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# “Privacy means for me...” - An exploration of privacy perceptions of people who use drugs

Thesis for MSc Programme Communication, Health and Life Sciences; Specialisation Communication and Innovation

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Carlo Alexander Thielecke; Under Supervision of Rico Lie and Monica Mars

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## Introduction

In the history of civilizations, mind-altering substances have been subjected to prohibition but also culturally accepted use. Recently, the scientific community as well as policy makers in many places of the world made efforts to change the status quo of quasi worldwide prohibition, by trying to provide the demanded scientific evidence on drugs and their effects on bodies, minds, and society (Aday et al., 2020; Earp et al., 2021). Especially the medical interest in psychedelic substances such as 3,4 methylenedioxymethamphetamine (MDMA) has increased steadily over the last decade. While the World Health Organization (WHO) successfully urged the United Nations (UN) to reclassify cannabis as a drug with therapeutic value (WHO, 2020), for many other drugs the scientific evidence on consequences of their use is still missing or difficult to obtain. The war on drugs can be considered a cause for the missing scientific evidence (Earp et al., 2021). The War on Drugs and resulting legal environment has stopped many officially working researchers to investigate drug effects, or potentially alternative models for mental health therapy (Carhart-Harris & Goodwin, 2017) and also led to fear and stigmatization of drug users (Ryan et al., 2019; Ahern et al., 2007). At the same time, many people continue to use drugs to have mind-altering experiences (Brunt et al., 2017), despite their legal status (Earp et al., 2021).

In contrast to regulated substances like alcohol or tobacco, authorities cannot control the contents and safety of the illegal drugs traded on the black market. Rather, criminals with economic interest control the contents of the drugs, which puts users at health risk due to laced substances to increase weight and or change effects of the substances to ultimately increase profits (Csete et al., 2016). Even though some countries have adopted harm reduction services (such as drug checking/testing) (Brunt et al., 2017), harm from these substances often remain, even when they are pure and when they are used according to harm reduction guidelines (Earp et al., 2021). Additionally, there are multiple other problems that can be related to drugs and their use e.g., economic harm to societies, violation of the public order or individuals facing racist police practices which make illegal drugs a complex problem or wicked problem with multiple stakeholders (Csete & Grob, 2012; Earp et al., 2021).

To help finding solutions to the complex problem of illegal drug use, including the lived experiences of people who use drugs (PWUD) is important (*Drugs, Habits and Social Policy*, n.d.). Though, this has the risk of potentially exposing sensitive data of individuals that participate and affect their privacy. Since people who use drugs are a sensitive part of the population, privacy issues can affect their motivation to participate in research and harm them economically or socially (Ahern et al., 2007; Barratt et al., 2012, 2015; Rudolph et al., 2020). The use of WhatsApp and other social media platforms to obtain, and discuss drugs (Bakken & Demant, 2019; Moyle et al., 2019; van der Sanden et al., 2022) is in contrast with some research that highlights perceived privacy threats for PWUD (Rudolph et al., 2020).

Studies investigating the willingness of people to share health data (for example genetic data) (Kim et al., 2015; Shah et al., 2019; Whiddett et al., 2006) for research purposes have found that there are multiple factors underlying the intention to share their data. Concerns regarding data security and related privacy of their data have been mentioned to be one factor in that. Furthermore, the control over their own data was said to have an impact on the distribution

of information, collected outside of the intended research setting (Willison et al., 2019) or data regarding a previously diagnosed illness (Whiddett et al., 2006) to commercial organisations.

Yet, many people make use of social media to connect with others and share own experiences within an online network of friends, relatives, colleagues, and other contacts (Kapoor et al., 2017). Moreover, users of social media sometimes receive help or support of medical problems, share news and political information, and engage in discussions online that can show personal and political opinions. Therefore, it is interesting to look at how PWUD perceive privacy regarding social media use and illegal drug research and if there are differences within these two potentially sensitive information containing realms.

## Problem Statement

In the 21<sup>st</sup> century, digital technologies, mobile devices and the related collection of information are in many cases increasingly determining the lives of the people (Acquisti et al., 2015; Lasi et al., 2014) And it is projected that increasingly more devices and technologies in addition to jobs will be digitalized. Additionally, many of these advances in technology come or are owned by private corporations, that – more often than not – take their users' privacy seriously (Archie, 2023). The implications for societies and individuals of this are yet unknown, however, privacy for the individual might be threatened (Gahi et al., 2016)

The issue of privacy is further highlighted regarding illegal drugs, which is in many societies around the world a sensitive topic due to stigma and the legal status of these substances (Hall, 2017). Privacy becomes for many an important topic, when talking about it or participating in research projects in that area, to protect themselves from repercussions (Barratt et al., 2015) Therefore, research investigating the perceptions of people in regard to privacy is important.

## Scientific Relevance

Participation in scientific research by volunteers is important for science, to generate data, to improve the reliability of the findings (in regard to the research population) and to prevent bias (by overrepresentation of certain sub-groups) in research more generally. Following from that, especially the representation of all social groups is important. Including PWUD in research, therefore is also necessary to have representative research findings. Since they face additional obstacles in their lives, looking what influences the participation of PWUD in researching illegal drug use is, especially from a privacy perspective seems logical.

## Societal Relevance

As this research may help scientists and researchers to identify issues of privacy relevant to PWUD in the participation in research, this research project may lead to recommendations for public health and harm reduction policies for a broader societal impact. In the context of prohibitionist policies, creating scientific evidence can help in supporting harm reduction approaches. Further, in the context of probable drug legalization and decriminalisation (Hall, 2017), any scientific contribution might help policymakers in designing policies that are understandable, justifiable, and trustworthy for the public.

## Conceptual Framework

This part will describe and define the previously mentioned concepts of illegal drugs, social media, privacy, and sensitive data. Explaining illegal drugs use is necessary to create understanding for the research matter. Social media is important to explain because people share private data and do this for certain reasons. This is followed by a brief explanation of sensitive data issues. Lastly a brief overview of privacy and certain elements therein is provided and relationships between the different concepts are highlighted to create a theoretical framework.

### Illegal Drugs

Illegal drugs are the focus of this research without any closer focus on what type of drug because it is about drug users in general rather than what type of substance is used. Differences in level of control do not affect the research outcome, rather it allows for a broader and more complete analysis of illegal drugs and their health effects. With illegal drugs the following is meant: *Any kind of mind-altering substance that is regulated **and** prohibited in and by the European Union for recreational purposes.*

The impacts of illegal drugs on the individual body as well as on society in general and public health in particular have been studied in many ways, from legal (Csete & Grob, 2012; Hall, 2017) to health & medical perspectives (Carhart-Harris et al., 2022; Polito & Stevenson, 2019; Szigeti et al., 2021) However, societal stigma of PWUD (people who use drugs; Rudolph et al., 2017) and the illegal status of the drugs make research difficult (Barratt et al., 2015; Csete et al., 2016). It is difficult to recruit participants who might be afraid of legal or social repercussions and related economic consequences when participating in studies that involve illegal drugs in any way (Barratt et al., 2015, 247; Rudolph et al., 2020, 309). Repercussions could be social exclusion from family, friends, or loss of employment with a resulting loss of livelihood or receiving, a prison sentence in the worst case (Ahern et al., 2007; Werse, 2016; Werse & Bernard, 2016). So therefore, maintaining a high level of privacy for participants is important to protect not only the participants themselves but also the wider scientific integrity (Rudolph et al., 2017, 2020; Ryan et al., 2019).

When it comes to health impacts of illegal drugs, research that administers illicit drugs to individuals is in many instances illegal and/or prohibited by ethical review boards (Andreae et al., 2016). Therefore, the administering of a substance is one of the biggest obstacles to researching the influences of illegal drugs on the human body. Administering the drugs to people can also be seen as a violation against the code of scientific conduct since it exposes people to an increased risk that could otherwise be avoided (Wet Medisch-Wetenschappelijk Onderzoek Met Mensen). Traditional research approaches are often not suited to investigate real-time effects of drugs on the body in recreational or scientific settings. Evidence from non-traditional research approaches may then hopefully be informing future public health and harm reduction policies to protect users, societies, and health systems alike.

### Social Media

Social media as a term is almost 30 years old now and since then underwent changes not only in its' functions and extend (Lomborg, 2017), but also in scientific definitions (Aichner et al., 2021). These definitions can partly be "technocratic ... [or] less technical" definitions (Wolf et



al., 2018). The technocratic definitions highlight the features of the social media technology in contrast to other definitions that highlight that people are the 'makers' of social media in the sense that they provide the contents of social media. To make use of both ends and show how social media can affect all aspects of life (private-professional), this paper will make use of the proposed definition by Kapoor and colleagues:

*“Social media is made up of various user-driven platforms that facilitate diffusion of compelling content, dialogue creation, and communication to a broader audience. It is essentially a digital space created by the people and for the people, and provides an environment that is conducive for interactions and networking to occur at different levels (for instance, person-al, professional, business, marketing, political, and societal).”*  
(2017, p. 536)

As broad as social media can be in their functions and services, ranging from simple blogs to big platforms such as Facebook (Aichner et al., 2021), so is the research scope (Kapoor et al., 2017). Aichner and colleagues (2021) state that the majority of functions of social media relate either to maintaining your personal and private connections, creating, or following romantic relationships, exposure to and the creation of contact to private companies and organisations (e.g., looking for employment/creating professional network, showing own products/services to an audience etc.). The access to social media can be restricted to registered users, but often data can be publicly accessible without creating a profile, therefore creating easy possibilities for researchers to extract the data (Lomborg, 2017). However, also restricted access does not stop researchers from conducting research on these platforms and extract data thereof. Especially in the case of openly available social media data, on for example networks of users, there is a focus on “less interpretive and explanatory work” (Lomborg, 2017, p. 8). Furthermore, the companies and technologies making social media possible contributed to a continuous change of certain social media (Lomborg, 2017, p. 7).

Due to this wide range of possibilities, the research dealing with social media comes from many different disciplines (Aichner et al., 2021; Kapoor et al., 2017). Therefore, also different theories and approaches have been developed to categorise or describe social media (Kietzmann et al., 2011) and why people use social media (e.g., Pelletier et al., 2020), qualitatively (Throuvala et al., 2019) and quantitatively (Menon, 2022). Important to mention is the “honeycomb” theory by Kietzmann and colleagues (2011) from a business point of view. It states that social media has seven angles or parts that describe how users experience a platform and what the implications for businesses are. These seven “building blocks” are *Identity, Conversations, Sharing, Presence, Relationships, Reputation* and *Groups* (see Figure 1). For the purpose of this paper only the user’s experience will be discussed here. *Identity* describes the aspect that users of social media differ in the amount of information they reveal about themselves depending on the platform. *Conversations* describes the “extent to which users communicate with other users in a social media setting.” (Kietzmann et al., 2011, p. 244). *Sharing* depicts how people share content with each other; *Presence* the visibility of availability of and for users on a platform. *Relationships* describes the type of relationship users have with each other on a platform. *Reputation* the reputation within a given social media. Lastly, *Groups* depicts “the extent to which users can form communities and sub-

communities” (Kietzmann et al., 2011, p. 247) According to the authors, each platform highlights different aspects for their purpose.

Another theory worthy to discuss is the uses and gratification theory applied to social media. Originally, the use and gratification theory was developed for traditional media that ascribed the viewer of media a more active role in following media, whereas before viewers were often ascribed a passive role (Katz et al., 1973). Namely, viewers choose what they want to watch based on a specific reasoning to fulfil certain needs that cannot be fulfilled elsewhere. Therefore, this theory is also well-suited to investigate motivations to use social media (Menon, 2022; Pelletier et al., 2020; Quan-Haase & Young, 2010; Whiting & Williams, 2013). In a qualitative study a total of ten “uses and gratification themes” were identified (Whiting & Williams, 2013) that are as followed: Social interaction, information seeking, pass time, entertainment, relaxation, expression of opinions, communicatory utility, convenience utility, information sharing, surveillance/knowledge about others (2013, pp. 366–367).

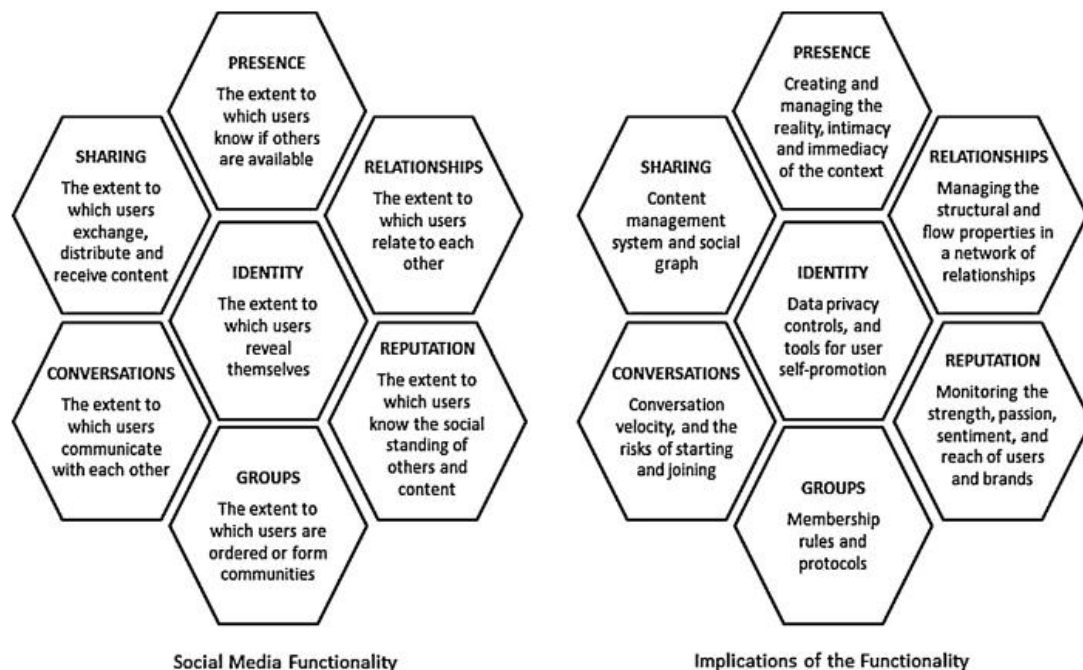


Figure 1 Honeycomb Framework (Kietzmann et al., 2011, p. 243)

### Sensitive Data

Sensitive data is an ambiguous term and has been used with different meanings in different areas of research with no clear general definition, as of yet. Often definitions on what sensitive data is, are not presented, only examples. In qualitative social science, it refers to information that concerns the private aspects of an individual’s life that are otherwise not freely shared with others (Bahn & Weatherill, 2012; Rohm & Milne, 2004). For example, in their research on ethical dilemmas regarding the collection of sensitive data in qualitative research, Bahn & Weatherill (2012) highlight the risk for the researchers when sensitive data is collected from “vulnerable” (p. 23) people. They say the risk for the researchers lies in the research subjects’ feeling of being invaded in their private lives. Therefore, it might cause intense reactions by the researched such as (the threat of) violence. While this reaction appears to be extreme, Rohm and Milne (2004) could show that trust in the institutions collecting sensitive medical

data influences the acceptance of collection and later use of the obtained data. However, among the investigated institutions (employers, insurance companies, drug stores and grocery stores) varying degrees of trust by the respondents were present, which was due to perceived power differences (Rohm & Milne, 2004).

In IT-related research, sensitive data concerns files and applications that contain private information of users and communication with institutions and others (Franzen et al., 2021; Nappi et al., 2018; Xiong et al., 2015) but also precise location data (Bowser-Livermore & Wiggins, 2015). In their study on different authentication methods in smartphones, Nappi and colleagues (2018) have used the concept of sensitive data in order to highlight the benefits of biometric authentication methods (facial recognition) in securing access to smartphones. Contradictory to their study, however, is that they did not explain how access to this biometric information is secured and protected. Since some EU-bodies have included biometrics in their definition of sensitive data (see below) I find it interesting that they did not explain this further. Similar to Nappi et al. (2018) Xiong and his colleagues (2015) have used the concept of sensitive data to show the importance of protecting such data in cloud computing. Bowser and Wiggins (2015) analysed different citizen science and participatory research projects' privacy policies to determine their compliance with mainly US-American laws and show how they protect the participants' privacy. From their findings, they have developed guiding principles that help in designing and organizing privacy matters in research projects so that sensitive data is protected. In some definitions, often but not excluding to health research, the sensitive character of health and medical information of an individual is highlighted (Bahn & Weatherill, 2012; Quinn & Malgieri, 2021; Rohm & Milne, 2004; Xiong et al., 2015).

In their attempt to define sensitive data based on the General Data Protection Regulation of the EU, Quinn and Malgieri (2021) have pointed out the importance of having a balanced approach to sensitive data that does not overly specify while also not losing the grip on what is considered sensitive data. As they state, what is needed is:

*“a hybrid approach: A purpose-based interpretation of sensitive data, with a relevant context-based backstop. In other words, personal data should be considered sensitive IF the intention of the data controller is to process or discover sensitive information OR if it is reasonably foreseeable that, in a given context, the data in question can be used to reveal or to infer sensitive aspects of data subjects.”*  
(Quinn & Malgieri, 2021, p. 1612).

For clarifying purposes, a data controller is the person/ institution/ organization that is 'in charge' of the data and uses thereof. In this quote another interesting issue related to sensitive data is visible, namely, the term sensitive data seems to be interchangeably used with personal information or data in research papers as well as official documents from the EU for example (Bowser et al., 2014; Cappa et al., 2022; Quinn & Malgieri, 2021; Regulation 2016/679).

The best and most elaborate definition of sensitive data comes from the EU's General Data Protection Regulation (GDPR) in which sensitive (i.e., personal) data is defined as follows:

*“any information relating to an identified or identifiable natural person (‘data subject’); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;” (Regulation 2016/679).*

This definition touches upon the most important aspects of sensitive data in my opinion, which is the identification of individuals through certain parts of information. Furthermore, it describes how personal data should be handled and worked with. Therefore, I will further use this definition in the conceptual framework.

The aspect of being able to identify a person from sensitive data is dealt with in an interesting data regulation from the USA, the HIPAA privacy rule aimed at medical data (Hoffman, 2015). It says that medical data does not fall under this rule if a total of eighteen identifiers have been removed from the dataset (see Hoffman, 2015, pp. 1767–1768).

The aspect of sensitive data in regard to PWUD then becomes important, as they are a vulnerable, to-be-protected part of the population. Information on drug use can then be considered sensitive as it includes personal identifiable information that describes and illuminates someone’s health or cultural identity. The next paragraph will discuss matters of privacy from three angles: technical, political, and subjective.

## Privacy

In the chapter on sensitive data, it becomes clear that sensitive data and privacy are closely related. Privacy is therefore also important to have closer look at. The Cambridge Dictionary’s definition of privacy is “someone’s right to keep their personal matters and relationships secret” or “the state of being alone” (Cambridge Dictionary, 2022). In this definition, the notion of personal information is visible and shows an interaction between the two concepts.

In their attempt to conceptualize privacy, Finn et. al. (2013) provide seven distinct types of privacy that are in their view important to respond to new and emerging technologies: “privacy of the person, privacy of behaviour and action, privacy of communication, privacy of data and image, privacy of thoughts and feelings, privacy of location and space and privacy of association” (7). These seven types highlight that privacy can be understood in, and related to different dimensions. Privacy of the person refers to having control over information over your body (for example one’s genetic code) while privacy of behaviour and action relates to political views, sexual orientation etc. Privacy of communication deals with private communication and interception thereof, so that no one interferes for example with your mail or phone calls by retracting information. Privacy of data and image refers to the right of having control over your own data and image and conveys notions of power balance according to the authors (Finn et al., 2013, p. 8). Privacy of thoughts and feelings can be related to the freedom right of free thought, as individuals should not be restricted in their thoughts, nor should they be revealed. This aspect, as the authors point out, may play a part in new technologies, as we have already seen in experiments by Facebook (nowadays Meta; Kramer et al., 2014). Privacy of location and space describes privacy within public spaces such as streets so that an individual can move freely without being ‘watched’ by emerging technologies, organisations,

or people. The last type of privacy that the authors provide, is privacy of association, that proscribes the right to assemble freely without the fear of being monitored by anyone (Finn et al., 2013).

As mentioned above, these categories of privacy can be understood in different dimensions. From a technical or application viewpoint, privacy can be protected by computer programmes and solutions, such as the citizen science project “BigO” has done (Tufford et al., 2022). These technical solutions are overarching and could relate to every type of privacy as identified by Finn et al. (2013).

The second dimension of privacy, the political dimension, is also important to mention, and can also be deduced from the conceptualization of privacy above. Finn et al. (2013), use “the right to” privacy, which hints at the hidden power structures within privacy and different types of data. Having knowledge over someone’s personal life can grant power over the individual by being able to decide when, if and how one releases certain information that could harm the other person in different ways. This is commonly observed in blackmailing, as information about an individual is used against them to create a leverage over the blackmailed. However, there is also a relationship between sensitive data, privacy, and economic gains, as in the case of social media, where personal information is collected and sold to third parties. Also, as one could see in the case of Cambridge Analytica and the US-American elections, using the abundance of data that social media is collecting, political power is also exerted when one owns the data. This is in line with Tufford et al. (2022) mentioning, that big data should be protected from commercial interests.

However, even though the public is aware that their data is collected and stored, what motivates people to share, post and spread information about them willingly on a platform that sells this data? To answer this briefly, the subjective dimension of privacy can be helpful to look at. In her book “Privacy in Context”, Helen Nissenbaum (2009) argues that perceptions of privacy are context dependent. Similar to Finn et al. she also makes emerging new technologies responsible for the need to rethink privacy. However, instead of trying to give rather normative explanations of privacy, she comes to the conclusion that people will interpret their feeling of privacy depending on the context where matters of privacy come to the fore (Nissenbaum, 2009) depending on the “informational norms” that rule the situation (p. 129ff).

In order to conceptualize subjective privacy for this underlying research, I will consider Nissenbaum’s approach to privacy of “contextual integrity” (2009). This approach suits the needs of different research approaches to have different understandings of privacy. Nissenbaum considers four different elements of privacy that allow for an “appropriate flow of personal information” (2009, p. 127): These are contexts, actors, attributes or information types and transmission principles. For her the term personal information conveys more meaning and to avoid confusion between different but similarly connotated words (e.g., sensitive data) she uses personal information in the same way as the EU in the GDPR (Nissenbaum, 2009, p. 4). Following from the four mentioned elements, certain norms or “context-relative informational norms” are established that can be used to determine if and how privacy is violated. With contexts, she means social settings that are governed by a set of

(informal) rules and have been established over time (short- or long-term) for example a donation gala or birthday party at work. Within these contexts one can find actors that can be differentiated in their function in the context: senders, receivers, and information subjects (Nissenbaum, 2009, p. 142). Information types refer to the kind of information a certain actor is available to share depending on the context. Transmission principles refer then to under which conditions this type of information is and can be shared in a given context.

Following from that is, people have to make certain trade-offs when it comes to their privacy. While in one context it is perfectly fine to not share any information about oneself, in a different context such as social media, it is expected or demanded from one to give away information to receive something in return. However, this contradicts in some way some scientific findings. In a study on privacy perceptions of PWUD regarding the participation in research projects in the USA, Rudolph, Young & Havens (2020) have found that PWUDs privacy perceptions not only differ per region (rural and urban) but are also not comfortable to use mobile devices to track their location. At the same time, the use of social media to sell and distribute drugs is widespread and becomes increasingly popular (Moyle et al., 2019; van der Sanden et al., 2022).

Participation in Research

The last important concept to be explained is participation in research. That people participate in research is a premise to research into the perceptions of privacy of human subjects and there are different motivations that influence the decision for or against partaking in research. While some studies have shown that altruistic motives of helping society (McCann et al., 2010), the general advancement of science or monetary incentives (Seddon, 2009) motivate to participate in research. Others have highlighted challenges to the participation in research, such as having a balanced sample or being able to reach stigmatized or “hidden populations” (Barratt et al., 2012, p. 216; Kelly, 2010). Yet, due to the cruciality of participation to advance science and create findings, finding out what drives or hinders PWUD to participate is important to find out.

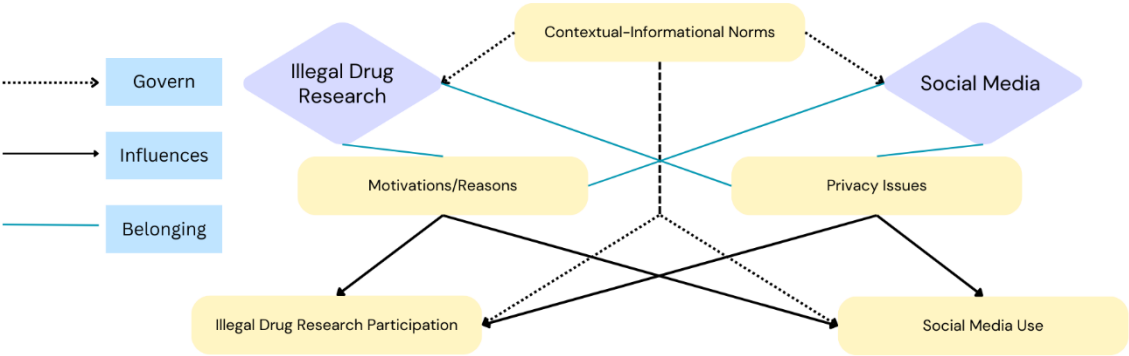


Figure 2 Theoretical Framework

Theoretical Framework Explained

To make sense of the figure displaying the Theoretical Framework above, the concepts *social media* and *illegal drug research* are both governed by contextual-informational norms. Thus, the contextual-informational norms influence how people act within *social media* and *illegal*

*drug research* respectively. However, social media use and illegal drug use have different motivations/reasons as well as privacy issues connected to them. They influence the participation in *illegal drug research* and *social media use*, respectively.

## Research Objective

This research establishes the differences in privacy perceptions of PWUD regarding participation in illegal drug research and social media use by:

- Identifying the social media platforms used by PWUD and the reasons for using them
- Highlighting privacy perceptions of PWUD in regard to illegal drug research and social media
- Noting the motivations to participate in illegal drug research

This is to shed light on how participation of PWUD in studies examining illegal drug use are influenced by privacy perceptions to facilitate equal participation in future studies. Further, by identifying what PWUD may deem as protection-worthy, communication to possible participants may be improved. This also counts for the reasons to use social media as they may help researchers design future studies that are more engaging for PWUD. Taken together, the findings may help create studies for scientific evidence on the impacts on drug use on individuals outside of classical research settings and help designing just policies, understandable for the public.

## Research questions

*What are the differences in privacy perceptions of PWUD in regard to the use of social media and participation in illegal drug research?*

*Which social media platforms do PWUD use and for what reasons?*

*How do PWUD perceive privacy in illegal drug research and in social media?*

*What motivates PWUD to participate in research on illegal drugs?*

## Methodology

### Data collection

#### Literature review

A brief literature search, inspired by a personal observation on privacy perceptions, was conducted. As a result, the following key words guided the search for relevant literature in PubMed, ScienceDirect in addition to Google Scholar: privacy perceptions, privacy issues, privacy behaviour, privacy trade-off, privacy concerns, PWUD, drug users, substance use. The findings were not satisfactory because many did not thematize privacy and/or include PWUD. Thus, it seems as if the topic is unexplored by other researchers. A second approach of gaining access to privacy guidelines or regulations of existing citizen science projects failed due to unresponsiveness of the contacted people. To account for the failed approaches regarding sources informing the interviews, an alternative approach investigating privacy contexts of



PWUD in social media settings and illegal drug research was chosen, as explained in the next paragraph.

#### Interviews & Interview Guide

The influential work of Helen Nissenbaum (2009) on privacy violations of new technologies was used in order to create parts of the interviews on privacy perceptions. Social media was chosen as another point of attention, as people who use drugs sometimes engage in discussions on illegal drugs on social media platforms.

The interview guide was divided into four themes: Personal information, social media use, privacy general and contextual integrity. The first theme was chosen to be able to describe the respondents in a very general way with information only noted on paper without recording anything yet. After that, the recording was started and the interviewee was asked to describe their social media use (e.g., platforms, frequency and shape and content of interactions). That was followed by a short exploration on how privacy is described and perceived from the respondents' point of view.

Then, the focal point of this qualitative research was explored, namely contextual integrity. Contextual integrity was explored individually for social media, general drug research and lastly, a hypothetical research setting was presented to the interview partners). More precisely, the respondents were asked to describe the various aspects of the contextual-informational norms.

The first draft of the interview guide was tested with a person from the personal environment to evaluate flow of the questions and to fine-tune the hypothetical research description in order to make it as easy as possible for the interviewees to imagine themselves in said setting. No changes were made only additional hints for the interviewees were suggested in case the respondents would not understand the questions.

#### Sample

To find interview partners, an online survey with short questions on privacy, social media and experience with drug use was distributed. The survey was posted on the author's personal network and via the Twitter account of the Centre of Drug Research, Goetheuniversitaet Frankfurt. The survey was tested and approved by Bernd Wese, head of the Centre for Drug Research at the Goethe University Frankfurt and experienced qualitative researcher on social problems of illegal drug use. This was to ensure proper and non-discriminatory wording, specificity of the questions and a general cross-check with someone who is knowledgeable in the topic of illegal drug research to prevent mistakes. Out of 70 completed questionnaires, 30 people were willing to participate in an interview. Later drop-outs or unresponsiveness led to a total of nine people that were interviewed by the author of this thesis via Microsoft Teams or Signal video calls, and who had no other information on the topic other than those provided in the survey. The respondents had an age difference of up to 30 years, currently living in Europe (Denmark, Germany, Netherlands) and having illicit substance use experience. 8 out of 9 respondents were younger than 30 years. Table 1 provides an overview of the respondents, that show that PWUD are just like anyone else, with hobbies like anyone else and interests like anyone else:



*Table 1 Overview Interview Partners*

Alias	Age	Education	Interests/Hobbies	Country of Residence
Bear	18-24	MSc Degree	Art, Reading, Music	Netherlands
Cat	50-55	University Diploma	Jogging, Hiking, Travelling	Germany
Hedgehog	18-24	Bachelor's degree	Football, Running, Games with friends, Parties, hanging out with friends	Netherlands
Reindeer	18-24	MSc Degree	Football, Gaming	Netherlands
Dolphin	25-30	MSc Degree	Music, Art	Denmark
Pony	25-30	MSc Degree	Art, Yoga, Sewing, Swimming	Germany
Platypus	25-30	Highschool Degree	Gaming, Cannabis, Cars	Germany
Wapiti	25-30	Bachelor's degree	Chill with people, learn to DJ, music, parties, food, cooking	Netherlands
Kangaroo	25-30	MSc Degree	Climbing, Music, Art, Cycling, Boardgames, Plants	Netherlands

### Data analysis

For the analysis of the interviews an open-coding system was applied with a thematic orientation towards the research questions. After coding 3 interviews, the established codes were evaluated then re-evaluated after 6 coded interviews again. This was to ensure coherence over all interviews, precision as well as reliability to the research questions. At the end of the coding process, the codes had to be evaluated again due to the number of codes (130). The total of codes that were deleted was 22, while another 15 were merged with similar codes. Deletion of codes was because of non-relatedness to research goal, merging codes was due to the similarity and/or identity of the merged codes. Additionally, for two codes (Context description & control of personal information), sub-codes were created to be more precise and help in the analysis. Furthermore, the codes were grouped into six groups (contextual integrity, transmission principle, type of information, social media, privacy issues and interesting but (ir)relevant) to be able to distinguish the information presented by the codes.

The different result sections were established according to the sub-research questions, therefore the code-group social media was used for the first section. The two most used social media platforms WhatsApp and Instagram have been described in more detail. The other mentioned platforms were merely summarized and shared features as well as differences highlighted. While the codes were used to extract the information from the interviews, especially from the code group type of information, the quotes related to each social media platform had to be searched for within each code.

The following section of the results dealt with privacy issues and ethical questions that were mentioned by the respondents, where the code-group privacy issues became the focal source of information. There the most frequent codes of the code group privacy issues were presented as well as some less frequent but related codes too.

For the last section, participation in research, three themes were explored, namely the interest in the topic, relationship with the researchers and to the data. There the codes from the code groups transmission principle and type of information were relevant but had to manually selected from the codes, as not all codes were related to the theme of participation.

### Positionality

This explorative qualitative research is inspired by the author's experiences regarding illegal drug use and therefore may have a slight bias. This bias can be expressed by past experiences in the close and distant personal network with law enforcement, societal stigma and an upbringing in a restrictive German environment regarding PWUD. From the author's experiences, law enforcement in Germany considers drug use still a criminal offense and accordingly treats PWUD as criminals in many cases. Incompetent educational staff in the early teenager years has shaped a proactive attitude towards changing the societal views regarding drug use in the author of this thesis. This thesis can be considered a natural outcome of yearlong enthusiasm to change the status quo.

Living in the Netherlands has further contributed to the will of changing the prohibitionist drug regime present in most parts of the world. The Dutch approach of harm reduction and treating drug dependence as a health issue rather than criminal offense has allowed the author to develop a balanced view on the issue.

The personal characteristics of a white, German privileged student studying abroad, may not have had an impact on this work but in the eyes of others it may have.

## Results

### Social Media Use

The findings for social media use are split into the following sub-categories: platforms used (to describe the platforms mentioned by the respondents); reasons to and mode of use of the most used platforms (WhatsApp and Instagram and briefly of all other mentioned platforms) and descriptions of the social media environment for WhatsApp and Instagram respectively.

### Platforms Used

There was a diverse use of social media platforms, with WhatsApp and Instagram being the most commonly and regularly used platforms. WhatsApp was used by everyone, while Instagram was not used by all but one respondent. Some platforms were used or mentioned only by a few, such as Facebook. Twitch, Wickr, and Twitter were each actively used by one different respondent. The messenger apps Telegram and Signal are used by two and four respondents respectively. The social network LinkedIn was used by five respondents. The next part will discuss the reasons to use a certain platform, the way the respondents used the platforms and how they described the platforms for each platform individually. Though, Twitter, Twitch, Wickr and Signal will be omitted due to the little information gained on them throughout the interviews.

### WhatsApp

The extent of the use of WhatsApp differed between the respondents, some were using it as their main form of communication with friends, family, and other private contacts. While one used it for work purposes too, another said, that a different messenger app, Signal, is dominating private conversations, because the private network is shifting away from WhatsApp.

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*Definition of Privacy by Wapiti: "privacy for me means that what I post on social media including whatsapps can't be used against me because I feel like when I write something it's for me and the person I write it too."*

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### Reasons and mode of use

The interviewees using WhatsApp were using basically all functions of WhatsApp, that is calling, sending text messages, voice messages, documents, and pictures.

The most common reason of using WhatsApp among the respondents was to stay in contact with friends, though it was also mentioned, that it was also a choice due to the popularity of WhatsApp among friends. Interestingly, it was often mentioned, especially by the Dutch respondents, that they prefer to have rather short and effective communication on the platform. They said that instead of having small-talk on WhatsApp, they prefer to call or meet-up. As one respondent put it: "WhatsApp is for 'hey meeting you there,' hey I'm there, where the fuck are you?' But not for: 'How is your day?'" (B,¶107). But it was mentioned by some that they had day-to-day conversations with friends or their partners. These sometimes contained sensitive information, personal feelings and opinions that described their inner worlds. Also, the ones that were working already, often did not interact with colleagues on their private WhatsApp, but preferably relied on the usual business channels that were offered through their workplace.

Only a few of the respondents used WhatsApp to discuss or buy drugs on a regular basis. It was interesting to hear that one of the respondents said, that she would be buying drugs via WhatsApp, but none of her dealers would have it, so she has to rely on different messenger apps. One respondent mentioned in regards to drugs, that he was sometimes asked to explain his drug experiences on WhatsApp to friends who wanted to try a new drug and get some advice.

*“Sometimes people ask me questions about drugs because they know I have some experience with it. So they ask me yeah do you think it’s a good idea to do this and this. And then I can advise them on my experience.” (W, 29).*

### *Descriptions of WhatsApp*

When it comes to how the respondents described what WhatsApp is to them, it is seen as a very functional app that helps with keeping in touch with friends and organising life and friendships. It was even described as necessary

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*Privacy Definition of Bear: “that you can have your own space. Real privacy in your house with the curtains closed ehmm - but also online that you can be in control of your own content.”*

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nowadays and that life without it is not as effective. What made it so necessary is the speed of communications and that conversations are not really time dependent. Non time-dependent in the eyes of one respondent meant that you could have a conversation over a couple of hours, but it is continued every once in a while, depending on the availability of the other conversational partner. Noteworthy, WhatsApp can have, according to some informal and formal ways of communications. Depending on if you are texting your boss, landlord or a close friend. Some have also highlighted, in their eyes, the private nature of their conversations that is better not to be read by others.

### *Instagram*

Instagram has been used in different ways and intensity by all but one respondent. Half-jokingly half-serious one of the respondents called it her addiction, another very similarly the biggest time-consumer. Two respondents deleted the app from their phones, but not their accounts. They continue to use it via a web-browser.

### *Reasons and mode of use*

The interviewees shared one communal way of using Instagram, namely following their interests or people relating to their interests, but that is it already. The majority of the people was using Instagram as a form of entertainment and overcome boredom or free time. At the same time, the act of posting pictures themselves was not widespread among the participants, though some did post pictures or videos of themselves or interesting things around them. Many were only watching their feed or getting lost in the explore section of Instagram. Only a few would like or even comment on pictures of friends or others.

As mentioned earlier, some people did delete the app off their phones, the reason for that was that they became annoyed by the showing-off mentality that many respondents

described. One statement describes it well: *“Everyone is always posting only the best picture of themselves”* (H, 19) One other respondent used the following words: *“I’m not really interested to see that you’re at a beach or wherever you are. If I feel like this with other people, probably random other people won’t be interested to see if I’m somewhere”* (W, 21). However, two of the interviewees were exactly highlighting that fact, which made Instagram attractive to them. The option to show-off is relevant if you use the platform to promote your art of almost any sort, such as paintings, designs, or DJ-sets. Which has a two-sided effect, depending on the kind of ‘show-off’.

If that form of art is your job, it is not only a platform of individuals posting their private lives, but it can also be seen as a business platform. Which in turn is used by some of the respondents to find inspiration for your personal interests such as art or cooking, as one respondent put it: *“Art inspiration – so I follow quite many people, who are artists or brands that I find cool”* (P1, 13). Or even more concrete: *“Instagram is really a source of inspiration sometimes. I follow a lot of art channels.”* (K,11).

At the same time Instagram is a platform for businesses and business-like organisations that depend on information spreading. That becomes apparent through the often-mentioned use of Instagram as a source for news, global or local alike. Different news outlets also provide their information to their followers on Instagram.

*“I feel like I should do it more because, well, I have business to run. Alright are - like it's good to have exposure or be active in that way, but I don't do it much, no”* (D,29).

But not only is there informative content from established news agencies, but also mental health related content or educational content related to illegal drugs. Some mentioned that they send informational or educational content on mental health to their friends and discussed how that is personally relevant to them. Similarly, providing awareness to issues such as drug use, some respondents mentioned that they do not only follow but also share this content with others. However, often the recipients of such content are not anyone, but people who can relate to them because of shared interests, current or a history of drug use. This is not restricted to awareness but also memes regarding drug use.

*“I think that’s also very much dependent on what types of dis – what you’re talking about with the people offline. Well, that’s also influenced by that. If we talked about something and you stumble across a related post, then you send it and say: hey look here blablabla.”* (P1,93)

*“oh yeah of course, I mean if it’s about drugs, I would say, I send it to a friend, of which I know, that they used to take drugs or still using drugs so they’ll get memes related to this rather than getting memes if you know they only smoke weed and don’t really know what to do with it, because they don’t find it as funny as the people who used to take drugs. Most likely, they know what it (meme) is about and will probably find it funnier.”* (P2, 81)

### *Descriptions of Instagram*

The majority of the respondents described Instagram as a platform in which visual content (photo and video) is shared, often supported by text. Especially the power of pictures was highlighted by a respondent who said that pictures are often more powerful in conveying a message than text only. Also as mentioned earlier, content can come from basically anyone, which made one respondent feel like *“It is a part of the real world but nothing matters to you that much”* (D,93). However, not everyone feels like that way as one put it: *“so it’s a nice collection of what you like, what your hobbies are, what your music taste is, everything comes together, since you created your own algorithm.”* (K, 31). Though not explicitly formulated by the respondents, Instagram is one big but fragmented community, in which everyone can follow basically anyone, except if they have a private profile. Users of Instagram build their own world within Instagram, based on their interests and opinions and each user can make it a mirror of their personality: *“for everyone there is something. Multi-purpose platform.”* (K,73).

At the same time, Instagram is influencing how people get into contact with content the users might like. Many respondents mentioned, that *“at the end of the day, it’s also the algorithm, because it decides what I see and what I don’t see”* (P2,75). Or as another respondent expressed it in regards to why drug jokes from drug-unrelated pages are shown in the feed: *“maybe it’s an algorithm for my age.”* (K, 103). Therefore, some of the respondents felt like Instagram is censoring or restricting certain content, for example drug content. One respondent mentioned regarding the visibility of the stories of drug-related pages, that these pages often do not appear in your story feed, and only in the normal feed. That is because they *“limit the interaction of these pages”* (P2,31) through a *“shadow ban”* (P2, 31).

### Social Media Others

Due to limited information and less frequent and spread use among the respondents on the other mentioned social media platforms, the following section will provide a summary of LinkedIn, Snapchat, YouTube and Facebook reasons and modes of use and descriptions of the platforms.

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*Privacy Definition of Cat: “Well that’s the self-determination, what’s happening with my data and who gets this data and what he could do with it or what he is allowed to do with it.”*

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The use for each platform varied per respondent between daily to irregular. One aspect that unites almost all remaining platforms is that they are often described as a source of inspiration. Be it for professional purposes in the case of LinkedIn or hobbies in the case of Facebook. Another aspect that can be applied to all platforms is to stay in contact with acquaintances of any sort. Furthermore, YouTube and Snapchat have been mentioned to also fulfil purely entertainment purposes. In contrast to that, Facebook has been mentioned by one respondent as a platform for their business and using it to maintain a professional network. Similar to the use of LinkedIn. Though LinkedIn was used by one respondent to ‘stalk’ old acquaintances.

## Privacy & Ethics

To be able to explain more motives of the respondents for and against partaking in research but also revealing information about themselves online, various privacy statements will be shown in this regard. To structure them first some of the most frequently mentioned worries are presented followed by less frequent though noticeable statements.

### Control over Personal Information

The most frequently mentioned statement was that respondents wanted to exert or were worried to lose control over their personal information. This corresponds with virtually all respondents' definition of privacy, that one has the ability to control access to one's own actions, beliefs and (online) data. This statement can be furthermore distinguished in three, sometimes overlapping categories of activities, online content and beliefs or personal opinions. Overlapping because the boundaries of what people post online, their activities outside social media and their beliefs are often blurred.

The respondents often used metaphors of a physical barrier, such as curtains in a house, to describe how they want to stay in control, and that if people find a way around it, they will feel threatened in their privacy. That also implies that people can decide whether they want to allow people to have a glimpse into their home so to say, as one respondent put it *"real privacy in your house with the curtains closed"* (B,63).

A repeatedly mentioned information that some of the respondents did want to protect was pictures of themselves, but also any information regarding their health. Similarly, some respondents mentioned their past experiences with drugs as protection worthy, also past contact with law enforcement should not become public. One respondent clearly stated that bank and social security numbers were something others should not have access to. Another respondent even considered hobbies as something randomers should not be able to find that about oneself.

### Nothing to Hide

The majority of the respondents though believed they had nothing to hide, especially online. One respondent, who was very careful about the available information online, even saw a trend in society: *"if you see what other people share – about their kids or even with their kids, then it seems as if it's not too big – not too big of an issue"* (P2,69).

Which aligns with a statement by someone else, who mentioned that there are *"millions of people, billions of people"* (D,49) so one just dissolves in the masses of people and becomes uninteresting or undistinguishable from others.

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*Privacy Definition of Hedgehog: "Privacy for me I would classify as – maybe more of a feeling that your data and your behaviours online but also offline are protected and nobody can look at this data or use this data to gain more knowledge about you as a person."*

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## Personal Preferences/ Opinions

Another point that was often mentioned is that the information people were providing online but also in the interview was “*very personal*” (P1, 130). It was also mentioned that social media makes one surround oneself with one’s preferred “*social bubble*” (P1, 66), which contradicts with the earlier mentioned undistinguishable notion of other respondents.

## Convenience over Knowledge

Some respondents said that they would like to engage in informed behaviour online as to what consequences the accepting of privacy policies means for your data.

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*Privacy Definition of Reindeer: “I would say in general, the privacy is just don't look into my. Don't look through my windows if you don't know me or if you have nothing to look for.”*

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However, they said that the length of the information or vocabulary in the policies themselves restricts them from doing so, so they would not do it. As one put it: “*then I would be occupied for years, decades centuries*” (C,20). The intention of formulating the privacy policies in that way is seen as wanted, even manipulation. At the same time, it was mentioned by some that laws govern these policies and therefore prevent misuse of data by the issuers of privacy policies.

## No Escape

By some respondents the worry that there was no area of life where you can really prevent companies or organisations listening to you or tracking your behaviour. Especially if you carry your mobile phone with you, the respondents said. On the question if one respondent claims ownership about the information provided in the interview the following answer came: “*I mean if you wouldn't collect it, then one of the 15 screens and connected devices would record it anyway. Also Alexa listens to me.*” (P2, 121). Statements like these are also related to the notion that some of the respondents felt they had no other choice than using certain social media platforms, especially WhatsApp. Since basically all their contacts use them and it would affect their personal relationships.

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*Privacy Definition of Dolphin: “You kind of feel like you don't. You're not followed or No, you're not seen or heard, or you know. Yeah, you're not noticed. You are unnoticed. That's basically. What it would mean - Uh, also online, I think. And in real life. Just the safe zone. To do anything, yeah.”*

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## Crime

Different sorts of crime; experienced, partaken in and worried about; have been mentioned by the respondents in relation to their data and resulting consequences for actions. Some respondents were afraid that their data in the wrong hands could lead to identity theft. One respondent

mentioned that the hackers threaten cyber security. Another tried to avoid (self) incriminating phrases when talking about drugs on social media due to a past as a drug dealer.

## Commercialization

As a last aspect worth noting is the often-reoccurring statement by the respondents, that they were afraid or worried that companies sell their data to third-parties or misappropriate them. However, some were aware that using free social media means *that “that's kind of the price*



*you pay. [with] Your data” (D,61). Some related this aspect also to the earlier mentioned algorithm-determining-what-you-see statements and said for example that “the platform you’re using is in some storing at least in some way storing your information and your messages and the things you watch.” (H, 73). Yet, it was also highlighted by one person that they appreciate targeted ads: “Well, me personally, I find it quite useful, because then I don’t get for lawnmowers – because I don’t have a lawn, so I don’t need a lawnmower” (P2,125).*

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*Privacy Definition of Pony: “Privacy has to do a lot with the choice (...) that I can keep certain things secret or for myself and that no one knows anything about me, what I don’t want others to know about me.”*

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## Participation in Research

When it comes to how the participants viewed participation in the research as well as the hypothetical research setting, motives relating to interest in the topic, one's own health and helping others came to the fore. Furthermore, how the respondents described their relation to the content and researcher(s) shows differences.

### Interest in Topic

Some respondents mentioned their interest in how privacy, social media and drug research would come together and therefore were willing to participate in the interview. As one respondent described it: *"also because it is quite interesting the thematic overlap of social media but also drug use"* (P1,165). Additionally, interest in the topic of illegal drug use would motivate some of the respondents to participate in the hypothetical research project. Especially when the respondents were proponents of drug research in general, then the motivation to participate in the hypothetical research setting and interview was increased. One respondent expressed it as follows: *"I'm all team drug research"* (B,167). An explanation following later: *"so I think that drugs are very misunderstood in our society. And I believe they have a high clinic value. So anything related to research on medical but also just scientific in general, research in drugs: I'm super up for it, I'd love to contribute too"* (B, 173). Similar statements about a present misunderstanding of illegal drugs within societies have been voiced by almost all respondents. Interestingly, there was a clear contrast between two respondents who disagreed about the (side-) effects of drugs and what new research could find out. One had a more nuanced picture, namely that drugs can also be more harmful to their users, and research might show that too. The other was very enthusiastic and one-sided in her opinion what drugs do to the human body, particularly that generally, illegal drugs are not more dangerous than legal drugs and even beneficial to human health. The following quotes illustrate this contrast:

*"so, when (the researchers) make a decent study, that maybe, show anything. There can also be negative findings. I would not only take part if they praise all drugs. But also if they say: hey friends, whatever, snow and alcohol is often taken by you, but in case you still want to keep your first liver until you're 40, you shouldn't do that. Stuff like that can very well also be a conclusion and that would teach one a lot."* (P2,169)

*"(the researchers) are gonna run some statistics and conclude that drugs aren't very unsafe or unhealthy for us here. Or that your heart rate while doing drugs is – and your body temperature or something blood pressure is lower than if you're doing alcohol. Which will conclude that alcohol might be bad – worse for you than drugs. Which I think is the case sometimes."* (B,178).

The interest in participating in the research becomes a bit blurred from this point on, because it partly overlaps with a topical interest in illegal drug use, but also its' effect on the (own) human body plays a role in the motivation. Some of the respondents not only mentioned one reason for the participation but often multiple. Their motives in creating awareness for PWUD and reducing social stigma regarding drugs for example in combination with a personal interest in the effects of using drugs on their own body.

## Relationship with Researchers

Another motive to participate in the stated research was because of the relationship to the researcher, which slightly ties in with a topical interest in the matter and needs elaboration.

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*Privacy Definition of Platypus: "As a sort of security in regard to one's own being."*

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Not only did a personal relationship to the researcher in the eyes of some respondents motivate people to even participate. It also helped in establishing trust with the research topic and willingness to provide information. Especially in regard to the conducted interviews, an informal relationship helped the respondents to feel more at ease as visible in the following quotes of a respondent:

*"Sitting outside. I think it's always better if you can sit outside than inside. The weather is good. (a friend) is here. I mean I'm sitting – I feel like it's more hanging out with friends than that I have to do an interview, I want to help you I want to do it. It's a really easy setting." (W,87).*

*"I try to just – I don't know – be honest and talk to you not differently than I would talk to somebody who would ask me the same question that is not a friend. But because we're friends it's sometimes it's easier to get into details for example because I already know or understand easier. So I think I wouldn't it's easier to just speak up and not really have to think about a good answer. But what comes to mind." (W,99).*

Even though the respondents considered the setting of the interviews informal and "private" (D,133&K,123), a certain professionalism regarding the seriousness was upheld. This was because, to the interview partners it was clear that there was a purpose of the interview and not a conversation among friends.

*"on the one hand do I see the usual Carlo, but on the other hand, a little like, that you have to do this for your master thesis and that's a little bit more serious. But still I would see you like I normally do." (P2, 113)*

*"Now we have quite an informal interview, I suppose. Because you're at home, I suppose and I am. And now I try to answer your questions to make it as useful for you as possible. (laughs) and quite professional." (B,143).*

Some respondents therefore regarded the relationship between interviewee and interviewer as equal, but one did see some power differences during the conversation. These power differences were because the interviewee thought the knowledge on the topic was unequally distributed, despite that there was more input coming from the interviewee.

Reacting on how carrying a smartwatch to collect health data in a familiar or festival setting while using drugs, respondents regarded the setting as less informal and stricter compared to the interview. But because it takes place in an environment where people are meant to have fun and enjoy themselves, the respondents have found it conflicting with the research part. As one respondent expressed it: "Just having fun while also doing something influential" (D,165).

Or another in more detail: *“I guess it would be an environment in which I would probably be with friends at this – it’s about having a good time. Because you know you’re being tracked it might also influence the atmosphere or like the ambience a little bit as you’re’ – of course you forget a bit about it but it might still be in the back of your mind.”* (H,137).

Not only was the setting perceived as less informal, the respondents also often mentioned that they would see themselves as more distant from the conducting researchers. This resulted in descriptions of themselves as a passive data source where *“it’s also not really about the participant”* (K, 175) or in which they felt like a *“guinea pig”* (W,117). However, there was also acceptance for this kind of impersonal, much larger research was also expressed *“because N=1 is of course not sufficient and significant, but N=100 gives a complete different picture.”* (C, 86). Nevertheless, the design of the study and distance to the researchers made the respondents more cautious regarding their participation. Especially uncertainty about who is responsible for the financing, conduction and motives of the researchers was expressed by many of the respondents. As visible in the following statements:

*“I think for me it’s really important to know exactly what the goal is of the research and who’s handling the information and for what purpose. And I think that’s easier if you know the researcher, cause then the line is shorter. But that is like a reason to do it but I don’t really care if I knew the person.”* (K,177)

*“My first response would not be, yeah let’s do it. But my first response would be why? And if somebody would explain, yeah I’m doing research about your heart rate and how that works and everything I would probably feel like that – if I can help with that sure, let’s do it. But the reasoning behind it should make logic to me. If I can help somebody with their research, it’s a good reason for me to help. If they just want random data, I don’t think I would participate, because I don’t see it as useful.”* (W, 119)

#### Relation to the Data

The respondents expressed their relationship with the data they provided in the interview (or would provide in the hypothetical research project) quite differently. While some were very open and willing to share basically all personal information for research purposes, others were more protective of their data. These two sides of the spectrum are visible in the following two statements: *“I don’t see how data about me, my heart rate during a festival could be of any use to anyone”* (B,179); *“I generally don’t really like giving away my personal data”* (K,141). This was further influenced by the feeling or condition that the information was handled anonymously and confidentially, *“so it doesn’t really matter what you say – so that’s nice too”* (H,133). Especially in regard to the hypothetical research project, legal consequences for participants were of concern for some of the respondents and where anonymization of the data would make them feel secure.

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*Privacy Definition by Kangaroo: “yeah by creating a barrier what’s yours and what’s other people’s.”*

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Some of the respondents regarded the information they provided in the interview as not personal or meaningful. They could not imagine how opinions, feelings or even body measurements can be used against them. At the same time, they voiced their relief about anonymisation of the data and the resulting freedom to talk. There was only one strong opposing opinion about the use of personal information in research.

## Discussion

This thesis aimed to identify differences between privacy perceptions of PWUD in regard to social media use and participation in illegal drug use. By interviewing a small sample of participants, this research found the following: Social media use varies per platform and the same counts for the motives to engage in one platform. Privacy perceptions indeed vary per context, and are seemingly governed by contextual-informational norms. These are influenced by the relationship between the people sharing data (read: researcher – participant, friends – friends, friends – like-minded people). Furthermore, the respondent's perception of how they relate to the data shaped their willingness to participate in research. The research project's goal and institution was mentioned to have an influence too, with trust playing into it.

In the following chapter, the findings will be discussed with two separate angles: once with a methodological angle and once with a content-related angle. This is done to describe the differences in privacy perceptions regarding social media use and participation in illegal drug research. The methodological part will look at how the interviews could have been improved and how future research in the area could address the issue. This is necessary because it will make some of the findings easier to understand and justify shortcomings. Then the findings' content will contextualize the findings within the literature on the uses and gratification theory, similar literature and lastly on contextual privacy. This will be used to help potential future studies to conduct research on illegal drug use using smartwatches or other tracking devices collecting health data. Lastly, these future studies may inform future policies regarding illegal drugs that are comprehensible by most stakeholders and the general public.

### Methodological Discussion

The following paragraphs will discuss some methodological shortcomings that are due to the inexperience in interviewing for scientific research. While the interview guide in itself was sound and the questions were understood by most of the respondents immediately, responses provided by the interviewees were often not as detailed as initially hoped for. Responses such as the switch of the personal network towards the messenger app Signal were mentioned and no explanation followed. Then there was also no probing coming from the interviewer as to why that switch happened. By asking follow-up questions the answers would have been most likely more informative and insightful and provided a deeper understanding of the respondents' views. Particularly on how they view social media, their social media use, motives to engage in different behaviours on a platform, a deeper understanding could have been created. In retrospect, creating a very detailed overview why, when and how people use social media may have been obstructing a more general outlook on the topic.

However, due to the novelty of the topic, as the attempted literature search has shown, the author of this study was presented with a challenge to gather information on the topic and therefore have enough understanding. The initial recruitment survey was aimed at finding out some rough outlining information on social media use and experiences with illegal drugs, but the answers were not focussed enough yet to extract information. Further, the survey was intended to screen for possible participants instead of gathering information. Therefore, the choices made regarding the content of the interview guide and recruitment survey were right.

It can be assumed that with a better trained interviewer, the elaborateness of the responses of virtually all interview partners could have been improved. As someone trained in conducting qualitative interviews, would have been more likely to trigger longer answers, also in people who may be at first reluctant to talk or not very talkative at all. This could have also helped in moments when respondents gave a response, but it was missing the essence. Therefore, additional probing into mentioned aspects could have proven valuable to deepen understanding therein too.

In the process of transcribing the first interviews, the above-mentioned shortcomings were identified partly. Due to the amount of information that was asked for and had to be discussed, the interviewees' answers seemed sufficient enough at first sight. As a methodological improvement or addition, one could pair qualitative and quantitative approaches. To assess the social media use, a survey asking for detailed information provided to participants before conducting interviews might improve the findings. The findings of the survey, then, could be studied individually to prepare for the interviews as well as taken together to form a quantitative assessment of the data. This proves certainly valuable if the sample size would be increased. However, since this was not known before the start of this project, the choices made to conduct a qualitative methods-only approach were just.

As an alternative for smaller sample sizes, focussing on popular social media platforms such as WhatsApp and investigating these individually could contribute to an easier flow of the answers, as participants do not have to switch from one to the other. More in-depth questions during the interviews may have been possible through that also. Follow-up studies could use the findings and structure of this work as a design template. As the next sub-chapter on the discussion of the findings will show, in regard to social media use, other researchers have made similar findings.

### Discussion of the Findings

The findings of this study have to be discussed in the light of previous studies on social media use, privacy perceptions of PWUD and how this relates to illegal drug use. Furthermore, an assessment of the contextual informational norms for WhatsApp, Instagram, and drug research will be included in this.

### Social Media Use and it's Motives

Interestingly, the non-representative sample of this study showed different preferences for the used platforms than the general population, Facebook, is considered the biggest platforms in terms of active users (*Facebook: Global Daily Active Users 2023 | Statista*, n.d.). However, this corresponds with a general trend within younger generations, similar to the age of the respondents (see Table 1) as numbers from the United States of America shows, where Snapchat, Instagram and TikTok have the largest user group (*A Look at Gen Z's Preferred Social Platforms - Insider Intelligence Trends, Forecasts & Statistics*, n.d.).

The contextual descriptions of WhatsApp and Instagram by the respondents of this study can be related to the honeycomb theory by Kietzmann et al. (2011). The platforms will be discussed individually to allow for a detailed assessment.

Comparing Kietzmann et al. (2011) forthcoming and the findings of this study, it seems as if WhatsApp is designed mostly along the building blocks of conversation and sharing. Conversations means “the extent to which users communicate with each other” (Kietzmann et al., 2011, p. 244). As the study sample also said their main use is to communicate with friends and other actors, the conversations block is one of the main components of WhatsApp. Further, according to the sample, sharing content in the form of pictures, documents, voice messages and more is an important feature of WhatsApp and therefore aligns with the building block of sharing as proposed by Kietzmann et al. “the extent to which users exchange, distribute, and receive content” (2011, p. 245).

Instagram’s building blocks, according to the sample consist of identity, sharing, relationship, and reputation. As Kietzmann et al. state regarding Identity: it is “the extent to which users reveal their identities in a social media setting” (2011, p. 244). Because respondents of this study have mentioned they present, or used to present their lives, or identities to their followers, for example art, identity is one building block of Instagram. This also holds true for the aspect of business promotion by some of the respondents. As Instagram is a platform described by the respondents to exchange content via their own profile or in direct messages, the sharing building block is also a major focus of Instagram’s design. Relationships, as “the extent to which users can be related to each other” (Kietzmann et al., 2011, p. 246) can be assumed to be a building block of Instagram, according to the study sample. This is because respondents described the content one is presented with as dependent on who you follow and the power of the algorithm. The last building block that Instagram seems to rely on is the feature of reputation; “the extent to which users can identify the standing of others, including themselves, in a social media setting” (Kietzmann et al., 2011, p. 247). Disregarding the level of reputation, virtually all of the interviewees have expressed at least noticing the show-off factor of Instagram which some people engage in.

These points suggest that WhatsApp and Instagram have different designs that influence how users engage on the platforms with each other. While Snapchat is based on communication with individuals or groups, Instagram can be used to share opinions, experiences and generally interests with a much larger audience that is not directed at individuals from one’s own environment.

Further it is interesting to compare what earlier studies have found on the motivations to use social media to what the respondents of this study have mentioned. Firstly, looking at WhatsApp, a different picture evolves than with Instagram. For WhatsApp, the reasoning to use the platform was often to stay in contact with friends which relates to the theme of social interaction as identified by Whiting and Williams (2013). There, especially the effective communication was highlighted as being beneficial in addition to convenience that using WhatsApp does not depend on the other person but rather you can respond when you find the time for it. This could be related to convenience utility as people chose it also as a mean of communicating due to the popularity among their friends and acquaintances of the platform. Another reason to use WhatsApp in the sample was to discuss drugs and sometimes also buy them on there. This can be related to the themes of information sharing and information seeking as William and Whiting (2013) identified in their study. Some



respondents' motivations to have text-based conversations about their opinions and feelings on WhatsApp fits also into these two information related themes.

Next, looking at Instagram, the respondents have described varying motives to use Instagram that can be related to the themes of William and Whiting (2013). The largest part of the respondents named entertainment, passing time and boredom as reasons to use Instagram. This aligns with the themes of pass time, entertainment and potentially also convenience utility due to the fact they were using it to pass free time at hand. In addition to that, the fact that the interviewees shared information about drugs, namely awareness posts, hints at another theme that was also identified by William and Whiting (2013), the information sharing theme. In line with that is also that some people in the sample post pictures sporadically, though not often. Further, by sharing their own artistic works or updates on events via their Instagram page, those who engage in it are in my opinion also using this in the information sharing theme. Similarly, as some respondents mentioned Instagram is their source of inspiration, the theme of information seeking as identified by William and Whiting (2013), seems fitting here. To this fits also that some mentioned that they receive many of their news through the platform.

However, some themes that were identified by William and Whiting (2013) have not been mentioned directly for Instagram and WhatsApp alike. Among these are relaxation, communicatory utility and surveillance/knowledge about others. Looking at the other social media platforms mentioned and the reasons to use them, largely the same can be said about these. Except for one respondent who used LinkedIn to gain knowledge on old acquaintances, which would fit the theme of surveillance.

Similarly, a preprint of a study on social media use of adolescents by van der Wal et al. (2022) identified four different needs that adolescents try to fulfil by using social media. These were "need for connection", "need for entertainment", "need for inspiration" and "need for information" (van der Wal et al., 2022, p. 8). Their study, interestingly, did not have the uses and gratification theory as a framework, nor did they mention it. Yet, the findings of motivations to use social media in the study of van der Wal et al. (2022) partially overlap with the findings of this study.

### *Privacy & Ethics*

The perception of privacy regarding social media and illegal drug research within the sample varied per respondent. While some had a high privacy affinity, often carefully thinking about what to share with others in different contexts; others had a low privacy affinity, putting little thought into what sharing certain parts of their life with others could mean to them. To situate the findings in the literature, first reflections on the conceptualizations by Finn et al. (2013) will be presented. This is followed by an attempt to establish relevant contextual-informational norms as presented by Nissenbaum (2009).

### *Privacy Dimensions*

In general, the respondents considered different aspects of themselves protection- and privacy-worthy, such as information about one's health, activities, beliefs, online data, but also very precarious data such as one's bank details or social security number. Previous studies looking at privacy attitudes towards health information sharing have had similar results in

regard to health information privacy (Kim et al., 2015; Page et al., 2016; Sikweyiya & Jewkes, 2013). This information about the individuals can be connected to the different types of privacy that Finn et al. (2013) have identified. Even though these types of information have been mentioned by some, only a few considered other types of information privacy-worthy than that information posted online and many even considered they were just one among many. In the context of online data, many considered their “privacy of data and image” (2013, p. 7) as important to protect. Furthermore, the synonym of curtains closed for the definition of privacy by many respondents could be associated with the “privacy of location and space” (Finn et al., 2013, p. 7) in a general sense.

The political dimension of privacy, namely the assurance of privacy by law has been mentioned by a few, though in relation to the existence of laws regarding privacy policies. Furthermore, by stating that there is no escape from commercial entities listening or tracking you, in addition to targeted ads mostly worries came to the fore. It could even be argued that companies engaged in this sort of behaviour are actively exploiting the right to privacy, by using their power of market share and possession of huge data sets – exposing hidden power structures – something Finn et al. (2013) have hinted at before. Some of the laws are designed to protect one from the harm of misuse of data, however as many respondents said, it is made virtually impossible to understand these privacy policies. By using difficult wording and lengthy texts, companies exploit the right to privacy, the laziness, and a non-existent legal savviness of the population.

Yet, this kind of behaviour is not a feature of current academic institutions, meaning collecting data for the sake of profits, as academic research should be largely independent of external influences (see discussion about WUR: Jongeling, 2023; Zegers, 2021). However, as some participants have mentioned, they would like to know exactly who is responsible for the funding of a given study and who benefits from it in order to determine if they want to participate. This has also been found by others (Kim et al., 2015; Page et al., 2016; Whiddett et al., 2006) who were looking at the attitudes of patients sharing health-related information. In a small study that surveyed 70 people, it was found that the purpose of the researching institution can have an impact on the willingness to share health information (Bell et al., 2014). Organizations with a commercial or for-profit purpose received lower support from their respondents. Which leads to the next section of the discussion, the participation in illegal drug research.

### *Contextual Privacy*

To be able to determine – if at all – privacy perceptions of the respondents impact the participation of the respondents, it is necessary to establish what the contextual-informational norms are that govern the information exchange. Further, to assess differences between social media and research, the same has to be done for Instagram and WhatsApp.

### *Contexts*

Starting with the social media parts and using the descriptions mentioned earlier, WhatsApp happens in the context of a digital technology sharing based on having conversations and sharing content of different types. It is deemed necessary by some and can be formal and informal at the same time. For Instagram, this is largely the same, it is even more directed at

sharing your content with others publicly.

Research on the contrary often happens in a non-digital, professional setting, yet the respondents described the interviews as rather informal. Further, in regard to the hypothetical research setting that the respondents were confronted with, they mentioned it takes place in a context that is more formal due to the technology used. But at the same time, designed to enjoy yourself.

#### Actors

In terms of the actors, in WhatsApp, the actors were described as mostly friends and family, but also (old) colleagues, dealers, landlords.

Instagram's actors in the information exchange are anyone from friends to an organisation that someone likes, to artists or news agencies.

In the interviews it was the interviewer and interviewee, except for one case where a common friend was present but did not participate in the conversation directly.

For the hypothetical research project, the respondents mentioned the researchers responsible for the execution of the research project, themselves as participants. Some mentioned friends being with them, but also here not actively involved in the information exchange.

#### Attributes/ Type of Information

For WhatsApp and Instagram, the type of information can be anything from political opinions to awareness campaigns for mental health. So basically, anything personal to impersonal work-related information.

For the interviews, as mentioned before, some considered it to be very personal information, some very general information about themselves. Yet since they voiced their opinions, or self-incriminating information, it could be considered sensitive data in the sense of the definition used in this paper.

Similarly, in the hypothetical research project, people considered information about themselves as very unspecific and impersonal. In the light of the definition used in this paper, it can be considered sensitive information too, since health-related data is included there.

#### Transmission Principle

To establish the transmission principles, it might be that the earlier mentioned shortcomings during the interviews will obstruct the attempt to do so. Nevertheless, the following paragraph will try it, starting with WhatsApp, followed by Instagram and lastly the research setting.

On WhatsApp the information exchange is influenced by the opposite actor, as the respondents described it, it can be formal or informal. While some wanted short, effective exchanges of messages with their friends, others also had unaffected, deep conversations about their feelings with their partners. For the respondents claiming WhatsApp conversations to be private, this could mean that they contain sensitive, information or even secrets worth being protected. Yet they put their trust into a commercial company that makes profits by selling the information they have over their customers (Tiku, 2022). In the case of the person with a drug dealer past, this is especially relevant. Also, if one assumes that drug consumption is illegal in a country, then being in contact with people who also use or deal

with drugs can potentially put one into the focus of law enforcement just by being in the contacts. Therefore, the WhatsApp users of my sample may not be aware that their seemingly private data may be at risk. A deeper understanding of the restrictions on sharing content is not possible and needs further exploration.

Within the sample, Instagram has also been described varyingly. On one hand some were reluctant to share pictures of themselves or stopped doing so during their time on the platform. On the other, identities, opinions or daily life was shared publicly on there without any restriction. But, in the private messages, many of the interviewees mentioned they would send content to each other that was much more revealing about themselves than the 'public' side of them. Through the more private exchanges, Instagram is most likely able to collect additional information on a person. Plus, the respondents seem to be engaging in more exposing behaviour because they are protected by the 'private messages'.

Summarizing Instagram's and WhatsApp's transmission principle and the resulting behaviour briefly, it appears as if the interviewees are feeling secure and unwatched through the private character of messages, and type of interactions on Instagram. Therefore, exhibiting revealing behaviour that can show their feelings, relationships, mental health issues and more.

Continuing with the transmission principles for the research settings, the interview partners have expressed different restrictions on the information exchange. As mentioned before, there was the opinion that depending on who funds and organises the research data will not be shared, or participation denied. Others were willingly sharing their data, if it helps the scientific advancements in that field which corresponds with findings of others (Kim et al., 2015). What stood out was, that almost all respondents were more likely to participate if they had personal contact with the researchers. Additionally, many respondents said this would also positively influence the amount and easiness to share their data with researchers. This could be due to a perceived higher trust in the 'institution' due to knowledge of the person as has been found in a study on the opinions on health information sharing within stigmatized populations (Willison et al., 2009). They also found, that trust in doctors and hospitals was higher than in researchers from universities. Even though, power differences between both parties were mentioned, these seemed to not have an influence on the information provided by the respondents. On top of that, the interest in the topic and for the respondents' own health were also positively influencing the willingness to share information with the researchers. A study from South Africa, looking at motivations to participate in health research, indirectly identified an interest or personal relation to the topic as being decisive for participating (Sikweyiya & Jewkes, 2013, p. 1005). By being pro-illegal drug research or expressing feelings of societal misunderstanding of drugs, these respondents had very little caveats to share their insights, opinions, or health data with researchers.

Additionally, how the respondents related to the data was said to be a determinant how willing they were in sharing information or participating in research. Some of the respondents have mentioned they could not imagine how health data could be used in other ways than being numbers, other studies have had similar findings (Bell et al., 2014). Yet it was mentioned by some respondents that they appreciate the anonymisation of data and person during this

study and interviews as it would make them feel safer. Similar findings were made by others too regarding de-identified data (Bell et al., 2014; Shah et al., 2019).

To establish the differences between privacy perceptions in regard to social media use and participation in illegal drug research, it can be said that interest in; or personal relevance of the research topic can motivate participation in research. Similarly do the respondents of this study engage in personally relevant content and information exchange on social media, especially Instagram. On WhatsApp, the personal relevance is created through the personal contact. Further is it interesting to see how the purpose of the researching institution can have an impact on the motivation to share data and participate. Commercial organisations, similar to what other studies have found (Bell et al., 2014; Shah et al., 2019), seem to have received less trust of the sample population. Contrastingly, on the social media platforms of Instagram and WhatsApp, both owned by the commercial company Meta, sharing personal information on, or using these platforms does not seem to be hindered by the fact that they pursue a commercial objective. Yet, these findings were also dependent on the individual and do not hold for all respondents. Interestingly, as other studies (Bell et al., 2014; Kim et al., 2015; Page et al., 2016; Whiddett et al., 2006) have found too, trust in government agencies or insurance companies is lower and participants may be worried that their data could be used against their benefit.

Coming back to the matter of complex problems of illegal drug research, as mentioned in the introduction, some have asserted citizen science the potential to create possibilities for tackling them appropriately (Ceccaroni et al., 2021; den Broeder et al., 2018; Schade et al., 2021). Citizen science often uses a democratic approach to knowledge production and dissemination (den Broeder et al., 2018; Gristwood, 2019; Katapally, 2022; Hecker et al., 2018) as in many instances the knowledge created can be deemed more inclusive and more engaging with the research population. This is because citizen science includes ordinary people in the complete research process, from establishing research questions and methodology to data collection (den Broeder et al., 2018). Further by actively engaging the research population, “quantity and quality of data to be obtained” (Barratt et al., 2015, p. 248) can be improved. Therefore, using the findings of this study to create and inform citizen science projects on the topic of illegal drug use may help the future advancement of illegal drug research and to involve the lived experiences of PWUD.

## Conclusion & Future Recommendations

Looking at the differences of privacy perceptions of PWUD regarding participation in illegal drug research and social media use, this study has shown that there are differences in how people perceive their privacy, more generally how their data is handled and specifically in regard to different organisations and types of data. Furthermore, the respondents have different intentions and interests in sharing data with others in social media and illegal drug research, respectively.

To answer the first sub-research question, the age cohort of this sample followed social media trends regarding the use of WhatsApp and Instagram among others, and correspond with previous findings of other studies. Motives for using social media differed per platform but were often connected to stay in contact with friends, relatives and other acquaintances. Another common reason was to follow personal interests and gaining information thereon and staying up to date.

Answering the second research question, the contextual-informational norms are different in social media and illegal drug research according to the respondents. To varying degrees, participants have showed clear differences into how they perceive their privacy in illegal drug research and social media. Some respondents shared content on social media rather unrestrictedly, while others appeared to be more careful of their sharing-behaviour. Related to that is that some respondents said that certain types of data seem unpersonal and therefore cannot harm them. Similar behaviours and perceptions were present regarding illegal drug research. Furthermore, trust in the 'institution' or representative of research seemed to have an influence on the willingness to share data, said some participants. However, more research into the governing contextual-informational norms is needed to fully understand this phenomenon.

Coming to the last sub-research question, PWUD have different motives to participate in illegal drug research, mainly, interest in the topic and creating awareness for the consequences of illegal drugs in society. Additionally, personal contact with researchers can contribute to increased willingness to participate in it. Assurance of anonymity was also a reason to be more willing to participate in illegal drug research as it protects the research subjects from harm. Furthermore, trust in the researching institution can play a role, too.

These findings may path the way to future studies aiming to engage participants in a non-traditional research setting. As mentioned before, citizen science may prove beneficial in engaging populations in research, establishing trust, and shifting the role of the participants from passive to active. It seems as if PWUD are already willing to help create awareness for the effects of illegal drugs on the human body, so future studies doing so may not lack eager volunteers but have to ensure privacy to the participants and make their goals clear and easy to understand. Future studies, then, may contribute to fair, just, and comprehensible policies that large parts of society can put their trust in.

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## Appendix

### Appendix 1 – Interview guide

Themes to discover:

- 1) Personal information (age cohort, education etc) not recorded
- 2) Social Media use; platforms, frequency of use, motivation to use, types of interaction with others (posting→types of posts, sharing, watching only etc)
- 3) (Privacy general: own definition of privacy, interpretation of privacy guidelines, value of privacy )
- 4) Contextual integrity explained: contexts, actors, attributes, transmission principle
  - a. Social Media
    - i. Contexts of social media
    - ii. Actors of platforms (specific to interviewee)
    - iii. attributes (specific to platform/interviewee)
    - iv. transmission principle (specific to platform/interviewee)
  - b. Drug research general
    - i. Context
    - ii. Actors
    - iii. Attributes
    - iv. Transmission principle
  - c. Drug research hypothetical project
    - i. Context
    - ii. Actors
    - iii. Attributes
    - iv. Transmission principle
- 5) Motivations to participate in this research (just for curiosity)

Questions to 1)

1. Tell me a little bit about yourself, what's your age, education, and interests? None of this will be recorded, only notes taken to be able to describe my sample. Note age in groups (18-25/26-32/33-40/40-50/50-60/60+)  
int

Questions to 2)

Intro: For the next set of questions I will ask you about your social media use, what platforms you use, for what reason and who and what you interact with

2. To get an overview of what types of social media you use, on which platforms do you have an account, and how often do you use each per week?
3. Why do you use these platform(s)?
4. (if not answered) who do you interact with?

5. How does the interaction look like? (clarification: posting only, sharing pol/soc/funny contributions (of others/self))
- 6.

Questions to 3) For the next part of the interview I am going to ask some questions about your own perception of privacy, what your definition of privacy is, what your view on internet privacy guidelines is, and what value do you see in privacy.

7. To start, what does privacy mean for you? How would you define it?
8. If you browse websites on the internet, or participate in research or fill in forms elsewhere (doctors etc) you often have to agree to privacy declarations in order to proceed. What is your opinion of them?
9. How do you deal with said privacy policies?
10. Why?
11. When is your privacy threatened in your opinion?
12. In a similar fashion like before, but what values do you see in privacy? Increased or decreased?

Questions to 4) For the following set of questions I will build on what you have said before about your social media use and give you a short explanation of the concept of contextual integrity. Later on, you will be asked some questions about drug research, further building on your contributions.

a) Social media

- a. How would you describe (specify) social media platform's design? What are the characteristics that make it stand out? How are posts shown what posts are shown? What is shown?
- b. Who is responsible for sending information and who receives it? Consider your position in given platform. What do you send and to whom? What is the relevance to you?
- c. What type of information is it that you yourself engage with? (Drugs?)
- d. How do you think that exchange or distribution of information is influenced? Consider mainly your own position?
  - i. What is your relationship with the person the information is transmitted to? (private profile?)
    1. Power relations present?
  - ii. What is the goal of the exchange of information?

b) General drug research: Now consider our interview (and the survey you filled in).

- a. How would you describe the setting of this interview in terms of the social environment we are in?
- b. How do you think it differs from social media platform X?
- c. How would you describe your role within this interview?
- d. What do you think of my role in the interview? How do I relate to you in the interview?
  - i. Power relations
  - ii. Subject of information?

- e. In what way would you describe the type of information you give to me?
    - i. Personal
    - ii. Superficial
    - iii. Does the information belong to you?
  - f. In what way is our exchange of information influenced?
    - i. Goal ?
    - ii. Relation?
    - iii. Voluntary?
    - iv. Power?
    - v. Trust?
- c) Hypothetical research (only with drug users)

Imagine that you participate in a voluntary research project on your personal drug with the goal of finding out physical health effects of the drugs on your body in a non-clinical setting. For example during the summer, since there are lot of festivals where the chances are high that drugs are used by you. Or you are a psychonaut that likes to experiment with drugs. (duration)

You will be tasked to wear a smartwatch or similar device given to you by the researchers that tracks your health status in terms of blood pressure, heart rate, body temperature, ECG . The smartwatch is connected to your personal smartphone also recording other values such as your GPS location and timestamps of your smartwatch. Not only will values recorded during times where you consume drugs, but to get reference values also in times where you don't take drugs. An app also gives you insights into the measurements that are transmitted safely, anonymized and encrypted to a university server where they are saved anonymously so no one can infer that you took part in this research.

Have you experience with wearing a smartwatch?

- a. How would you describe the 'social environment' of this research? What stands out?
- b. How would you describe your role in this research setting?(motives?)
  - i. How would you describe the researchers' role? (motives? Researching, public benefit, health)
  - ii. What would you say is the subject of the information that is exchanged between you and the researchers'
- c. What is the type of information that is transmitted from you to the research team?
- d. How is the transmission of information influenced?
  - i. what is your goal of transmitting the information?
  - ii. What are the inter-personal relations within the project?
  - iii. Are there any limitations in sending the information