participant information sheet or leaflet is appropriate for this research project**		**Yes**
The procedures for recruiting participants and obtaining informed consent are appropriate**		Yes
The collection and handling of data is appropriate and in accordance with the Data Protection Act		Yes
Signature of supervisor/PI*		
Date	22nd March 2019	

** For email submission, please type your name in place of a signature.*

***All applications for projects involving human participants (or their tissue) must be accompanied by an information sheet, consent form and recruitment materials (e.g. posters, flyers, text for emails) where relevant.*

- The **supervisor/principal investigator** is responsible for emailing the completed form, together with any information sheets and consent forms, to cs-ethicsadmin@cs.nott.ac.uk.

- The **supervisor/principal investigator** is also responsible for providing feedback to the student/researcher following Ethics Committee consideration.

Appendix 2b: Study 2 Information Sheet

Online health communities: understanding and improving the challenges facing Inflammatory Bowel Disease patients using social media platforms

What is the study about?

Kate Green is currently pursuing her PhD at the University of Nottingham under the supervision of Dr Elvira Perez Vallejos. As part of her PhD studies, she is interested in learning more about how patients with Inflammatory Bowel Disease (IBD) use social media platforms to talk about their health, as well as seek and share support. In a time when there are increasing reports around personal data use by companies, the PhD aims to explore the concerns shared by the IBD community.

This particular study focuses on organisations engaged with the IBD online community, who adopt social media platforms, to enable patients and carers to seek and share support. With the previous study focusing on the perceptions of users (IBD patients), this study aims to uncover the benefits and concerns of sharing personal health information on social media platforms, from an organisational perspective. Its second aim is to identify how patients' digital well-being can be improved to enable a safer online community.

Why have you been asked to participate in the study?

You have been invited to join the study because you have been identified as someone who is involved with an organisation that is engaged with the IBD online health community.

What does your participation entail?

You will be invited to a presentation given by Kate about the experiences and concerns shared by IBD patients, that were identified in her previous study. In a focus group setting with your colleagues, you will be asked a series of questions about your thoughts and opinions on these findings, giving you an opportunity to share your perspectives on the issues that have been raised. Following this, a scoping exercise will be undertaken to discuss the direction of what practically needs to be done next to improve the well being of patients using social media platforms for health-related communications.

What data will be collected and how will it be used?

You will be asked to sign a consent agreement which will ask for some personal information. The focus group will be audio-recorded and Kate may take written notes throughout.

The audio recordings will be transcribed into text that will be used for analysis. Personally identifying information (such as your name and role within the organisation) will be removed from the transcriptions to make them anonymous. You will be referred to as a participant number throughout the analysis process. The anonymous transcripts will be used to support research publication (including PhD thesis) and presentations. You will only be identified in any resulting publications or presentations if you request this in the consent form.

The data may be reused by Kate Green in future studies, until the data's deletion, 7 years following her PhD submission.

How will your data be stored?

Your data will be stored securely on password-protected University-approved research storage in accordance with the General Data Protection Regulation (2018). Only Kate Green and her supervisory research team will have authorised access to the full collected data. However, note that no computer system is completely secure, so it is always possible that a third-party could obtain copies of your data. If Kate Green leaves the University of Nottingham within the 7 years following PhD submission, the data will be removed from the University of Nottingham servers and stored on an encrypted hard drive by Kate Green.

Your data will be destroyed 7 years after the PhD is submitted and it will not be made publicly available.

Can you withdraw from the study?

Your participation is entirely voluntary and you may withdraw from the study at any time until publication. once the study is published (in conference proceedings, academic articles and/or in the PhD thesis) withdrawal is not possible. If you withdraw after the interview has taken place, then your data will be excluded from further use. A Privacy Notice can be found below.

If you wish to withdraw then please inform Kate Green (kate.green@nottingham.ac.uk).

What are the benefits of this study?

Your participation in this study will increase our knowledge around the benefits and concerns that are shared between patients and organisations around online health communications. These findings will be used to identify ways to improve the experience and safeguarding of patients online. The results will be made available to you as a thank you for your participation.

Who is doing the study?

This research is being conducted by PhD candidate and IBD patient Kate Green from Horizon Digital Economy Research at the University of Nottingham. This research project is supported by the EPSRC funding body. It has been reviewed and approved by the University of Nottingham, School of Computer Science Research Ethics Committee (CS-2018-R46)

.

Who do you ask if you have further questions?

If you have questions please talk to a member of the research team, or after the event contact: Kate Green, Horizon Digital Economy Research, School of Computer Science, The University of Nottingham, Jubilee Campus, Nottingham NG8 1BB; email: kate.green@nottingham.ac.uk

Appendix 2c: Study 2 Consent Form

Consent Form for: Online health communities: understanding and improving the challenges facing Inflammatory Bowel Disease patients using social media platforms

Please tick the appropriate boxes	**Yes**	**No**
Taking Part		
I have read and understood the project information sheet dated [26/04/2019].	o	o
I have been given the opportunity to ask questions about the project.	o	o
I agree to take part in the project. Taking part in the project will include focus group participation.	o	o
I understand that my taking part is voluntary; I can withdraw from the study at any time, until research publication, and I do not have to give any reasons for why I no longer want to take part.	o	o
Use of the information I provide for this project only		
I understand my personal details such as name will not be revealed to people outside the project.	o	o
I understand that my words may be quoted in publications, reports, web pages, and other research outputs.	o	o
Use of the information I provide beyond this project		
I agree for anonymised transcripts of my interview to be archived for up to 7 years after PhD thesis publication.	o	o
I understand that other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	o	o
I understand that other authenticated researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	o	o
So we can use the information you provide legally		
I grant Kate Green a worldwide, non-exclusive, royalty-free, sub-licensable license to use, copy, distribute, display, excerpt and annotate any collected materials related to this project for which I hold the copyright (e.g. written and spoken responses) *only* for the purposes for which I have given consent.	o	o

__________________________ _______________________ _________

Name of participant [printed] Signature Date

________________________ __________________ ________

Researcher [printed] Signature Date

Project contact details for further information: Kate Green, kate.green@nottingham.ac.uk

Appendix 2d: Focus Group Schedule

Study 2 Focus Group schedule

1. What are your thoughts on the findings that I shared with you?
    a. Bullet findings here
2. What do you think about the positive ways social media impacts patients?
3. Would you say that you are aware of some of the concerns around personal data use by social media platforms?
4. How do you feel about how personal data is used?
5. Do you feel that patients should have a better understanding about how it is used?
6. Do you feel that something should be changed?
    a. Either by social media companies
    b. Regulation
    c. Bottom up approaches
7. What do you think could be done to help improve patients' privacy on the internet?
8. If a learning intervention was designed for patients to learn about what happens with their information, how best do you feel the community responds to new information?

Appendix 2e: Focus group coding

Excerpts	Code	Theme
"I think it's more powerful when it's coming from patients than from the national charity. Because these companies want to know the patients – companies the NHS, doctors and surgeons they want to hear from the patient not from the institution or a charity. We live it, we know it." (P2: FG2) "I think is the sharing of information and I think that's really powerful. Particularly around standards of care, so there's a real mixed up experiences of healthcare across the country even though we have one NHS it's very different between hospitals in different locations. So although there are things like the standards, there still not everywhere, or on a select basis. So it's made patients have the knowledge of what the standard of care should be or could be and it's helping to see that. So from healthcare research it takes about 17 years from research to make it back to the actual practice. Whereas with social media we can help accelerate that." (P3: FG2)	Impact on treatment and care	**Digital civic engagement**
"It's the access because that is then the gateway to every other thing that we have – the groups, pages, connections, friends, support it just unlocks it all" (P4: FG2)	Easy access to social media and support	
"So they've consent in a legal, so legally we're fine. But whether they legally understand what that's meant." (P2: FG1) "the problem is that people likely are going with Facebook, not especially Instagram but people may have signed up seven or eight years ago so maybe there's some whether they may be obliged every two or three years to say 'by the way here are the terms and conditions'" (P3: FG1) "The benefits that everybody's getting now, that outweighs the small print doesn't it, they could spend three hours reading that or they could be using the platform. That three hours could be really important. That's how we are now, we quickly do something and onto something else. It's just accepted where we just want things to go away and move on.: (P1: FG2)	Terms and conditions	**Current privacy awareness challenges**
"Because it's so complicated and none of us will ever get to grips with how it is behind the scenes I think the message should just be careful how you use it" (P2: FG1)	Complexities of digital economy and algorithms	

"I get a sense just from my social networks that people are just a bit resigned to it, it's become so big that you possibly couldn't keep tabs on it all." (P2: FG1)		
"But it's not considered until a need. i.e. something goes wrong or they're not happy about" (P4: FG2) "If negative impacts can be identified first then it's a lot easier to say 'in order to avoid this, we suggest you do this' but we don't really know what if anything is happening.: (P3: FG1)	Need for precedent	
"that's why when there's a disruption in a Facebook Group, it's not our issue, it's Facebook's issue because they are the data controllers for Facebook." (P1: FG2) "One thing I do wonder with recent times whether GDPR has been a bit of false sense of security for people because that's abit of a mine field in itself trying to get your head around all of that, but I do wonder if people think 'there's the new rules in now and they can only do this and that with my information and you have to opt in and if you havent' opted in then it's fine' so whether or not there is also a little bit of eople who have relaxed thinking that they're all covered by that nowadays." (P2: FG1)	Awareness and understanding of GDPR	
"I suppose a negative of that is people with a cure they can target people and like.. they've changed it now so you can't see the members that are in a group. Whereas before people were adding people because they could see that they were in the group and they were targeting. I suppose that's more on Instagram these days how these companies will see who they're all following and give them all them an inbox so that's a negative of that information being out there because you can find all these people." (P2: FG2) "It's almost better to have personalised ads because there's a new thing that Facebook has talked about, that you can opt out. It looks like they're going down the route of you have to opt out of individual websites, you can't just opt out of everything. I think that's the way it's going but also there is an advantage of not doing that because at least you will see ads that are relevant to you. You're still going to get ads." (P3: FG2)	Advertisements	**Phenomenology – Doesn't feel like a privacy invasion/harm.**
"I think it's accepted that you're going to see adverts regardless so do you want to see adverts that are tailored to you or do you just want rubbish in your newsfeed so in a way you give in and say sure, at	Normalised experience	

least it's what I'm interested in rather than all the things that I don't need." (P1: FG2)		
"the problem is that people likely are going with Facebook, not especially Instagram but people may have signed up seven or eight years ago so maybe there's some whether they may be obliged every two or three years to say 'by the way here are the terms and conditions'" (P3: FG1)	Long term users	
"We've got people who have changed their names on Facebook purely for that reason. They click to join again and I think that's the same person. They said they had to change their name because of it." (P2: FG2)	Welfare benefits	**Legitimate 3rd party access**
"Certainly employers check out. A massive amount of them check on people's social media." (P3: FG1)	Employment	
"So for instance, if someone comes to our website and they're signed into Facebook, we've got the pixel so we pick them up and then we are at the moment we are running a membership ad. It's free membership so it's not like we're trying to make money out of them. So I guess we can claim a bit of moral highground because they've been on our website, we can assume they have some kind of interest in childrhood IBD. And now we're saying with a free membership you get this, this, this and this, join us. We've had at least one person sign up but whether she was on our website or just through Facebook… Anyway! So in that particular instance and we've done the classic advertising thing, in my mind, there is a moral purpose to it." (P1: FG1)	Charities	
"You wouldn't do it anyway but you've got to go by your guidelines but somebody else, what might be common sense for your average person, but sometimes that doesn't always happen online." (P4: FG2)	Personal responsibility	**Responsibilities**
"I guess in the sense that there's a reason for someone with a health condition to go back because they can use that, but at the same time they might be scrolling through their feed.. because they're in a crohn's forum they're then on Facebook another hour each day but I can see, I can imagine there are members… 'we've set up a forum on Facebook, and while oyu're in tehre you won't get anything market anything at you, but the reason why Facebook is letting us do it is because you'll be on their platform for longer each day which means that you'll see more shoe adverts' they might start saying 'hang on why are you serving the beast of capitalism?'" (P1: FG1)	Self-regulation by social media platforms	

"he's Facebook's PR type thing and he said a couple of weeks ago that it's not up to Facebook to self regulate, governments need to do it." (P3: FG1)		
"I think it would be worthwhile for Governments but I just can't see individuals organisations taking responsibility and if they did they would all have different methods. It has to be government thing." (P3: FG1)	Government regulation	
"I guess you can only do what is in your power to do unless you're going to do something that's permanently managed by yourself i.e. outside Facebook, Instagram whatever and you can set the rules from the very beginning." (P4: FG2) "Our ideal scenario, it will never work. Or won't anymore is for the reason that it's where everyone is and if everyone would come to the CICRA website and do it on the website brilliant. But in reality that's just – in some places they have those long-standing forums and they're still very popular but a lot of charities that have no got that length of service or for various reasons it's kind of, they've ended up getting rid of their own and using Facebook." (P1: FG1)	Independent platforms	**Alternative interventions**
"Or something just as you're about to post, at the bottom that says 'be warned' some kind of warning or a reminder of what they're about to put out there is going to be out there," (P 2, FG1). "It's like now with them cookies you go onto websites. You just go yes, 'cos you're just like 'I wanna see what I wanna see' it's just there, go away." (P2, FG2).	Pop-up warnings	
"It would have to be simple, easy on the eye. Engaging for people. I know it's a bit different but I seen the Lifeboat Association stories on Instagram just telling you what to do if you fall in cold water, it's literally like a 6 second ad but I remember it now. It was a six second thing. Something really engaging can really work – that ad has stuck with me all day I can remember it now." (P4: FG2) "It is about keeping it simple isn't it. I think as the generations go through school. I mean my six year old talks to me about internet safety and she doesn't use the internet. She's got it from school. She says things and I'm like alright okay. We have been offered workshops to go in and talk to people around internet safety. I think they are becoming more aware of it, so	Information guide	

having a reminder and you know maybe if you want to know more, go here so that it’s not in your face too much.” (P2: FG1)		
“Yeah it’s true and why is it then another thing to go and check. So how do you manage that and being aware with what’s wrong and I think it’s important that we help educate people as much as we can but I also think that we can go too far and then scare the people” (P3: FG2)	Requirement for support	**Ethical considerations**
“I think people throw caution to the wind; they know that the same type of support isn’t available elsewhere so they say they’ll have the trade-off because they need that support system.” (P1: FG2) “I think sometimes when you – sometimes they’re in such a state – a lot of people in groups they need support cos they’re in a bad place or they’re looking for friends. So I know it sounds – they’re at a level when they’re probably like ‘I don’t even care - they’re not bothered about all that but they don’t think about it until later on when they’ve got the help they need. They just need—desperation yeah – they just need someone to tell them that it’s normal to feel like this or think like this.” (P2: FG2)	Requirement for support	

Appendix 3: Study 3

Appendix 3a: Study 3 Ethics Application

School of Computer Science
Research Ethics Checklist

for PGR students & staff

- This checklist must be completed for every research project that involves human participants, use of personal data and/or biological material, b*efore* potential participants are approached to take part in any research.
- Any significant change in the design or implementation of the research should be notified to cs-ethicsadmin@cs.nott.ac.uk and may require a new application for ethics approval.
- It is the applicant's responsibility to follow the University of Nottingham Code of Research Conduct and Research Ethics and any relevant academic or professional guidelines in the conduct of the study. **This includes providing appropriate information sheets, consent forms and recruitment materials, and ensuring confidentiality in the storage and use of personal data.**
- Completion of this form confirms that you have read and understood the guidelines on the CS Intranet regarding:
  - what is defined as *personal data;*
  - what is required for *valid consent;*
  - the key requirements of the Data Protection Act (2018), which includes GDPR
- The supervisor/principal investigator is responsible for exercising appropriate professional judgement when completing Section VI of this form.
- **Sections I to V should be completed by the student or researcher undertaking the study. Section VI should be completed by the supervisor/principal investigator.**
- The **supervisor/principal investigator** is responsible for the submission of the completed form to cs-ethicsadmin@cs.nott.ac.uk and for providing feedback to the student/researcher if needed.

SECTION I: Applicant Details	
1. Applicant's name	Kate Green
2. UoN Email address	Psxkg1@nottingham.ac.uk
3. Status	**PGR Student**
4. Student ID (PGR students only)	**4288178**
5. Supervisor/PI's name	Elvira Perez-Vallejos
6. Supervisor/PI's email address	**mszep@exmail.nottingham.ac.uk**

SECTION II: Project Details	
1. Project title	**Understanding attitudes to learning about online privacy with awareness raising tools**
2. Proposed start date and latest end date of study	**1st January – 28th February 2020**
3. Date and version of this submission	**4th December 2019, Version 2**
4. Type of submission?	**First submission**
5. Application ID (if known[33])	**CS-2019-R12**

6. Description of Project, including aims/objectives and procedures. *Please include any information which may affect the consideration of the ethics involved, e.g. how participants will be recruited and rewarded, data to be collected/used (see also II.7), location of study, unusual circumstances, age range of participants:*

Overview
Previous research indicates that individuals with a health condition are more sensitive to privacy concerns than healthy individuals (Bansal et al., 2010; Tisnado et al., 2006). However, privacy on the internet can be split into two types: 'social privacy' which is the control of information flows with other people using the internet, and, 'information privacy' which is the control of information flows with companies, government and other organisations.

Privacy research in online health communities have focused on the former (Frost et al., 2016; Brady et al, 2016; Patterson, 2013), indicating that people with a health condition carefully manage their health disclosure on the internet. My first PhD study conducted in 2018 highlighted the nuanced ways people leverage privacy settings and multiple accounts to control what audiences have access to what they share about their health on social media. With a qualitative understanding of how 38 people living with Inflammatory Bowel Disease (IBD) perceive their information and social privacy, this study takes a quantative approach to discover whether these findings are substantiated at scale.

It was clear from my second study (2019) that IBD online community leaders and representatives from a charitable organisation believe that the lack of data literacy of patients is a concern and that they should have an increased level of awareness to how information is collected and used by online platform providers. The second part of this study explores the IBD community's attitudes to learning more about information privacy and what are the barriers to learning.

Aims
1. To quantifiably examine social and information privacy attitudes amongst patients with Inflammatory Bowel Disease using social media platforms for support.
2. To identify the appetite to learn more about information privacy through self-reported surveys and through demonstrated activity to learn.
3. Understand what are the barriers to learn
4. Draw comparisons between patients with IBD with 'healthy' individuals; do people with a health condition still perceive higher privacy concerns, as according to Bansal et al (2010) and Tisnado (2006).

Recruitment
- IBD Participants will be recruited through Twitter, Instagram as well as through Facebook Groups (with permission from group admins).

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[33] Normally each ethics application will be allocated an ID by the University *after* its initial submission

- ‘Healthy’ participants will be recruited through Twitter, Instagram and email.
- Participants (if they consent) will be put into a prize draw for a Amazon gift card of £100.
- Participation is voluntary

Sample

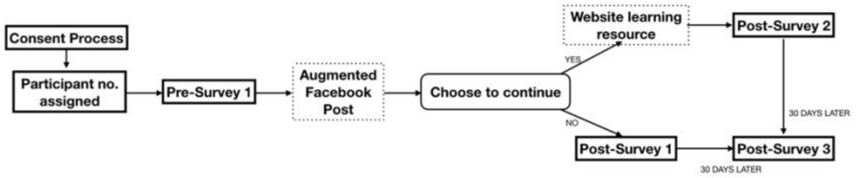
- Participants who are considered ‘healthy’ (without chronic illness)
- Participants who are individuals with IBD
- Participants are over 18 years
- IBD Participants must use Facebook, Twitter and/or Instagram for health-related communications

Study Procedure

The study will take place remotely over the internet. This study is broken down into different stages (Figure 1). Following a consent procedure individuals are directed to the study. Participants answer a survey (Pre-Survey 1) before being directed to an augmented snapshot of Facebook/Instagram/Twitter. On this screenshot of a social media page, there will be a post inserted onto the feed. Participants will be asked to view the augmented post and asked if they would like to learn more. This acts as the primary ‘intervention’ designed to encourage critical thinking.

Under the screen shot, participants are asked whether they wish to learn more about their digital footprints. The ‘YES’ will hyperlink to the website resource while ‘NO’ links to Post-Survey 1. For participants choosing ‘YES’, after two hours of submitting Pre-Survey 1, they will be emailed with a link to complete Post-Survey 2.

After one month all participants are emailed with Post-Survey 3.



Data collection

Data will be mostly quantitative and with some qualitative answers. Participants will be asked to undertake a pre-survey that will employ likert scales to measure their privacy preferences, awareness of data collection practices and appetite to learn. Demographic information such as age, gender and education will be collected at this point to analyse whether there are any disparities between different demographics and attitudes to privacy. The surveys following the interventions will employ likert scales to measure any attitude change towards privacy and appetite to learn.

Email addresses will be collected throughout the study to link survey responses to a particular participant. The email addresses will be replaced in the data set with a participant number. The participant number log, that details what email addresses belong to each participant, will not be used for data analysis and shall only be retained to identify survey responses for deletion, in the event of consent withdrawal.

Ethical considerations

The priority for the intervention design is that it is informative, balanced and provides tools for individuals to take more control over their personal data, if they wish to. There is a risk that raising awareness of some of the negative privacy outcomes from using social media could lead individuals to withdraw from using the web to connect with others and seek support. In order to mitigate this risk, the designed interventions (the social media post and website resource) have been assessed by a Public Patient Involvement panel who have deemed the resources suitable for the community. Should individuals require further support, Kate Green’s email will be available through the project’s documentation as well as on the website.

Individuals’ names and email addresses will be removed from the dataset to anonymise participants’ involvement.

The dataset will be stored on UoN servers (or until Kate leaves the university, where it will be stored on an encrypted hard drive) and deleted after 7 years following her PhD submission.

References

Bansal, G., Zahedi, F., & Gefen, D. (2010). The impact of personal dispositions on information sensitivity, privacy concern and trust in disclosing health information online. Decision Support Systems.

Brady, E., Segar, J. & Sanders, C. (2016). “I Always Vet Things”: Navigating Privacy and the Presentation of Self on Health Discussion Boards Among Individuals with Long-Term Conditions. Journal of Medical Internet Research.

Frost, J., Vermeulen, I., Beekers, N. (2014). Anonymity Versus Privacy/ Selective Information Sharing in Online Cancer Communities. Journal of Medical Internet Research

Patterson, H. (2013). Contextual Expectations of Privacy in Self-Generated Health Information Flows. TPRC 41: The 41st Research Conference on Communication, Information and Internet Policy

Tisnado, D., Adam, J., Liu, H., Damberg, C., Hu, F.A., Chen, W., Carlisle, D., Mangione, C., Kahn, K. (2006). Does the concordance between medical records and patient self-report vary with patient characteristics? Health Serv Outcomes Res Method (2006) 6:157–175

7a. What is the source of funding for the project?	EPSRC (Horizon CDT)
7b. Does the funder expect research data to be made available to others? *See SHERPA/JULIET* *http://www.sherpa.ac.uk/juliet/index.php*	**Yes**
7c. Will data from the project potentially support an academic publication? *(Not just a dissertation or assessment.)*	**Yes**

8. Will personal data (including photos, video or audio) or biological materials be collected, recorded or used?

Yes

If Yes, please give details below.

What data *(or materials) will be collected or used*	Demographic information (age, gender, education, diagnosis) through surveys. Attitude surveys.
What if any ***constraints*** *apply to use of this data (or materials)*	
How *will this data (or materials) be:*	
collected or obtained	Through surveys.
processed before analysis	Participants will be given a participant number for their surveys. Names and emails will not be collected in the dataset. The survey results will be presented in a spreadsheet.
stored and secured	Securely on University of Nottingham servers with password protection or on an encrypted hard drive if Kate Green leaves the University of Nottingham.
formatted	
organised	*Standard structure*

analysed	Statistical analysis; thematic analysis for qualitative data.
reported in publications, including reports and dissertations	The raw dataset will not be made public. Tables of statistical results will be used to demonstrate findings. Direct quotes may be used in results, but will not be attributed to any person's name.
***How** and **when** (if ever) will this data (or materials) be:*	
reused	Data may only be re-used by Kate Green in the 7 years following PhD thesis submission, the data set will not be publicly available.
archived, indexed, published or otherwise made available to others	*The data set will be available to read by supervision team during the PhD.*
deleted or destroyed	Data will be deleted 7 years after PhD thesis has been submitted. A calendar reminder (on work and personal calendars to ensure reminders aren't deleted) will be set for the deletion date when the thesis has been agreed, witnessed by supervisors.

*If human subjects are involved then at what point(s) can they **withdraw** and what will happen in each case? (if no human subjects are involved enter "Not Applicable")*

They can withdraw at any time, until results are published in the PhD thesis or research journal/conference papers

*What will happen to this data if/when you **leave** the University?*

The data will be deleted from University of Nottingham servers. A downloaded copy will be stored on an encrypted hard drive and kept in a secure location by Kate Green until 7 years after PhD submission, when it will be deleted.

9. Will personal data or commercially sensitive (i.e. "restricted") data be collected or stored?

Yes

If Yes, please give details below for the University data asset inventory.

***Title** of data asset*	*KG-PhD-Study3-IBD*
***What** personal/sensitive information (fields) does it contain?*	IBD Diagnosis
*Data **owner***	*Kate Green*
*Data **stewards** (and responsibilities)*	*Elvira Perez Vallejos, Supervisor*
*Data **users***	*Kate Green, Elvira Perez Vallejos, Neil Coulson and Derek McAuley*
*Data **location***	*University of Nottingham Microsoft One Drive*

SECTION III: Research Ethics Checklist (Part 1)

Please answer all questions:	**Yes/No**

31. Does the study involve participants who are unable to give informed consent (e.g., children, people with learning disabilities or dementia[34], prisoners, your own students)?	No
32. Will the study involve participants who are particularly vulnerable[35]?	No
33. Will it be necessary for participants to take part in the study without their knowledge and consent at the time (e.g., covert observation of people in non-public places)?	No
34. Will it be necessary for participants to be kept in ignorance, misled or deceived at any point in the study (e.g., if revealing the full aims of the project during the consent process would undermine the research)?	No
35. Will the study involve the discussion of sensitive topics (e.g., sexual activity, drug use)?	No
36. Will participants be asked to discuss anything or partake in any activity that they may find embarrassing or traumatic?	No
37. Is it likely that the study will cause offence to participants for reasons of ethnicity, religion, gender, sexual orientation or culture?	No
38. Are drugs, placebos or other substances (e.g., food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?	No
39. Will body fluids or biological material samples be obtained from participants? (e.g., blood, tissue etc)	No
40. Is pain or more than mild discomfort likely to result from the study?	No
41. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	No
42. Will the study involve prolonged or repetitive testing for each participant?	No
43. Will financial inducement (other than reasonable expenses and compensation for time) be offered to participants?	No
44. Will the study involve the recruitment of patients, staff, tissue sample, records or other data through the NHS or involve NHS sites and other property?[36]	No
45. Will the study involve the use of animals?[37]	No

SECTION III: Research Ethics Checklist (Part 2)

Please answer all questions:	**Yes/No/NA**

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[34] If participants are adults who lack the mental capacity to give informed consent then you must obtain approval from an "appropriate body" approved by the Secretary of State (instead of this committee).

[35] "who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation" (Department of Health (2000): *No Secrets: guidance on protecting vulnerable adults in care)*

[36] If Yes then you must obtain NHS REC and R&D approvals from the relevant Trusts (instead of this committee).

[37] For work with animals always seek advice from the University's Animal Welfare and Ethical Review Body (AWERB). If the animal(s) are vertebrates or cephalopods then you must obtain approval from AWERB (instead of this committee).

43. For research conducted in public, non-governmental and private organisations and institutions (such as schools, charities, companies and offices), will approval be gained in advance from the appropriate authorities?	Yes
44. If the research uses human participants, personal data or the use of biological material, will explicit consent be gained?	Yes
45. Will participants be informed of their right to withdraw from the study at any time, without giving explanation?	Yes
46. If data is being collected, will this data be anonymised before publication or sharing?	Yes
47. Will participants be assured of the confidentiality of any data?	Yes
48. Will all data be stored in accordance with the Data Protection Act?	Yes
49. Will participants be informed about who will have access to the data?	Yes
50. If quotations from participants will be used, will participants be asked for consent?	Yes
51. If audio-visual media (voice recording, video, photographs etc) will be used, will participants be asked for consent?	NA
52. If digital media (e.g. computer records, http traffic, location logs etc) will be used, will participants be asked for consent?	NA
53. If the research involves contact with children, will appropriate safeguards be in place (e.g. supervision, DBS checks if required)?	NA
54. If research data itself is to be published, shared or reused (e.g. alongside a publication or in an archive) will participants be asked for consent?	NA

- If you have answered ‘No’ to all questions in SECTION III Part 1 and ‘Yes’ to all relevant questions in SECTION III Part 2 the project is deemed to involve **minimal risk** - go to the signature page.

- If you have answered ‘Yes’ to any of the questions in Part 1 or ‘No’ to any of the questions in Part 2 the project is deemed to involve **more than minimal risk**. Please explain in SECTION IV why this is necessary and how you plan to deal with the ethical issues raised

SECTION IV: If the project involves more than minimal risk, please explain why this is necessary and how you plan to deal with the ethical issues raised

RESEARCH ETHICS CHECKLIST – SIGNATURE PAGE

SECTION V: Applicant Declaration	
Please confirm each of the following statements:	**Yes/No**
The project is deemed to involve **minimal risk** as defined in SECTION III	**Yes**
I confirm that I have read the University of Nottingham Code of Research Conduct and Research Ethics	Yes
I confirm that I have read the guidance documents listed on page 1	Yes
I confirm that the information provided in this application is correct	Yes
Signature of applicant*	K Green
Date	30th October 2019

SECTION VI: Supervisor/PI Declaration	
Please confirm each of the following statements:	**Yes/No**
The participant information sheet or leaflet is appropriate for this research project**	
The procedures for recruiting participants and obtaining informed consent are appropriate**	
The collection and handling of data is appropriate and in accordance with the Data Protection Act	
Signature of supervisor/PI*	
Date	

** For email submission, please type your name in place of a signature.*

***All applications for projects involving human participants (or their tissue) must be accompanied by an information sheet, consent form, privacy notice and recruitment materials (e.g. posters, flyers, text for emails) where relevant.*

- The **supervisor/principal investigator** is responsible for the submission of the completed form, together with any associated material (information sheets, etc.), which should be emailed to cs-ethicsadmin@cs.nott.ac.uk

- The **supervisor/principal investigator** is also responsible for providing feedback to the student/researcher following Ethics Committee consideration if needed.

Appendix 3b: Study 3 Information Sheet

PROJECT INFORMATION

Date: 30/10/2019]

Project: Understanding attitudes to learning about online privacy in the IBD online community with awareness raising tools

School of Computer Science Ethics Reference: [CS-2019-R12]

Funded by: Horizon Centre for Doctoral Training at the University of Nottingham (RCUK Grant No. EP/L015463/1)

Purpose of the research. Kate Green is currently pursuing her PhD at the University of Nottingham under the supervision of Dr Elvira Perez Vallejos, Prof Derek McAuley and Prof Neil Coulson. In a time when there are increasing reports around personal data use by companies, the PhD aims to explore what members of the Inflammatory Bowel Disease (IBD) community think about online privacy. As part of the final study for her PhD studies, she is focusing on the privacy attitudes of patients with IBD, their understanding of data collection practices and their appetite to learn more about online privacy.

This particular study's aim is to understand the widespread privacy perceptions of the IBD community and individuals'' attitudes to learning more about online privacy.

Nature of participation. You will be invited to answer a survey and engage with online resources that are aimed to increase awareness of the data collection practices on the internet. You will also be invited to a second survey immediately after your engagement with the materials, and a third one month later. You can do this from your internet-connected devices from home and can take anywhere between 10 and 40 minutes, depending on your engagement.

Benefits and risks of the research. You will have the opportunity to learn more about data collection practices and how information is processed about you on the internet. If you consent, you will be entered into a prize draw with the chance of winning £100 Amazon Voucher.

Your participation will be critical in helping us further understand the complexities of issues facing patients seeking support on social media. It will provide new insights into what people think about online as well as how interested people are in learning more about this area. This knowledge will be useful for charities, researchers, policy makers and online platforms.

Use of your data. You will be invited to review and agree to a consent agreement, which will ask for some personal information. Personally identifying information (such as your name and email) will be removed from the raw dataset to make your contribution anonymous and you will be referred to as a participant number throughout the analysis process. Your email address will be stored to correspond with you throughout the study and to log your participant number, so we can find your data if you decide to withdraw. Your email address will be only made available to Kate and her supervisors. If you consent, you may be contacted if you win the prize draw.

The anonymized data set will be used to support research publication (including PhD thesis) and presentations. Please note the raw data will not be shared beyond the research team (Kate Green and her supervisors). Direct quotes from the surveys may be used only if you provide consent. The data may be reused by Kate Green in future studies, until the raw dataset is deleted, 7 years following her PhD submission (due September 2020).

Storage of your data. Your data will be stored securely on password-protected University-approved research storage in accordance with the General Data Protection Regulation (2018). Only Kate Green and her supervisory research team will have authorised access to the collected data. However, note that no computer system is completely secure, so it is always possible that a third-party could obtain copies of your data. If Kate Green leaves the University of Nottingham within the 7 years following PhD submission, the data will be removed from the University of Nottingham servers and stored on an encrypted hard drive by Kate Green. Your data will be destroyed 7 years after the PhD is submitted and it will not be made publicly available.

Further questions. If you have questions please talk to a member of the research team, or after the event contact: Kate Green, Horizon Digital Economy Research, School of Computer Science, The University of Nottingham, Jubilee Campus, Nottingham NG8 1BB; email: kate.green@nottingham.ac.uk

Procedure for withdrawal from the research. You may withdraw from the study at any time and do not have to give reasons for why you no longer want to take part. If you withdraw, your anonymised data will be removed from analysis and will not be quoted in publications. Please note that data deletion is not possible after the results have been published in the thesis and other publications. If you receive no response from the researcher please contact the School of Computer Science's Ethics Committee. If you wish to withdraw then please inform Kate Green (kate.green@nottingham.ac.uk).

Contact details of the ethics committee. If you wish to file a complaint or exercise your rights you can contact the Ethics Committee at the following address: cs-ethicsadmin@cs.nott.ac.uk

PRIVACY NOTICE

The University of Nottingham is committed to protecting your personal data and informing you of your rights in relation to that data. The University will process your personal data in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 and this privacy notice is issued in accordance with GDPR Articles 13 and 14.

The University of Nottingham, University Park, Nottingham, NG7 2RD is registered as a Data Controller under the Data Protection Act 1998 (registration No. **Z5654762,** https://ico.org.uk/ESDWebPages/Entry/Z5654762**).**

The University has appointed a Data Protection Officer (DPO). The DPO's postal address is:

Data Protection Officer,
Legal Services
A5, Trent Building,
University of Nottingham,
University Park,
Nottingham
NG7 2RD

The DPO can be emailed at dpo@nottingham.ac.uk

Why we collect your personal data. We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are to critically understand the privacy perceptions, attitudes and appetite to learn more about data collection practices, of the Inflammatory Bowel Disease online community.

The legal basis for processing your personal data under GDPR. Under the General Data Protection Regulation, the University must establish a legal basis for processing your personal data and communicate this to you. The legal basis for processing your personal data on this occasion is Article 6(1e) processing is necessary for the performance of a task carried out in the public interest.

Note: Article 6(1e) public interest should be used by default whenever possible, as this fits the University's role as a teaching and research body to advance education and learning. This does not mean that you do not need to obtain consent from research participants, only that consent does not provide the legal basis for processing participant's data. In exceptional cases, where the public interest clause does not apply, e.g., if you are doing research on behalf of an external organisation (such as a commercial company), then Article 6(1a) consent of the data subject should be used instead.

How long we keep your data. The University will store your data for 7 years after Kate Green has submitted her PhD thesis. If she leaves the University of Nottingham within the 7 year period, the data will be transferred to an encrypted hard drive, stored by Kate Green until its deletion. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research.

How we keep your data safe. We keep your data securely and put measures in place to safeguard it. These safeguards include anonymization of data and file encryption

Your rights as a data subject. GDPR provides you, as a data subject, with a number of rights in relation to your personal data. Subject to some exemptions, you have the right to:

- withdraw your consent at any time where that is the legal basis of our processing, and in such circumstances you are not obliged to provide personal data for our research.
- object to automated decision-making, to contest the decision, and to obtain human intervention from the controller.
- access (i.e., receive a copy of) your personal data that we are processing together with information about the purposes of processing, the categories of personal data concerned, recipients/categories of recipient, retention periods, safeguards for any overseas transfers, and information about your rights.
- have inaccuracies in the personal data that we hold about you rectified and, depending on the purposes for which your data is processed, to have personal incomplete data completed
- be forgotten, i.e., to have your personal data erased where it is no longer needed, you withdraw consent and there is no other legal basis for processing your personal data, or you object to the processing and there is no overriding legitimate ground for that processing.

- in certain circumstances, request that the processing of your personal data be restricted, e.g., pending verification where you are contesting its accuracy or you have objected to the processing.
- obtain a copy of your personal data which you have provided to the University in a structured, commonly used electronic form (portability), and to object to certain processing activities such as processing based on the University's or someone else's legitimate interests, processing in the public interest or for direct marketing purposes. In the case of objections based on the latter, the University is obliged to cease processing.
- complain to the Information Commissioner's Office about the way we process your personal data.

If you require advice on exercising any of the above rights, please contact the University's data protection team: data-protection@nottingham.ac.uk

Appendix 3c: Study 3 Consent Form

CONSENT FORM

Date: [*generated by Survey Monkey*]

Project: Assessing the appetite to learn about data collection practices and information privacy within an online health community through awareness interventions

School of Computer Science Ethics Reference: [CS-2019-R12]

Funded by: Horizon Centre for Doctoral Training at the University of Nottingham (RCUK Grant No. EP/L015463/1)

Please tick the appropriate boxes

Yes No

1. Taking part in the study

a) I have read and understood the project information sheet dated [30/10/2019], or it has been read to me. I have been able to ask questions about the study and my questions have been answered satisfactorily. ○ ○

b) I consent voluntarily to be a participant in this study and understand that I can choose not to answer questions and I can withdraw from the study at any time, without having to give a reason. ○ ○

c) I understand that taking part in the study requires me to undertake 3 surveys and engage with online materials. ○ ○

2. Use of my data in the study

a) I understand that data which can identify me will not be shared beyond the project team. ○ ○

b) I agree that the data provided by me may be used for the following purposes:

- Presentation and discussion of the project and its results in research ○ ○ activities (e.g., in supervision sessions, project meetings, conferences).
- Publications and reports describing the project and its results. ○ ○
- Dissemination of the project and its results, including publication of data on web pages and databases. ○ ○

c) I give permission for my words to be quoted for the purposes described above. ○ ○

3. Reuse of my data

a) I give permission for the data that I provide to be reused for the sole purposes of future research and learning. ○ ○

Please tick the appropriate boxes

Yes No

4. Security of my data

a) I understand that safeguards will be put in place to protect my identity and my data during the research, and if my data is kept for future use. ○ ○

b) I confirm that a written copy of these safeguards has been given to me in the University's privacy notice, and that they have been described to me and are acceptable to me. ○ ○

c) I understand that no computer system is completely secure and that there is a risk that a third-party could obtain a copy of my data. ○ ○

5. Copyright

a) I give permission for data gathered during this project to be used, copied, excerpted, annotated, displayed and distributed for the purposes to which I have consented. ○ ○

6. Signatures (sign as appropriate)

Name of participant (IN CAPITALS) Signature Date

If applicable:

For participants unable to sign their name, mark the box instead of signing

I have witnessed the accurate reading of the consent form with the participant and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness (IN CAPITALS) Signature Date

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Name of researcher (IN CAPITALS) Signature Date

7. Researcher's contact details

Name: Kate Green

Phone: 07538692404

Email: kate.green@nottingham.ac.uk

Provide the participant with a copy of the completed form either by email or hard copy as they prefer.

Appendix 3d: Study 3 Survey 1

Demographic information

What is your email address?

What is your age range?
- 16-20
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71+

What is your highest level of education?
- I do not have any formal qualifications
- GCSEs, O-Levels or equivalent
- A-Levels, BTEC or equivalent
- Bachelor’s degree
- Master’s degree
- PhD

What is your gender?

What is your Inflammatory Bowel Disease (IBD) diagnosis?
- Crohn’s
- Ulcerative Colitis
- Indeterminate Colitis
- Not yet diagnosed
- I do not have IBD

What social media platforms do you use for everyday use?
- Facebook
- Twitter
- Instagram
- YouTube
- Snapchat
- Tik Tok
- LinkedIn
- WhatsApp
- Tumblr
- Reddit
- Other:

What social media platforms do you use for IBD support/sharing information about your IBD?
- Facebook
- Twitter

Instagram
YouTube
Snapchat
Tik Tok
LinkedIn
WhatsApp
Tumblr
Reddit
Other:
NA: I do not have IBD

For roughly how long have you been a social media user?

How do you typically access social media?
Smart phone
Laptop
Tablet
Other

For roughly how long have you been using social media to seek support for your IBD?
Less than a month
1-6 months
6-12 months
1-2 years
2-3 years
3-4 years
4-5 years
More than 5 years
NA: I do not have IBD

How many Facebook Groups have you joined relating to Inflammatory Bowel Disease?
0
1
2
3
More than 4
Not Applicable
NA: I do not have IBD

Describe how you use social media to interact with other people with IBD (if applicable)

***Social Privacy Concerns (SPCON):**
{7 Point Likert scale (Strongly disagree to Strongly agree)}
SPCON1 I am concerned about sharing personal health information to social media because of what other people might think of me.
SPCON2 I am concerned about sharing personal health information on social media because of what other people might do with it.
SPCON3 I am concerned that other people can find private information about my health from social media.

Information Privacy Concerns (IPCON)

{7 Point Likert scale (Strongly disagree to Strongly agree)}

IPCON1 I have thought about how social media platforms handle my personal information in the past.

IPCON2 I am concerned that social media platforms can make assumptions about my health.

IPCON3 I am concerned about providing personal information about my health to social media platforms, because it could be used in a way I did not foresee.

IPCON4 I am concerned that the information I share on social media about my health could be shared with other companies.

I am concerned that companies/government/organisations can find private information about my health from social media platforms.

I feel that information I share about my health is safer in Facebook Groups

{Must include a ‘not applicable’}

***Privacy Risks (RISK):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}

RISK1 In general, it would be risky to give personal information about health to social media platforms.

RISK2 There would be high potential for privacy loss associated with giving personal health information to social media platforms.

RISK3 Personal information about health could be inappropriately used by social media platforms.

RISK4 Providing social media platforms with information regarding my health would involve many unexpected problems.

***Privacy Control (PCTL):**

{7 Point Likert scale (Strongly disagree to Strongly agree & Not applicable)}

SPCTL1 I believe I have control over which people can get access to information I share about my health on social media.

SPCTL2 I use privacy settings to control who can see what I post about my health on social media.

SPCTL3 I use Facebook Groups to control who can see what I post about my health on Facebook.

{Must include a ‘not applicable’ answer}

SPCTL4 What I share about my health online differs depending on who I am sharing it with.

IPCTL1 I think I have control over what personal information (including about my health) is collected by social media platforms.

IPCTL2 I believe I have control over how my personal information is used by social media platforms.

IPCTL3 I believe I have control over what personal information (including about my health) is shared by social media platforms to other companies and organisations.

PBHV1 My online behaviours reflect my privacy concerns.

I think it is important for people to have control over how their personal data is used.

***Perceived Effectiveness of Privacy Policy (POLICY):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}

Some companies post privacy statements on their websites to give information about their information practices, e.g., what information is collected, how your information is used, with whom your information may be shared, and etc. Please indicate the extent to which you agree or disagree with each statement by ticking the appropriate number.

POLICY1 I feel confident that social media platforms' privacy statements reflect their commitments to protect my personal information.
POLICY2 With their privacy statements, I believe that information I share about my health will be kept private and confidential by social media platforms.
POLICY3 I believe that social media platforms' privacy statements are an effective way to demonstrate their commitments to privacy.
I have read the privacy policies of platforms you use in the past 12 months?
I trust the social media platforms I use to keep information about my health confidential from other companies and organisations.
I trust some platforms to keep my information safe more than others.
List the social media platforms you use in order of trustworthiness, starting with the most trustworthy.
{Open ended Q}

***Disposition to Value Privacy (DTVP):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}
Using social media to connect with other people with Crohn's and Ulcerative Colitis is important to me.
To me, information that I share with other people with IBD on social media is more sensitive than other information I share on my timeline.
Compared to other people I know, I feel more sensitive about the way companies handle my personal information.
5. Compared to others, I tend to be more concerned about threats to my information privacy.

***Previous Privacy Experience (PEXP):**

How often have you been a victim of what you felt was an improper invasion of privacy?
Never
Once
Twice
More than three times
Have you ever felt that your privacy has been invaded as a result of how social media platforms use your data?
How often have you experienced incidents where your personal information was used by a company without your authorization? {7 Point Likert scale (Never to frequently)}

***Privacy Awareness (AWARE):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}
AWARE1 I am aware of the privacy issues in our society.
AWARE2 I keep myself updated with the news and developments about the privacy issues and privacy violations of tech companies.

AWARE3 How much have you heard or read during the last two years about the use and potential misuse of the information collected from tech companies? Please tick the most relevant answer to you.

I haven't heard about any misuses of personal information by tech companies.
I have not heard about any incidents following the Cambridge Analytica scandal in 2018.
I have heard about a few incidents of personal information misuse
I keep up to date with personal information misuses when they are reported by the media

Activity to learn (LEARN):

{7 Point Likert scale (Strongly disagree to Strongly agree)}

ACTL I would like to learn more about how my personal information is collected and used by social media platforms
BAR-T I would like to learn more about how my personal information is used, but I do not have the time
BAR-O I would like to be more aware of how my personal information is used, but I haven't had the opportunity to learn about it.
BAR-LOWDL I would like to learn more about how my personal information is used, but I feel I don't have the technical knowledge to understand it.
BAR-ATT I don't think that I need to know about how my personal information is used because it is not important to me
BAR-TRUST I don't think that I need to know about how my personal information is used because I trust social media platforms with it
I believe that people with a health condition should be more aware of how their self-disclosed health information is collected and used by social media platforms.

Adapted from Xu et al., 2011 Information Privacy Concerns: Linking Individual Perceptions with Institutional Privacy Assurances.

Appendix 3e: Study 3 Survey 2a

For participants who decide not to continue

1. What is your email address?

2. Did you learn anything new based on the social media post you seen?
   {Likert scale – nothing at all to a lot}

3. If you saw this post on your social media feed, how likely would you be to take a moment to read it?
   {likert scale – very unlikey to very likely}

How far do you agree with the following statements:
{likert scale – strongly disagree to strongly agree}

4. The information on the post was interesting
5. The information on the post was relevant
6. The information on the post has made me think more about my online privacy.

7. Please rate the design of the post
   {likert scale – not visually appealing to very visually appealing}

8. How could this post be improved to increase engagement?
   {open question}

9. Please describe why you chose not to learn more about how your data is collected and used.
   {open question}

Appendix 3f: Study 3 Survey 2b

For participants who decided to continue

1. What is your email address?

Social Media Post

2. Did you learn anything new based on the social media post you seen?
{Likert scale – nothing at all to a lot}

3. If you saw this post on your social media feed, how likely would you be to take a moment to read it?
{likert scale – very unlikey to very likely}

How far do you agree with the following statements:
{likert scale – strongly disagree to strongly agree}
4. The information on the post was interesting
5. The information on the post was relevant
6. The information on the post has made me think more about my online privacy.

7. Please rate the design of the post
{likert scale – not visually appealing to very visually appealing}

8. How could this post be improved to increase engagement?
{open question}

Website resource

9. Did you learn anything new based on the website resource?
{Likert scale – nothing at all to a lot}

How far do you agree with the following statements:
{likert scale – strongly disagree to strongly agree}

10. The information on the website was interesting
11. The information on the website was relevant
12. The information on the website has made me think more about my online privacy
13. I would you share this resource with other people in the IBD community
14.
15. How can this online resource be improved?
{open question}

Information Privacy Concerns (I-PCON)
{7 point likert scale – strongly disagree to strongly agree}
1. I am concerned that social media platforms can make assumptions about my health.

2. I am concerned about providing personal information about my health to social media platforms, because it could be used in a way I did not foresee.
3. I feel that information I share about my health is safer in Facebook Groups
{Must include a 'not applicable'}

***Privacy Control (PCTL):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}

1. Because of this resource, I feel that I have more knowledge of how I can control my data.

***Privacy Awareness (AWARE):**

{7 Point Likert scale (Strongly disagree to Strongly agree)}

1. Because of the information I have seen in this study, I feel more aware of some of the privacy issues society faces today.
2. Because of what I have seen in his study, I will take more notice of technology-related developments in the news.

Activity to learn (LEARN):

{7 Point Likert scale (Strongly disagree to Strongly agree)}

1. I would like to learn more about how my personal information is collected and used by social media platforms
2. I believe that people with a health condition should be more aware of how their self-disclosed health information is collected and used by social media platforms.

Appendix 3g: Instructions to PPI for Social Media

Patient and Public Involvement

Background

As part of the development of my third and final PhD study, I am seeking feedback from community leaders to help shape the design.

This study aims to understand what attitudes and awareness of information privacy are to people with IBD using Facebook to seek support. It will do so by giving participants a survey, followed by presenting a Facebook post and also the opportunity to learn more about their digital footprints on a website. Participants will then do another survey after having engaged with the awareness materials.

The findings from this study will enable us to understand the appetite for patients to learn more about their digital footprints (information privacy). We will be able to reshape the materials for individuals to engage with outside of a research study context.

Feedback

I am looking to select 1 of the following designs to present in the study. It will act as the post that individuals would hypothetically see in their Facebook feed or in a group.

There are three types of posts to choose from:

1. Questions – aimed to provoke individuals to think
2. Stories – examples taken from the media
3. Facts about data collection

Please can you provide me with your preference over which type you like and indicate the most appealing/engaging one and why. E.g S2

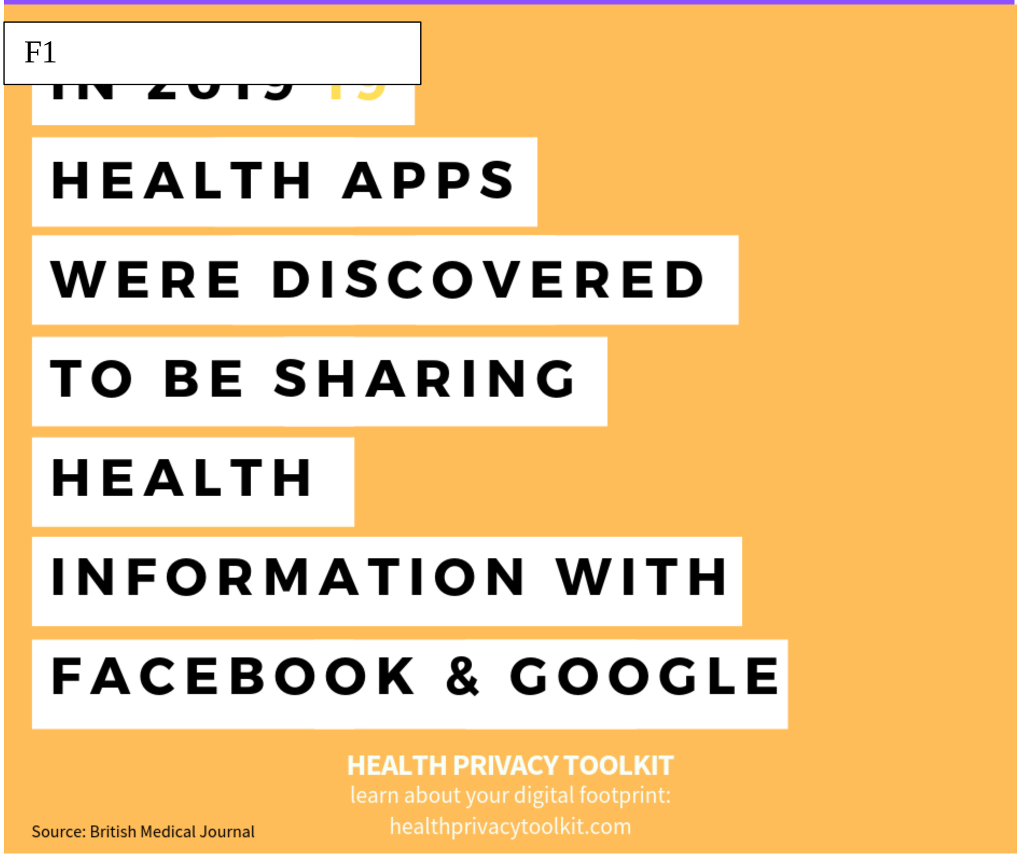
I am aware that there are so many different ways to engage people. In the interest of saving time, simple text-based designs have been adopted.

Please can you indicate which of these designs you think would be the most engaging for the IBD community and why. E.g. Q1

SOCIAL MEDIA PLATFORMS TRACK YOU WITHIN THEIR APPS AND ACROSS THE WEB. THIS BUILDS A DETAILED PROFILE ABOUT YOU

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

F1



IN 2019 19 HEALTH APPS WERE DISCOVERED TO BE SHARING HEALTH INFORMATION WITH FACEBOOK & GOOGLE

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Source: British Medical Journal

F2

HAVE YOU STOPPED TO THINK ABOUT WHAT DATA FACEBOOK COLLECTS ABOUT YOU?

AND HOW IT IS USED?

HEALTH PRIVACY TOOLKIT

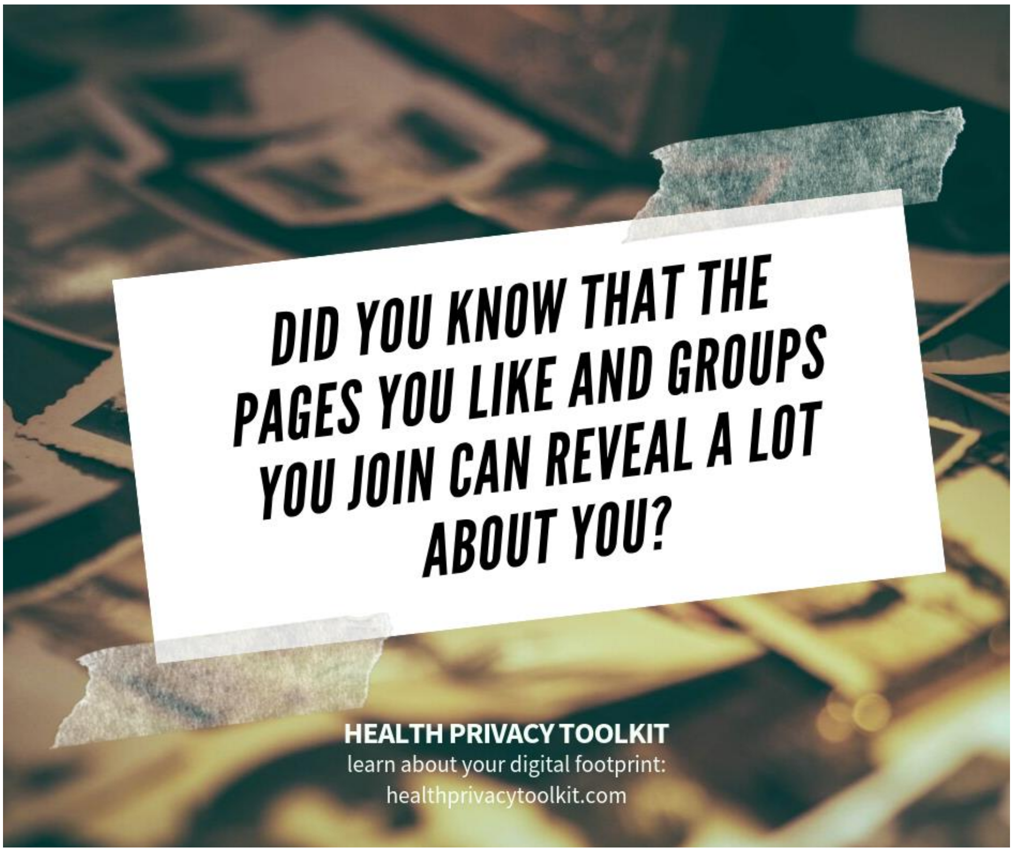
learn about your digital footprint:

healthprivacytoolkit.com

Q1


DO YOU KNOW WHAT DATA FACEBOOK IS COLLECTING ABOUT YOU?
HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Q2


DID YOU KNOW THAT THE PAGES YOU LIKE AND GROUPS YOU JOIN CAN REVEAL A LOT ABOUT YOU?
HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Q3

Do you trust Facebook with
information about your health?

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Q5

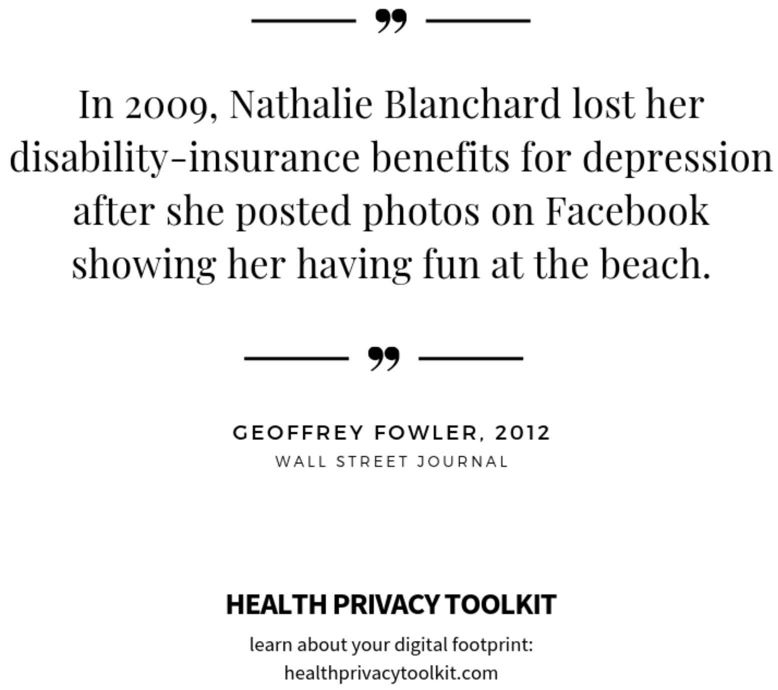

DO YOU TRUST FACEBOOK WITH INFORMATION ABOUT YOUR HEALTH?
HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Q4

HAVE YOU THOUGHT ABOUT THE LONG TERM IMPACTS OF SHARING INFORMATION ABOUT YOU ON SOCIAL MEDIA?

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

Q6

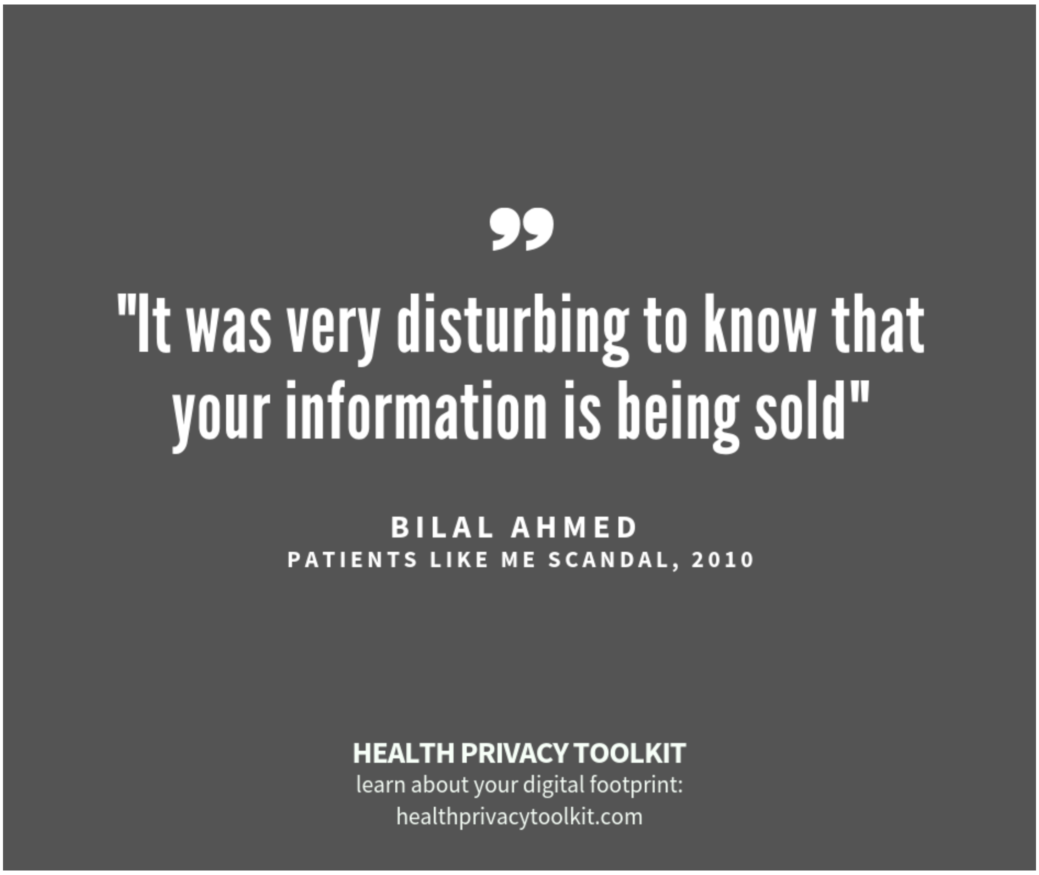


> In 2009, Nathalie Blanchard lost her disability-insurance benefits for depression after she posted photos on Facebook showing her having fun at the beach.

GEOFFREY FOWLER, 2012
WALL STREET JOURNAL

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

S1



> "It was very disturbing to know that your information is being sold"

BILAL AHMED
PATIENTS LIKE ME SCANDAL, 2010

HEALTH PRIVACY TOOLKIT
learn about your digital footprint:
healthprivacytoolkit.com

S2

Appendix 4: Study 3 Data Tables

Appendix 4a Spearman's Correlation Table: Antecedents and Privacy Concern (Test Sample)

Correlations

			InformationPrivacyConcern	SocialPrivacyConcern
Spearman's rho	What is your age range?	Correlation Coefficient	.224*	0.078
		Sig. (2-tailed)	0.031	0.455
		N	93	93
	What gender do you identify with? (1= male / 2 = female)	Correlation Coefficient	-0.137	-0.015
		Sig. (2-tailed)	0.189	0.886
		N	93	93
	What is your highest level of education?	Correlation Coefficient	-0.002	-0.006
		Sig. (2-tailed)	0.988	0.956
		N	93	93
	For approximately how long have you been a social media user?	Correlation Coefficient	-0.012	0.091
		Sig. (2-tailed)	0.906	0.386
		N	93	93
	How many Facebook Groups have you joined relating to Inflammatory Bowel Disease?	Correlation Coefficient	-0.131	-0.077
		Sig. (2-tailed)	0.212	0.465
		N	93	93
	My online behaviours reflect my privacy concerns	Correlation Coefficient	.228*	.277**
		Sig. (2-tailed)	0.032	0.009
		N	89	89
	What I share about my health online differs depending on who I am sharing it with.	Correlation Coefficient	.239*	0.08
		Sig. (2-tailed)	0.024	0.456
		N	90	90
	I trust the social media platforms I use to keep information about my health confidential from other companies and organisations.	Correlation Coefficient	-.353**	-0.056
		Sig. (2-tailed)	0.001	0.602
		N	88	88
	Have you ever felt that your privacy has been compromised by social media platforms?	Correlation Coefficient	-.357**	-0.18
		Sig. (2-tailed)	0.001	0.095
		N	87	87
	How much have you heard or read during the last two years about the use and potential misuse of the information collected from tech companies?	Correlation Coefficient	.289**	0.034
		Sig. (2-tailed)	0.007	0.755
		N	87	87
	I am aware of the privacy issues in our society.	Correlation Coefficient	0.139	-0.146
		Sig. (2-tailed)	0.201	0.181
		N	86	86

	I would like to learn more about how information about me is collected	Correlation Coefficient	.312**	0.117
		Sig. (2-tailed)	0.003	0.283
		N	86	86

**** Correlation is significant at the 0.01 level (2-tailed).**

*** Correlation is significant at the 0.05 level (2-tailed).**

Appendix 4b: Spearman's Correlation Table (Control Sample)

Antecedents And Privacy Concerns

Correlations

			Social Privacy Concern	Information Privacy Concern
Spearman's rho	What is your age range?	Correlation Coefficient	0.084	-0.206
		Sig. (2-tailed)	0.696	0.335
		N	24	24
	What gender do you identify with?	Correlation Coefficient	0.055	0.09
		Sig. (2-tailed)	0.797	0.676
		N	24	24
	What is your highest level of education?	Correlation Coefficient	0.028	0.085
		Sig. (2-tailed)	0.897	0.692
		N	24	24
	For approximately how long have you been a social media user?	Correlation Coefficient	-.407*	-.431*
		Sig. (2-tailed)	0.048	0.036
		N	24	24
	My online behaviours reflect my privacy concerns	Correlation Coefficient	0.324	0.294
		Sig. (2-tailed)	0.131	0.173
		N	23	23
	I trust the social media platforms I use to keep information about my health confidential from other companies and organisations.	Correlation Coefficient	-0.278	-0.35
		Sig. (2-tailed)	0.211	0.111
		N	22	22
	Have you ever felt that your privacy has been compromised by social media platforms?	Correlation Coefficient	-0.412	-0.176
		Sig. (2-tailed)	0.057	0.432
		N	22	22
	How much have you heard or read during the last two years about the use and potential misuse of the information	Correlation Coefficient	0.167	0.141
		Sig. (2-tailed)	0.458	0.533
		N	22	22

	collected from tech companies?			
	I am aware of the privacy issues in our society.	Correlation Coefficient	0.273	0.11
		Sig. (2-tailed)	0.22	0.627
		N	22	22

*** Correlation is significant at the 0.05 level (2-tailed).**

**** Correlation is significant at the 0.01 level (2-tailed).**

Appendix 4c: Spearman's Correlation Table: Control As A Reflection Of Privacy Concerns

Correlations

			My online behaviours reflect my privacy concerns
Spearman's rho	What I share about my health online differs depending on who I am sharing it with.	Correlation Coefficient	0.014
		Sig. (2-tailed)	0.898
		N	89
	I use Facebook Groups to control who can see what I post about my health on Facebook.	Correlation Coefficient	-0.084
		Sig. (2-tailed)	0.436
		N	89
	SPC1: I am concerned about sharing personal health information on social media because of what other people might think of me.	Correlation Coefficient	.263*
		Sig. (2-tailed)	0.013
		N	89
	SPC2: I am concerned about sharing personal health information on social media because of what other people might do with it.	Correlation Coefficient	.309**
		Sig. (2-tailed)	0.003
		N	89
	SPC3: I am concerned that other people can find private information about my health from social media.	Correlation Coefficient	0.059
		Sig. (2-tailed)	0.583
		N	89
	IPC1: I am concerned that social media platforms can make assumptions about my health.	Correlation Coefficient	.215*
		Sig. (2-tailed)	0.043
		N	89
	IPC2: I am concerned about sharing personal information about my health on social media platforms, because it could be used in a way I did not foresee.	Correlation Coefficient	0.193
		Sig. (2-tailed)	0.07
		N	89
	IPC3: I am concerned that the information I share on social media about my health could be shared with other companies.	Correlation Coefficient	.261*
		Sig. (2-tailed)	0.013
		N	89
	IPC4: I am concerned that companies/government/organisations can find private information about my health from social media platforms.	Correlation Coefficient	0.114
		Sig. (2-tailed)	0.285
		N	89
	I believe I have control over what information about me (including about my health) is collected by social media platforms.	Correlation Coefficient	0.059
		Sig. (2-tailed)	0.586
		N	89
		Correlation Coefficient	0.102

	I believe I have control over how information about me is used by social media platforms.	Sig. (2-tailed)	0.341
		N	89

*** Correlation is significant at the 0.05 level (2-tailed).**

**** Correlation is significant at the 0.01 level (2-tailed).**