Big Data, bigger challenges

On the ethical impact of Big Data on scholarly research practices

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Summary

The development of Big Data technologies has had a great impact on society and research. The ubiquity and huge quantities of human generated data, together with the enhancement of computational capabilities, hold great promises for the advancement of knowledge in numerous fields from medicine, to behavioral science, to economy. At the same time, however, Big Data is also raising numerous ethical concerns due to the unpredictability of the harm that it poses for research subjects. For this reason, policymakers and scholars, especially in the context of academic research, alike are struggling towards the appropriate ethical management and regulation of research that uses Big Data methods.

The goal of this dissertation is therefore to contribute to the development of appropriate ethics frameworks for Big Data research that will assist investigators in navigating the multifaceted ethical issues of Big Data, design ethically sound research projects and avoid regulatory drawbacks. In order to meet this objective, a mixed methods approach was followed. First, two systematic reviews on the ethical issues of Big Data were performed using the PRISMA method. Second, the opinions and attitudes of academic scholars were investigated through a qualitative interview study with Swiss and American university-based scholars working on behavioral Big Data studies.

The thesis is arranged in three main parts: (1) Introduction, objectives and methods (Chapters 1 and 2), (2) journal articles (Chapters 3-8), and (3) general discussion (Chapter 9).

The first part of this dissertation provides an introduction on the methodological, ethical and regulatory impact that Big data is currently having on research practices. It presents the multifaceted definition of Big Data, the challenges it introduces, and it provides an overview of the regulatory practices for scholarly research with human participants (Chapter 1). Finally, it also delineates the research objectives and the description of the methodology (Chapter 2).

The second part of the thesis (Chapters 3 to 8) is composed of six journal articles, one for each chapter.
Chapter 3 focuses on the understanding of the issue of discrimination in Big Data technologies and data analytics. The performed systematic review highlights the potential risk of discrimination deriving from data technologies in numerous aspects of daily life together with the emergence of new forms of discrimination such as economic and health prediction discrimination. The study also analyses the causes of data discrimination and possible solutions.

Chapter 4 investigates the ethical issues associated to digitalization of dental medicine and research. The analysis demonstrated how the most common ethical issues that emerge for digital dental technologies, such as electronic dental records, mHealth and Teledentistry, and developments in personalized medicine, are patient privacy, confidentiality, anonymity, data security and informed consent.

Chapter 5 delineates the definitional boundaries of the term "Big Data". The qualitative analysis of the interviews performed with Swiss and American scholars identified no univocal definition for Big Data and an overall uncertainty and uneasiness towards the use of the term. The study concludes that such uncertainty might derive from the tendency to recognize Big Data as a shifting and evolving cultural phenomenon rather than a fixed entity.

Chapter 6 gives insight into the personal code of ethics and research practices of behavioral scientists involved in Big Data studies. The analysis revealed that academic scholars still find well-established principles such as *beneficence*, *respect for persons* and their recognized practices (e.g. informed consent, protection of privacy) a relevant guidance for Big Data research, despite recognizing the challenges posed by Big Data methods to traditional research ethics.

Chapter 7 argues for the implementation of regulatory bodies in order to face the changes and challenges introduced by Big Data methods. The study illustrates how academic scholars are currently in need of more support from regulatory entities, such as ethics committees, with the ethical design and follow-up of Big Data research projects. However, in their experience with ethics committees, scholars have noticed a lack of appropriate expertise of board members to face the novelties introduced by Big Data methods, and the absence of harmonized evaluation criteria across different committees.

Chapter 8 focuses on practices of academic-corporate collaboration in Big Data research. It investigates the willingness of university-based scholars to engage in partnership with private firms and to use data provided by them. The qualitative study reveals how scholars are generally interested in such an association. At the same time, they also expressed a number of methodological concerns and ethical reservations that need to be levelled in order to enable sustainable partnership.

Finally, the last part (Chapter 9) provides a general discussion of the main findings of the dissertation. It also provides some recommendations on how to appropriately implement ethical frameworks for Big Data research, enhance the role of ethics committees and enable collaborative endeavors between academic scholars, ethics committees and private companies.

Zusammenfassung

Die Entwicklung von Big-Data-Technologien hat grosse Auswirkungen auf Gesellschaft und Forschung gehabt. Die Allgegenwärtigkeit und die enorme Fülle der von Menschen erzeugten Daten sowie die Verbesserung von Rechenkapazitäten versprechen grosse Wissensfortschritte in zahlreichen Bereichen, von der Medizin über die Verhaltenswissenschaften bis hin zur Wirtschaft. Gleichzeitig wirft Big Data aber auch zahlreiche ethische Bedenken auf, da der potentielle Schaden für Personen, die sich der Big Data-Forschung zur Verfügung stellen, unabsehbar ist. Aus diesem Grund ringen Politik und Wissenschaft insbesondere im Kontext akademischer Forschung, um eine angemessene ethische Gestaltung und Regulierung von Forschung, die sich auf Big-Data-Methoden stützt.

Ziel dieser Dissertation ist es daher, einen Beitrag zur Entwicklung geeigneter ethischer Rahmenbedingungen für die Big-Data-Forschung zu leisten, die den Forschenden helfen sollen, sich in den vielfältigen ethischen Fragen von Big Data zurechtzufinden, ethisch fundierte Forschungsprojekte zu entwerfen und regulatorische Probleme zu vermeiden. Um dieses Ziel zu erreichen, wurde ein Ansatz mit gemischten Methoden gewählt. Zunächst wurden zwei systematische Übersichtsarbeiten zu ethischen Fragestellungen im Kontext von Big Data mit der PRISMA-Methode erstellt. Im Anschluss untersuchte eine qualitative Interviewstudie an schweizerischen und amerikanischen Universitäten die Ansichten und Einstellungen von Wissenschaftlerinnen und Wissenschaftlern, die an verhaltensorientierten Big-Data-Studien arbeiten.

Die Dissertation ist in drei Hauptteile gegliedert: (1) Einführung, Ziele und Methoden (Kapitel 1 und 2), (2) Zeitschriftenartikel (Kapitel 3-8) und (3) allgemeine Diskussion (Kapitel 9).

Der erste Teil dieser Dissertation liefert eine Einführung in die methodologischen, ethischen und regulatorischen Auswirkungen, die Big-Data derzeit auf die Forschungspraxis hat. Er stellt die facettenreiche Definition von Big Data und die damit verbundenen Herausforderungen vor und gibt einen Überblick über Regulierungspraktiken in der wissenschaftlichen Forschung mit menschlichen Probanden (Kapitel 1). Daran anschliessend werden Forschungsziele und Methodik beschrieben (Kapitel 2).

Der zweite Teil der Dissertation (Kapitel 3 bis 8) besteht aus sechs in wissenschaftlichen Zeitschriften veröffentlichten Artikeln, einer für jedes Kapitel.

Kapitel 3 beleuchtet das Problem der Diskriminierung durch Big-Data-Technologien und Datenanalyse. Die systematisch angefertigte Übersichtsarbeit beleuchtet das potenzielle Diskriminierungsrisiko, das von Datentechnologien in zahlreichen Aspekten des täglichen Lebens ausgeht, sowie das Aufkommen neuer Formen von Diskriminierung, beispielsweise aufgrund wirtschaftlicher oder gesundheitlicher Vorhersagen. Das Kapitel analysiert die Ursachen solcher Datendiskriminierung und skizziert mögliche Lösungen.

Kapitel 4 untersucht ethische Fragen im Zusammenhang mit der Digitalisierung der Zahnmedizin in Praxis und Forschung. Die Analyse zeigt, dass die häufigsten ethischen Fragen, die sich für digitale Dentaltechnologien wie elektronische Zahnarztunterlagen, mHealth und Teledentistry sowie Entwicklungen in der personalisierten Medizin ergeben, die Privatsphäre der Patienten, Vertraulichkeit, Anonymität, Datensicherheit und informierte Einwilligung sind.

Kapitel 5 umreisst die definitorischen Grenzen des Begriffs "Big Data". Die qualitative Analyse der Interviews, die mit Schweizer und amerikanischen Wissenschaftlern durchgeführt wurden, ergab keine eindeutige Definition für "Big Data", stellte aber eine allgemeine Unsicherheit und ein Unbehagen gegenüber der Verwendung des Begriffs fest. Die Studie kommt zu dem Schluss, dass eine solche Unsicherheit aus der Tendenz herrühren könnte, Big Data eher als ein sich wandelndes und sich entwickelndes kulturelles Phänomen denn als eine feste Einheit zu betrachten.

Kapitel 6 gibt Einblick in den persönlichen Ethikkodex und die Forschungspraktiken von Forschenden, die an Big-Data-Studien im Bereich der Verhaltensforschung beteiligt sind. In einer weiteren Analyse der erhobenen Interviews zeigte sich, dass trotz der Herausforderungen, die Big-Data-Methoden an die traditionelle Forschungsethik stellen, gut etablierte ethische Prinzipien in der Wissenschaft nach wie vor als relevante Richtlinien für die Big-Data-Forschung gelten. Dazu zählen insbesondere Wohltätigkeit, Respekt für Personen und ihre anerkannten Praktiken wie informierte Einwilligung und Schutz der Privatsphäre)

Kapitel 7 plädiert für die Implementierung von regulatorisch wirksamen Strukturen, um den durch die Big-Data-Methoden eingeführten Veränderungen und Herausforderungen begegnen zu können. Die Studie veranschaulicht, wie Forschende gegenwärtig bei der ethischen Ausgestaltung und dem Follow-up von Big-Data-Forschungsprojekten mehr Unterstützung von regulatorischen Stellen, wie z.B. Ethikkommissionen, benötigen. In ihrer Erfahrung mit Ethikkommissionen beklagten die Befragten jedoch einen Mangel an angemessener Fachkenntnis der Mitglieder, um den durch die Big-Data-Methoden eingeführten Neuerungen begegnen zu können, sowie das Fehlen harmonisierter Bewertungskriterien zwischen verschiedenen Kommissionen.

Kapitel 8 konzentriert sich auf Praktiken der Zusammenarbeit zwischen Hochschulen und Unternehmen in der Big-Data-Forschung. Es untersucht die Bereitschaft von Forschenden an Universitäten, Partnerschaften mit privaten Unternehmen einzugehen und die von diesen zur Verfügung gestellten Daten zu nutzen. Die qualitative Studie zeigt, wie Wissenschaftler im Allgemeinen an einer solchen Zusammenarbeit interessiert sind. Gleichzeitig äusserten sie aber auch eine Reihe methodischer Bedenken und ethischer Vorbehalte, die ausgeräumt werden müssen, um eine nachhaltige Partnerschaft zu ermöglichen.

Der letzte Teil (Kapitel 9) bietet schliesslich eine allgemeine Diskussion der wichtigsten Ergebnisse der Dissertation. Er enthält auch einige Empfehlungen dazu, wie ethische Rahmenbedingungen für die Big-Data-Forschung angemessen umgesetzt, die Rolle der Ethikausschüsse gestärkt und die Zusammenarbeit zwischen akademischer Forschung, Ethikausschüssen und privaten Unternehmen ermöglicht werden kann.

Chapter 1 – Introduction

1.1 Big Data, a definitional conundrum

“Big Data”, described as a popular buzzword by media and scholars alike (De Mauro et al., 2015; Small and Anderton, 2014), is a very complex, extensive and sometimes controversial phenomenon that has permeated both the public and academic debate. On the one hand, Big Data is claimed to hold enormous beneficial potential for individuals, society and research. On the other hand it is said to raise great methodological and ethical challenges.

Despite its huge popularity, the very definition of Big Data is still loaded with conceptual vagueness. It is generally defined as the growing technological capacity to create, store, and analyze massive amounts of data to reveal patterns and trends related to human behavior and predict answers to complex questions (Crawford, 2013). Still, since its first appearance in the early 2000, the term has had fluctuating meanings (Ward and Barker, 2013). As suggested by Mittelstadt and Floridi (2016a), the different definitions attributed to Big Data can be divided in two categories: they can either refer to a) big datasets possessing certain characteristics or b) the process of analyzing such datasets.

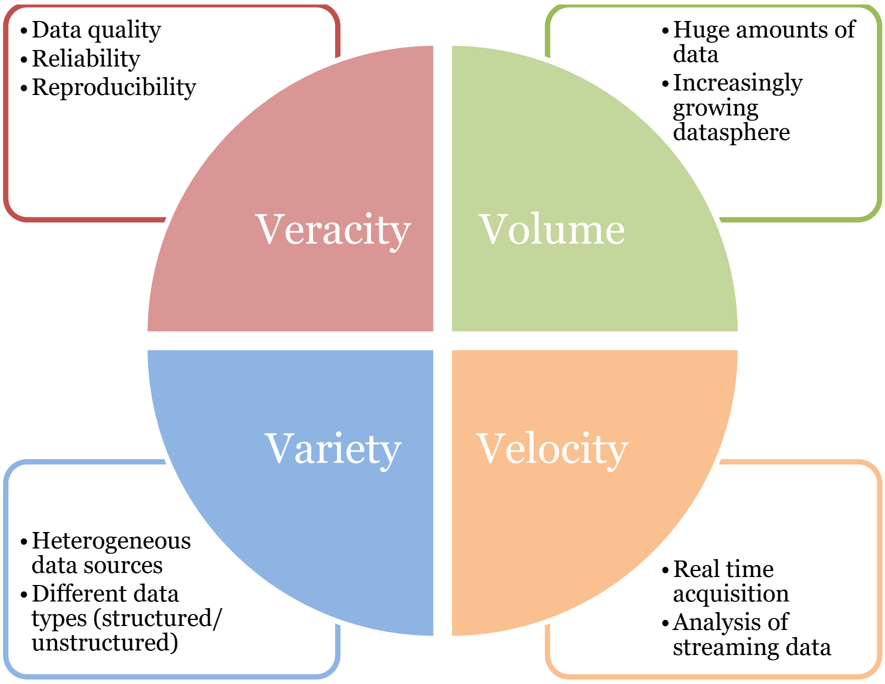
The first category contains all those definitions that describe Big Data in terms of its characteristics. For instance, the European Commission describes Big Data as:

> large amounts of different types of data produced from various types of sources, such as people, machines or sensors. This data includes climate information, satellite imagery, digital pictures and videos, transition records or GPS signals. Big Data may involve personal data: that is, any information relating to an individual, and can be anything from a name, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer IP address. (2016)

Scholars in the fields of data science/computer engineering and tech companies generally define Big Data in terms of more specific attributes or dimensions, starting from the traditional 3Vs – volume (huge amounts), velocity (high-speed processing) and variety (heterogeneous data) (Laney, 2001) – to other qualities such as veracity (IBM), value (Ishwarappa and Anuradha, 2015), variability (Fan and Bifet, 2013), exhaustivity (Mayer-Schönberger and Cukier, 2013), and extensionality (Marz and Warren, 2015).

The second approach defines Big Data in procedural terms rather than based on its attributes. It considers Big Data as data that is too complex to be analyzed and processed by traditional computational systems (Perry, 2017). For instance the American Science National Foundation describes it as: “data that challenge existing methods due to size, complexity, or rate of availability” (NSF-14-543) (2014).

Figure 1-1: *The 4 Vs of Big Data*



In the context of the evolution of the definition of Big Data, it is interesting to notice, that the characteristics attributed to this term have often been described in strict relation with the technical challenges that the phenomenon raises. For instance, *volume* an *velocity* are related to the challenges that Big Data poses to traditional IT structures as companies and institutions do not have the necessary infrastructure to collect, store and analyze the huge amount of data that is produced at increasingly higher speed; storage and processing are made more *complex* by the day due to the *variety* characteristic that entails the analysis of heterogeneous structured and unstructured data coming from different sources; and issues of *veracity* emerge as the accuracy of big datasets is challenged by high speed, heterogeneity and volume (Ishwarappa and Anuradha, 2015).

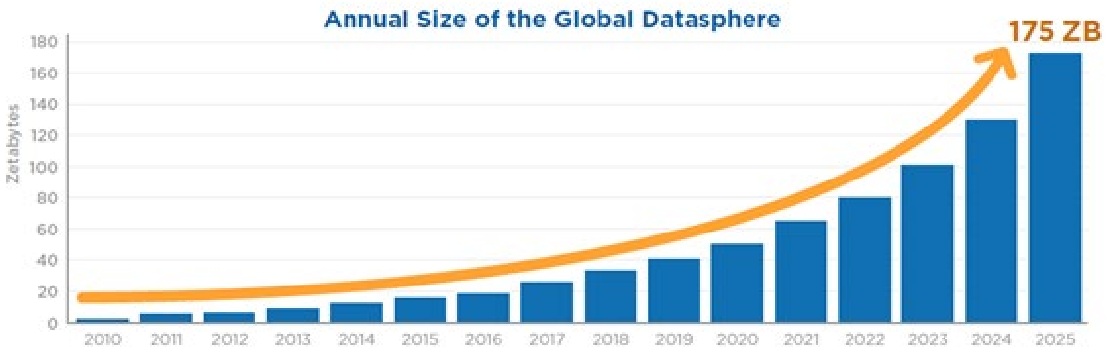
Although helpful to understand the technical challenges posed by Big Data, these "standard" definitions have been criticized for being vague and obscure and for not clarifying what implications Big Data actually has for society, culture and research (Floridi, 2012). Big Data has therefore started to be defined more as the intersection of a cultural, technological and scholarly phenomenon (boyd and Crawford, 2012) and a method or approach to science and research (Trottier, 2014). Big Data in this sense is recognized as the "capacity to search, aggregate, and cross-reference large datasets" (boyd and Crawford, 2012: 633) and as "an emerging technologically-driven phenomena focusing on analysis of aggregated datasets" to improve knowledge and research in multiple fields (Mittelstadt and Floridi, 2016a: 3).

Big Data, in this dissertation, is understood as a cultural, technological and scholarly phenomenon that comprises a set of advanced digital techniques (e.g. data mining, neural networks, deep learning, profiling, automatic decision making and scoring systems) that are increasingly used in research to analyze large datasets with the aim of revealing patterns, trends and associations. Moreover, the type of Big Data this dissertation in interested in is the kind related to information produced by people, in line with the definition given by the European Commission (2016). This definition was selected among those presented above because it is the one that most comprehensively refers to the cultural, societal, and methodological transformations that Big Data is having on society and research. The challenges raised by the fluctuating definition of Big Data will be further addressed in Chapter 5.

1.2 Big Data and research

As we live in an growingly networked world the production of digital data has drastically increased (Lynch, 2008). According to the International Data Corporation (IDC), we have now exceeded the threshold of 40 Zettabytes (ZB) of generated data predicted for 2020 and the datasphere is estimated to grow to 175 ZB by 2025 (Coughlin, 2018).

Figure 1-2: *The growing datasphere*



Source: Reinsel D, Gantz J, Rydning J (Nov 2018), Data Age 2025, The Digitization of the World. From Edge to Core, An IDC White Paper - #US44413318, IDC (https://www.seagate.com/files/www-content/our-story/trends/files/idc-seagate-dataage-whitepaper.pdf)

Thanks to such abundance of data and the emergence of new and enhanced forms of data streams (eg. social media, online messaging, online purchasing, smart devices such as smartphones and fit trackers, health apps, streaming services etc.) that contain possibly useful information about human cognition, behavior, emotion and attitudes, Big Data applications have started to pervade research in numerous sectors including government (Kim et al., 2014), national security (Lyon, 2014), business (Minelli et al., 2012; Davis, 2012) and healthcare

(Dash et al., 2019). The rapid emergence of Big Data practices has been met with enthusiasm in scholarly research due to its high research capability (Salganik, 2019; Woo et al., 2020) and its promising beneficial applications.

To give a few examples: intensive research is conducted over the uses of Artificial Intelligence (AI) and Machine Learning (ML) to improve clinical care and accurate diagnosis (Raghavendra et al., 2019; Janssen et al., 2018) and Big Data analytics are employed for the development of *smarter hospitals* where predictive analysis of EHR (Electronic Health Records) is applied to identify patients at higher risks for health deterioration in real time (Mertz, 2014). Within social and urban development, Big Data finds application in many different projects, from the development of self-driving cars (Shaw et al., 2020), to the design of *smarter cities* to improve many sectors of urban living such as transportation, education and energy through the analysis of aggregated data from different sources - social media, GPS, radio frequencies and consumer data (eg. data from supermarket fidelity cards) (Hashem et al., 2016).

1.2.1 The impact of Big Data on behavioral research

Behavioral science research[1], the field that this study mainly focuses on, has been hugely impacted by Big Data. According to boyd and Crawford (2012), Big Data created a profound change at a level of epistemology, methodology and even ethics in many research fields by reframing "key questions about the constitution of knowledge, the processes of research, how we should engage with information, and the nature and the categorization of reality" (boyd and Crawford, 2012: 665). In this section, I will discuss some of the novelties and challenges of Big Data methodological approaches.

The data driven vs theory driven debate

An extensive and ongoing debate has emerged regarding the usefulness and value that Big Data research and methods have for behavioral science. The Big Data era has in fact seen the emergence and expansion of data driven research strategies in many research fields including psychology and social sciences. Data driven research uses exploratory approaches to extract scientifically interesting insights from huge amounts of data and is praised for its supposed higher objectivity and accuracy (Kitchin, 2014). In this scenario, where data is claimed to "talk for itself" and data driven/quantitative research are supposed to fully replace qualitative methods and theory driven approaches (Anderson, 2008), some scholars in the behavioral

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[1] In the present dissertation I will refer to "behavioral sciences" as a discipline that includes both the fields of sociology and psychology and that mainly analyzes data generated by individuals/research participants and therefore deals principally with research with human subjects.

sciences have raised concerns regarding the loss of theoretical depth and specificity and have argued that more thoughtful and contextualized discussions are needed about what Big Data approaches can actually achieve in research (Woo et al., 2020; Salganik, 2019; boyd and Crawford, 2012). For instance, Woo et al. (2020) highlight that while data driven methods are useful to highlight patterns, correlations, and relationships, "psychologists are using data not only to maximize one's ability to predict meaningful outcomes, but also to develop and further establish theories that can explain observed relationships" (Woo et al., 2020: 4). Correlation does not imply causation therefore traditional approaches of social science and psychological research, such as establishing causality and drawing on existing theory, are still considered fundamental to deliver scientifically sound research (Tay et al., 2020; Cowls and Schroeder, 2015).

New methods call for different expertise

In the debate surrounding Big Data, the "redistribution" of the roles in digital research constitutes an important methodological crisis (Marres, 2012). This redistribution is mainly related to the increased need of novel expertise and interdisciplinarity that the introduction of digital methods has imposed upon research. Digitalization has in fact driven behavioral research to focus on approaches that maximize the role of mathematical techniques and methods in order to fully exploit the opportunities that online media and digital technologies offer for the development of large-scale data analysis (Marres, 2012). Novel techniques that are extensively employed in digital behavioral science include web scraping and digital crowdsourcing (Bates and Lanza, 2013), together with more sophisticated data processing techniques such as natural language processing (NLP), network analysis, machine learning algorithms, automated sentiment analysis, artificial intelligence, agent-based modeling and so on (Lazer et al., 2009; Harlow and Oswald, 2016). The emergence of these new methods raises the question of what kind of research skills are valued, and needed, for the future of behavioral research since the appropriate management of the aforementioned methods is generally restricted to those with a computational background (boyd and Crawford, 2012). As a consequence, some scholars claim that we are witnessing a redistribution of expertise across disciplines together with an increased division of labor between scholars with heterogeneous backgrounds (Marres, 2012; Ruppert, 2013). This redistribution calls for the creation of paradigms of increased interdisciplinary collaborations in scholarly research that brings together social scientists and psychologists trained in traditional behavioral methods and, data scientists in possession of the expertise to run increasingly sophisticated mathematical methods. Such crisis also requires an educational revolution by establishing new educational patterns towards the creation of computational social scientists, or teams comprised of computationally literate social scientists and socially literate computer scientists (Lazer et al., 2009).

A new research actor

Finally, the trend towards digitalization of research underlines another type of shift or redistribution of the roles in behavioral research due to the growing importance of additional actors in the ecosystem of scholarly research: private companies and corporations. The data that is progressively needed to perform digital research is in fact collected and, most of the times, owned by search engine companies, gaming industries, Internet service providers and social media platforms, a matter that outsources a great part of the research endeavor to corporations and technology/media actors (Hand, 2014). This creates a number of concerns.

First, it has been argued that Big Data is introducing a new digital divide in terms of access to valuable data streams (boyd and Crawford, 2012; Mittelstadt and Floridi, 2016b). As the main holders of data, companies are blamed of excluding the greater research community from valuable insights and research prospects. Some companies in fact restrict access to data entirely; others allow only a small proportion of university-based researchers to have access to their databases; and others plainly sell portions of their data for a fee (boyd and Crawford, 2012).

Second, Big Data is increasingly entwining industry and academic interests (Leetaru, 2018) and incentivizing partnership and data sharing programs between companies and academia (Jain et al., 2014). Academic-industry collaborations are a well-established reality. However, for long such collaborations have raised controversy due to the possible threats to research integrity posed by corporate for-profit motives (Bekelman et al., 2003) and the potential conflict of interest that might raise between academic scholars and companies, the firsts being driven by the desire of advancing knowledge and the latter wanting to maintain corporate secrecy to ensure a competitive advantage over other corporations (Dooley and Kirk, 2007).

Finally, the use of readily available data entails outsourcing data collection to companies themselves. This results in massive loss of control over one of the most crucial steps of the conduction of a study as the researcher will be unaware of the procedures and methods used for data collection (Davis, 2012). This in turn might create issues of data quality and validity of research where researchers find out that the data offered by the companies is biased and limited in its interpretability (Mittelstadt and Floridi, 2016b; Lazer et al., 2014). In addition, as tech companies have been accused of lacking transparency when it comes to research practices and having the habit of "performing research behind their user's back" (Rothstein, 2015), university-based researchers might find themselves unconsciously performing research with data collected without complying with ethical standards for data collection, thus fueling societal distrust towards Big Data studies as it happened in the case of well-known research scandals such as the Facebook Contagion Study (Caplan and Seife, 2014).

Despite the aforementioned methodological and ethical challenges introduced by the trend towards data driven studies, the necessity of heterogeneous expertise, and the emergence of companies as actors involved in scholarly research, Big Data is indelibly embedded within current research practices. There is a growingly rich corpus of research (see for instance (Hand and Hillyard, 2014; Ruppert, 2013; Lazer et al., 2009; Marres, 2012; Woo et al., 2020; Salganik, 2019) that considers Big Data as a methodological opportunity rather than a crisis and that analyzes the challenges posed by Big Data to traditional methods in order to smoothly integrate these novel models into the dynamics of behavioral research. As this thesis will not analyze in depth the methodological challenges of Big Data, I refer to the aforementioned literature for more information on the matter. However, this dissertation will investigate the ethical and regulatory concerns that are related to the interdisciplinary breakthrough in research (Chapters 6 and 7) and the appearance of companies as research actors (Chapter 8).

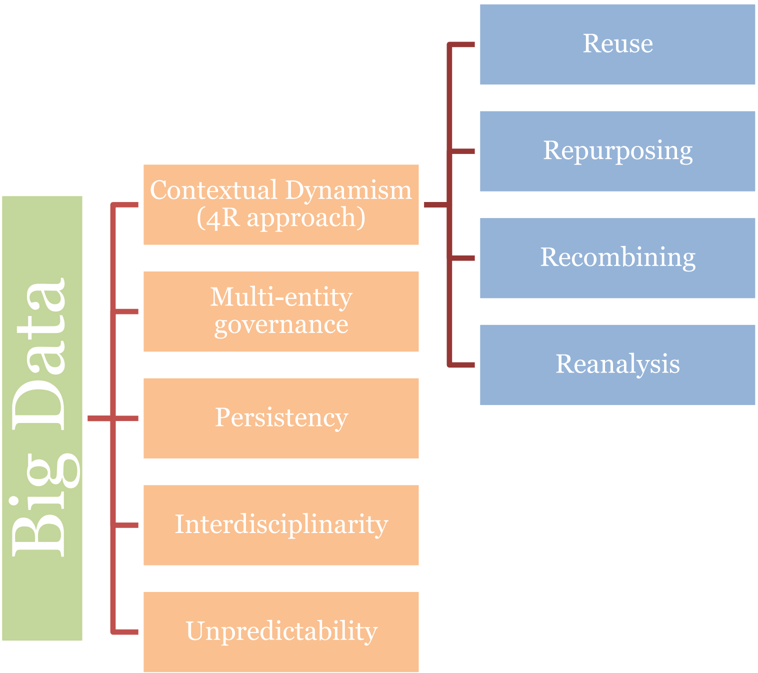
1.3 Big Data and ethics

While promising on numerous fronts, Big Data also raises a plethora of important ethical questions. As mentioned in Section 1.1, the type of Big Data this dissertation focuses on is the kind produced by people/research subjects by their daily activities and interactions with digital technologies. This type of Big Data is used to influence individuals, predict their behavior, analyze psychological traits, infer upon the health of a subject, and might therefore create harm to the individuals involved in its domain. Such ethical challenges stem from different elements related to Big Data, including: the sensitivity of the data that is manipulated (Mittelstadt and Floridi, 2016b), the sensitivity and unpredictability of the insights deriving from the analysis of the data (Herschel and Miori, 2017), and the lack of knowledge regarding many of the procedures involved in the collection, aggregation and analysis of the data (Davis, 2012). This paragraph will provide an overview of some of the ethical issues associated with Big Data research and the characteristic of Big Data methods that are at the core of such challenges.

1.3.1 Challenging features of Big Data

The are some technical characteristics and features that are at the center of some of the most crucial ethical questions raised by this plethora of technologies. For instance, Steinmann, Matei, and Collman (2016), highlight how ethical issues of Big Data derive from its ability to be *reused*, *repurposed*, *recombined* and *reanalyzed*. Their 4R approach considers Big Data as an interconnected phenomenon where its elements can be arranged and reconnected to obtain new insights and knowledge that could produce unforeseen harm to the individuals or populations under investigation.

Figure 1-3: *Big Data features*



With *reuse*, the authors refer to taking data originally collected for a specific scientific purpose and using it for other comparable purposes (eg. data collected for medical research being reused for psychological research). This possibility raises questions of responsibility for what happens to the data once it is made available to other investigators. *Repurposing*, the analysis of data for unrelated purposes from those the data was originally collected for (eg. administrative data used for research purposes), raises both issues of responsibility of making data public but also about the legitimacy of analyzing data acquired under one context and analyzing it under a different one. *Recombining* refers to the practices of data linkage that Big Data methods are currently offering. Different databases can be connected and crossed referenced to produce new knowledge and information that could contain sensitive information that individuals are not willing to share. Finally, *reanalysis* pertains to the assembly of huge archives of data to be stored indefinitely and reanalyzed subsequently with more sophisticated methods to obtain more information from it. Such practices of data archiving highlight the importance of creating an environment of trust between the actors involved in research (data holders, investigators and research subjects) as data will be used in ways that were not imagined at the moment of data collection (Steinmann et al., 2016).

The characteristics highlighted by Steinmann et al. (2016), underlie the *contextual dynamism* of Big Data. It has in fact been argued that data, in the realm of data driven/Big Data methodologies and research, assumes value and different meaning within (and depending on) the context it is analyzed in (Davis, 2012). Therefore the ethical issues deriving from Big Data studies will greatly depend on the context of the research and the meanings that data assumes in a particular study (Steinmann et al., 2016). For instance, data that is generally considered not sensitive (eg. streaming preferences) might reveal sensitive information (eg. sexual orientation) when linked with other publically available data (eg. gender) (Barocas and Selbst, 2016).

Another feature of Big Data that might raise consistent and unpredictable harm to individuals is *multi-entity governance*. This means that, most of the times, management of big datasets extends beyond the control of a single institution, organization or group of researchers (Davis, 2012). Information and data are in fact aggregated and correlated not only by the originating entity, but also by others who may seek to extract further information and knowledge. As a consequence, control on how information is used is lost once it is out of the purview of the researcher or the institution, thus creating unpredictable challenges. This raises urgent questions about data handling and responsibility in research that will be further analyzed in this dissertation (Chapters 6, 7 and 8).

In addition, it has been argued that tracks of data that are left by individuals and collected by companies and institutions are *persistent* (Davis, 2012). Users, through the use of multiple platforms and devices - such as social media, (Facebook/Twitter/Reddit), streaming platform (Spotify, Netflix), Google search queries, online purchases, mobile location, smartwatch recordings and more - create extensive records of habits and preferences that are used to investigate interactions and personality traits. This digital footprint cannot be controlled or deleted by investigators or users as it is intended to stay archived for analysis by companies and holders (Davis, 2012). A social media platform like Facebook, for instance, admits to retain copies of “some material” from deleted accounts indefinitely, and due to the networked nature of social media data (eg. shared posts, tags, messages) it is virtually impossible to delete the entirety of a user's data trace (Picchi, 2018).

Finally, Big Data is also inherently *interdisciplinary* in nature. The actors involved in the collection and analysis of data are multiple and include practitioners from many diverse backgrounds that might not have the necessary resources for recognizing the multifaceted context dependent ethical issues of Big Data or even have the technical expertise to prevent harm of research participants (Tractenberg, 2016). A scenario could be envisaged where a data scientist involved in a Big Data study is not aware of the ethical challenges posed by the analysis of a dataset obtained without the consent of the participant (something that might happen with social media data). On the other hand, a psychologist fully trained in research ethics might not understand the technical limitation of data anonymity in a data driven study.

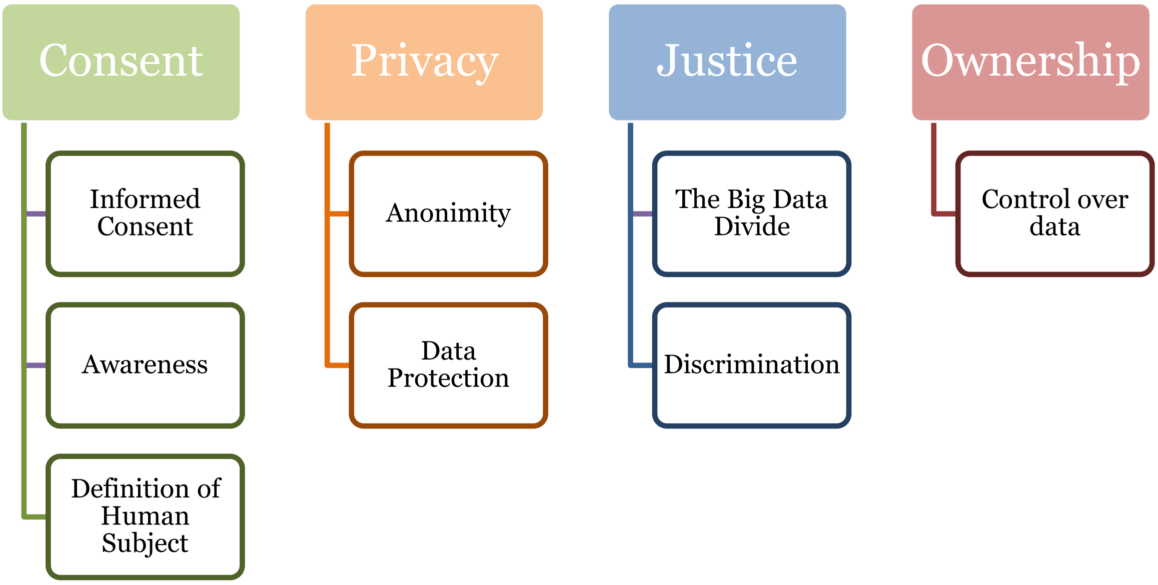
1.3.2 Ethical challenges

Despite the contextual dependency of the ethical issues raised by Big Data and the unpredictable nature and amount of harm that it might cause to individuals and populations, there are a number of generally recognized ethical themes and concerns that are attributed to Big Data practices.

Consent

According to Mittelstadt and Floridi (2016b), consent is the ethical concept that is challenged the most by Big Data practices. It has been argued that the concept does not straightforwardly translate to research involving Big Data because Big Data is designed to reveal unforeseen connections, patterns and information. The unpredictability at the heart of Big Data makes it difficult for an investigator to clearly delineate, at the time of consent, what will be the nature of the information and the consequences that will emerge from a study that the participant should be clearly informed about (Mittelstadt and Floridi, 2016b). It has also been argued that the implementation of strategies to obtain consent is challenged by the unobtrusive nature of Big Data methods (Ioannidis, 2013). Much of the studies conducted in behavioral sciences make use of data coming from either public/semi-public spaces (eg. social media, public online records) or data coming from private companies (eg. phone records, administrative data), where the subjects/users are both unaware of the fact that their data is being collected and analyzed and lack the appropriate control over their data (Xafis, 2015; Henderson et al., 2013). Finally, issues of consent are strictly linked to the challenges that Big Data creates within the definition of human research subject. Growing digitalization of research is creating an wider gap between research subjects and the investigator, since most of the times participants are detached if not even invisible to researchers. As a consequence, the concept of human subject is becoming increasingly opaque, raising the concern that the research subject will be increasingly considered and treated as mere data points rather than persons, and making the implementation of appropriate strategies and regulations to protect research subjects more difficult by the day (Fiske and Hauser, 2014; Metcalf and Crawford, 2016).

Figure1- 4: *Concepts challenged by Big Data*



Privacy

A large corpus of literature in numerous fields recognizes privacy threats to users and research subjects as one of the main harms that could derive from Big Data practices (Mittelstadt and Floridi, 2016b). Privacy has many definitions and it is a complex concept that brings together ethics, philosophy, and law. It can generally be regarded as “a condition of limited access to an individual or information about an individual” (Rothstein, 2015). In the realm of Big Data, privacy deals with protecting disclosure of an individual’s data and is concerned with the appropriate use of their information (Sangeetha and Sudha Sadasivam, 2019). In addition it is strictly linked with protection of personal/sensitive data and ensuring the anonymity of research participants in research studies (Zhang et al., 2014). Issues of privacy in Big Data might emerge in numerous ways: for instance linkage of different digital datasets or the use of data mining techniques might reveal sensitive information about research participants or uncover their identity (boyd and Crawford, 2012; Matzner and Ochs, 2017); studies that use publically available information, or data on social media, might be disrespectful of people’s privacy by intruding their lives and those of their bystanders (Metcalf and Crawford, 2016); in addition, the release of de-identified datasets for additional analysis, secured by softer means of anonymization, that are usually preferred by investigators to preserve the quality and future uses of the databases, might threaten participants' anonymity (Daries et al., 2014). The debate surrounding privacy in Big Data therefore focuses on both conceptual and technical fronts: on the one hand, scholars are currently debating issues such as the necessity of protecting the privacy of subjects engaging in activities in internet spaces (Buchanan and Zimmer, 2018; Salganik, 2019) or the level of privacy users expect in digital platforms such as social media (Buchanan et al., 2011). On the other, data scientist scholars are working to develop new computational strategies to ensure protection of the privacy and anonymity of research participants (Sangeetha and Sudha Sadasivam, 2019).

Justice

The use of Big Data in research has also been claimed to create issues of justice and fairness due the creation of new divides and increased risk of harm for vulnerable populations. In our society we witness a deepening of the digital divide between people who have access to digital resources and those who do not, on the basis of a significant number of demographic variables such as income, ethnicity, age, skills, geographical location and gender (Hargittai, 2019). As a consequence, Big Data knowledge and interventions have been claimed to favor only a part of the population (Mittelstadt and Floridi, 2016b) and exacerbate already existing inequalities (Geneviève et al., 2020). In addition, it has been highlighted that Big Data practices in research and corporate procedures pose the risk of discrimination and disparate treatment, together with possible harm to vulnerable populations (eg. children, pregnant women, elders) and ethnic minorities (Barocas and Selbst, 2016). Thanks to Big Data, in the shape of profiling and predictive strategies, new forms of discrimination and inequality are emerging, such as economic or marketing discrimination (Peppet, 2014) or discrimination based on health data and health prediction (Hoffman, 2010), together with digitalized practices of singling out at risk individuals and excluding entire segments of the population from opportunities of socio-economic development (O'Neil, 2016).

Ownership

Finally, an intense debate has also emerged regarding matters of ownership. In the context of Big Data, ownership can refer to rights regarding the redistribution and modification of data but also to the benefits deriving from its analysis (Mittelstadt and Floridi, 2016b). As matters of data ownership in Big Data are extremely complex and pertain mainly to the legislative area, this dissertation will not analyze the details of this the complex subject. It is however relevant to shortly outline the conceptual dimension of this issue within the context of the research subject/investigator/data holder dynamic. Such debate mainly refers to the analysis of the degree of ownership that subjects hold over specific information about them (Davis, 2012). By granting them ownership, research subjects would be entitled to a degree of “control” over how their data is analyzed and manipulated in a way that could prevent misuse and harmful consequences (Tene and Polonetsky, 2012). Numerous legislations that either were created or amended in the past few years (see for instance the European General Data Protection Regulation (GDPR) or the Swiss Data Protection Act) try to adequately regulate data-related rights, however there is still an open debate over who actually has ownership claims over personal data; whether it is the subject/user whose information is collected from, or some other entity such as the one that collects it, the one that analyses it, or even the one that stores it (Hummel et al., 2020).

Despite the efforts of delineating the ethical issues of Big Data, the level of risk and harm that could derive from Big Data practices it is still unknown by virtue of its unpredictability and high context dependency. In order to fill some of the gaps that are still present in Big Data ethics, this dissertation will provide an in-depth analysis of one of the most pressing ethical issues associated with Big Data: discrimination (Chapter 3). In addition, it will also explore and give a comprehensive overview of the ethical issues of digital dentistry, so far one of the most under-investigated fields of Big Data ethics (Chapter 4).

1.4 Regulating Big Data

Due to the aforementioned ethical challenges posed by Big Data practices, together with the unpredictability of the level of harm for participants in research studies, focus on appropriate development of research regulations and ethical strategies for research has become a crucial endeavor. It has been claimed that like every technology with tremendous potential, Big Data is per se ethically neutral, as it does not have a built-in value system. However, institutions, corporations and investigators act within a set of different values systems and rules (Davis, 2012; O'Neil, 2016). Big Data has great beneficial potential for society, but at the same time societal fear deriving from misuse of data methodologies and misconduct in research, could result in overregulation of research practices. Unfortunately, some recent academic studies have been deemed unethical due to the poor assessment of some ethical challenges involved in the design and conduction of the study. For instance, the now infamous Facebook Emotional

Contagion study[2] conducted at Princeton University (Kramer et al., 2014), created an extensive scholarly and media debate over the possible psychological harm it could have caused to Facebook users, together with the appropriateness to have conducted this study without the participants' consent (Shaw, 2016; Caplan and Seife, 2014). It becomes therefore of the outmost importance to create a sustainable ethical framework for Big data studies in different disciplines to reduce the possibility of regulatory whiplash (Mittelstadt and Floridi, 2016a). To sustain and further develop such ethical framework, there are two key factors that need further investigation in the context of Big Data research: 1) the ethical standards and guidelines that are currently governing research practices and their appropriate translation to Big Data studies; and 2) the ethical and regulatory oversight aimed at supervising scholarly research and the challenges that regulatory bodies are facing in suitably evaluating Big Data studies.

1.4.1 Code of ethics and research standards

Research ethics have traditionally been governed by deep-rooted documents such as the Belmont Report (2014) and the Declaration of Helsinki (2001). These guidelines were originally developed in 1978 (Belmont Report) and 1964 (Declaration of Helsinki) as an effort to create a legal and ethical framework for human subject research globally as a response to infamous research abuse scandals that violated human rights in the 20th century such as the Tuskegee Syphilis Study and the ethics violations that Nazi physicians committed during World War II in their experiments (Heimer and Petty, 2010). Although primarily created for medical research with human subjects, the core principles stated in these documents have been shared and used by the research community as the ethical foundation of research practices in many other fields such as psychology and social sciences (Anabo et al., 2018; Paxton, 2020; Salganik, 2019). Three fundamental principles are at the core of these documents: *respect for persons*; *beneficence*; and *justice*. *Respect for persons* is defined as the acknowledgment of participants' autonomous participation and the need to collect informed consent from study participants. *Beneficence* is interpreted as the minimization of harm that could derive from a project – either material (physical harm) or immaterial (privacy invasion), the importance of appropriately balancing risks and beneficial outcomes, and the need to maximize the beneficence deriving from a research project. *Justice* generally refers to fairness in distribution and dissemination of research outcomes and it is widely interpreted practically as the attention to the selection of

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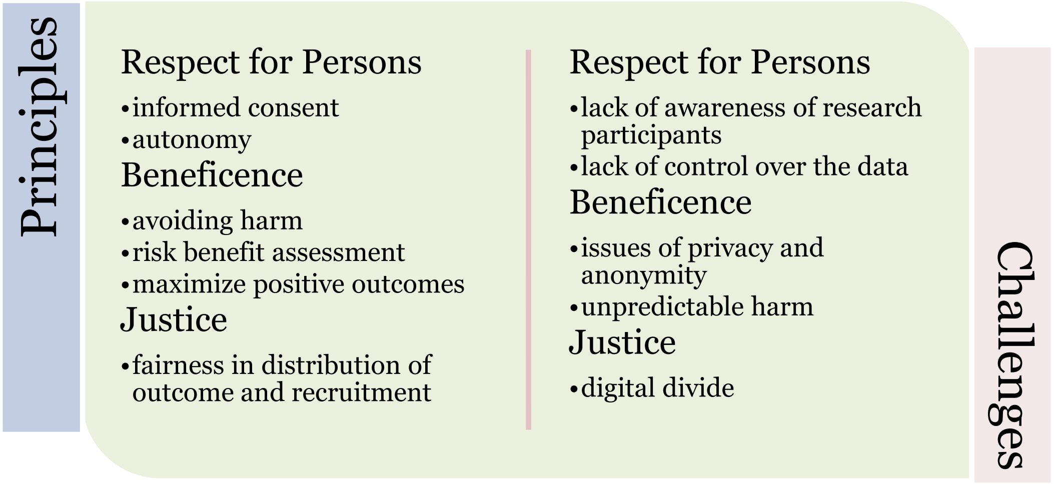
[2] To avoid repetition I refer to the details of the Facebook Emotional Contagion Study described in chapters 6, 7 and 8.

research participant in order to avoid additional burden to vulnerable populations and individuals (Hargittai, 2015; Hoffmann and Jonas, 2017).

The principles are considered general guidelines to appropriately design protocols for research studies. They are not hierarchical, nor binding and they were conceived to be flexible in order to accommodate a wide range of different research settings and methods (Salganik, 2019). Therefore such principles might be in conflict in certain research settings and require deliberation, judgment, critical analysis and appropriate balancing by the investigator (Gillon, 2015).

Figure 1-5: *Principles and challenges to research ethics*



In the context of Big Data research, it has been argued that the interpretation of such principles is challenged by the type of analysis and methods used in the specific study, the amount and type of data that is collected, and some of the features of Big Data outlined in Section 1.3.1 (Anabo et al., 2018; Paxton, 2020; Zimmer, 2018). *Respect for persons*, for instance, is challenged when the subject is unaware of the collection of its data and does not have control over what data is collected on them (boyd and Crawford, 2012). In addition, due to lack of *ownership* and the *persistency* feature of Big Data, subjects of a study might lack the possibility to control the flow of their data or to withdraw from a study. When it comes to *beneficence*, it has become increasingly difficult to appropriately balance the risks and benefits of a study due to the *unpredictability* of some of the outcomes of Big Data analysis (Vitak et al., 2016). In addition risk of harm in form of issues of anonymization and privacy infringement abound (Zook et al., 2017). Finally, due to the deepening digital divide, the principle of *justice* is challenged because ensuring unbiased and uniform sampling and therefore maximizing fairness in the distribution of the benefits of research is growingly difficult (Hargittai, 2015).

Despite these substantial challenges to research practices and principles, scholars still agree on the relevance and importance of the principles of the Belmont Report also in Big Data studies (Salganik, 2019; Rothstein, 2015). Therefore, scholarly efforts are being made to appropriately reshape and update the guiding principles of research ethics in order to provide adequate guidance to investigators in Big Data studies (Anabo et al., 2018; Vitak et al., 2016; Paxton, 2020; Markham and Buchanan, 2012). This dissertation aims at contributing to the development of the construction of adequate principles by exploring the code of conduct of researchers involved in digital research and their attitudes on the value of traditional ethical principles (Chapter 6).

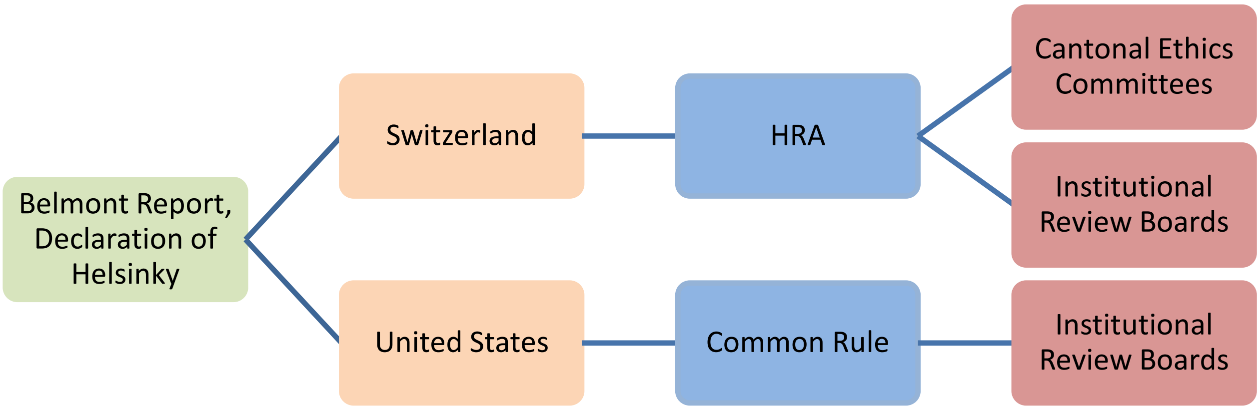
1.4.2 Regulatory framework and ethics approval

To appropriately develop a research ethics framework, it is also crucial to investigate the practices of ethical oversight for Big Data research studies. Research ethics committees (RECs), in this context, are globally well-recognized regulatory bodies in charge of reviewing proposed studies with human participants to ensure that they conform to internationally and locally accepted ethical guidelines. RECs operate within an institution or on a regional or national basis. In addition they operate within different countries, therefore their structure, function and legal reference changes from country to country (World Health Organization, 2009). Since this dissertation focuses on two specific countries, Switzerland and the United States, the analysis of the role and purview of RECs will be limited to these two countries.

The Role of Ethics Committees in Switzerland

In Switzerland (CH) research projects involving human subjects are evaluated by seven federally mandated RECs organized in one joint working group, the Swiss Association of Research Ethics Committees (swissethics). As stated by the documents provided by the Federal Department of Home Affairs and the Federal Office of Public Heath (kofam, 2016) the type of research projects that need to be submitted and approved by ethics committees in CH are those projects falling under the scope of the Human Research Act (HRA).

Figure 1-6: *Regulatory overview for academic research*



The HRA defines the principles that must be observed in relation to research projects involving human subjects. The main objective of such legislation is to protect the participant's health in the context of research. Projects that fall under the scope of the HRA are "Research projects on human diseases as well as on the structure and function of the human body that involve: human subjects/persons; cadavers; embryos and fetuses from terminated pregnancies; biological material or health-related personal data" (kofam, 2016: 9). Excluded from the scope of the HRA, and therefore from the requirement of approval, are "Research projects with anonymized biological materials and anonymously collected or anonymous health-related personal data" (kofam, 2016: 9). It has been argued however, that the current definition of human subject research underlined by the HRA gives rise to uncertainty about what falls under the scope of the legislation especially in the case of research projects in fields such as psychology and sociology (2015). In order to fill this gap, numerous universities in Switzerland are starting to establish Institutional Review Boards (IRBs) to evaluate research projects in fields that are not covered by the HRA. However the implementation of such IRBs is relatively recent and not homogeneous throughout universities, due to the sectorial regulation allowed by the Swiss federal system that requires only Cantonal Research Ethics Committees (2017). As a consequence, increasingly digitalized Big Data research and research that involves anonymized data from research participants are facing a regulatory void and a lack of institutional support to ethically design and evaluate research projects.

The Role of IRBs in the United States

In the United States (US), IRBs are independent panels established by the Common Rule responsible for a) providing an evaluation regarding the ethical acceptability of research projects in medicine and behavioral sciences and b) assessing compliance with regulations and laws designed to protect human subjects (Grady, 2015). The main aim of IRBs is to "assure, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in the research" (FDA, 2019). The main legislation IRBs refer to is the Common Rule that regulates human subject research across the country. According to the legislation human subject "means a living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information" (Department of Health and Human Services, 2018: 45 CFR 46). IRB review applies to research funded by the Department of Health and Human Services (DHHS) and other US federal agencies, such as the Food and Drug Administration (FDA). In this context all research involving human subjects, from medical to behavioral studies, needs to withstand the evaluation and approval of an IRB. However due to the aforementioned challenges introduced by Big Data regarding the definition of human subject, it is unclear whether a specific research project should or should not undergo ethics approval procedures (Ioannidis, 2013). A recent relevant amendment of the Common Rule has been enacted in 2018 in order to face these challenges, however scholars have already argued that these revisions, such as excluding data science research that deals with individuals' data (such as publically available or anonymized personal data and social media data) from review might result in more harm than good for research participants (Metcalf and Crawford, 2016). The Facebook Emotional Study, which will be discussed further in Chapter 7, is an example where harm to individuals came precisely from this regulatory void: the project was analyzing aggregated anonymized data provided by a company, therefore it fell out the purview of the IRB (Kramer et al., 2014).

In addition to the debate surrounding the inclusion of data science research project in the human subject research regulation domain, the digitalized turn that behavioral research is undertaking is also creating a struggle among both researchers and research ethics committee members on how to appropriately evaluate some of the issues embedded in their research projects. Some studies in the United States in fact highlight that IRBs are currently unequipped to appropriately handle the evaluation of digital research: they miss the technical knowledge to understand the potential for intrusion and individual harm stemming from Big Data studies and they are poorly equipped to evaluate the possibility that complex data could be de-anonymized (Lazer et al., 2009; Vitak et al., 2016; Shilton and Sayles, 2016; Bruckman, 2014).

In addition, scholars have also highlighted how the absence of specific guidelines and comprehensive ethical frameworks are aggravating uncertainty for ethics committees on what criteria to follow to review and evaluate research projects with Big Data methodologies (Ienca et al., 2018). Some guidelines and frameworks are starting to be developed such as the "ethics framework for decision making in Big Data health and research" (Xafis et al., 2019) and the guidelines provided by the Association of Internet Researchers (AoIR) (franzke et al., 2019) but they are still relatively new, and not well known among investigators (Chapters 6 and 7).

This thesis aims at contributing to the ongoing and young debate over research ethics approval in Big data studies by investigating the experiences of researchers with RECs and IRBs in both Switzerland and the United States (Chapter 7).

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Chapter 2 – Research objectives and methodology

2.1 Research objectives

The thesis is part of a larger research study entitled *Regulating Big Data research: A new frontier* conducted in the framework of the National Research Project (NRP) 75. Overall, the study aimed at examining existing regulations and the ethical issues related to Big Data research in order to provide researchers and ethics committees with recommendations to further develop an efficient and safe framework for beneficial Big Data research. The NRP 75 project gathered interview data from academic scholars in the field of psychology and sociology performing research with Big Data methods and with data protection officers and data lawyers both from Switzerland and the United States.

The present research project aimed at investigating some of the most under-investigated fields of Big Data ethics such as the issue of data related discrimination and the ethical issues surrounding digital dentistry. The second objective of the thesis was to explore the perceptions of academic researchers involved in Big Data studies in relation to a) the terminological boundaries of the term Big Data and b) research practices linked to personal code of ethics, ethics approval processes, and collaboration with private companies. This was made in order to contribute to the development of suitable research ethics framework for Big Data research projects that will assist researchers in navigating the multifaceted and complex ethical challenges of Big Data, avoiding regulatory drawbacks, and designing ethically sound research projects that provide appropriate protection for research participants in Big Data research.

More specifically, the thesis investigates the following research questions:

1. What are the main ethical issues attributed by the literature to Big Data methods and technologies? (Chapters 3 and 4)

As underlined in Section 1.3, Big Data is currently raising a plethora of unpredictable ethical challenges due to its applications both within and outside research. The proliferation of occurrences of harm for individuals caused by the inappropriate/inattentive use of Big Data technologies calls for a careful analysis of such ethical issues. Chapters 3 and 4 therefore examined the literature surrounding the ethics of Big Data in order to uncover the most pressing and underrepresented ethical issues. Chapter 3 focused on understanding the causes and consequences of discrimination in data analytics and analyzing suggested solutions to the problem of discrimination of Big Data. Chapter 4 explored the ethical issues associated to digitalization of dental medicine and research and investigated the solutions suggested by the literature. The analysis of the different and multifaceted ethical issues of Big Data together with possible solutions and strategies becomes relevant in order to foster the implementation of ethical guidelines.

2. How do academic scholars interpret the term Big Data and its multifaceted definition? (Chapter 5)

Due to the definitional opacity that surrounds Big Data, Chapter 5 explored how researchers in the fields of sociology and psychology define and understand the term. Without appropriate boundaries to define what is meant with Big Data, overarching regulations, guidelines and legislations might not be effective. Therefore Chapter 5 aimed at discovering if an overarching and straightforward discipline centric definition of Big Data in psychological and sociological research is actually possible and desirable.

3. What are the ethical standards that should be applied in Big Data research practices? (Chapter 6)

As highlighted in Section 1.4.1, research ethics is heavily challenged by the novelties introduced by Big Data. Chapter 6 explored the code of ethics and research practices of behavioral scientists involved in Big Data studies in order to assess whether traditional research principles are considered still relevant in digitalized research and investigated new strategies to promote ethical and responsible conduct in Big Data research.

4. What are the challenges that researchers face when approaching ethics approval? (Chapter 7)

Conceptualization of what constitutes human subject research is currently being challenged by Big Data methods. As a consequence difficulties arise in the design of appropriate regulatory practices for the evaluation and assessment of Big Data studies in behavioral research. The aim of Chapter 7 was to provide some suggestions towards appropriate implementation of regulatory bodies by investigating the challenges and needs of academic scholars regarding their relationship with RECs and IRBs.

5. What is the current state of academic-company partnership in Big data research? (Chapter 8)

Big Data is incentivizing partnership between academic scholars and private companies, however there is currently a gap in the assessment of the challenges, issues, and opportunities associated with these practices in Big Data studies. The aim of Chapter 8 was therefore to investigate the experiences and opinions of academic researchers regarding collaboration with private firms in order to find strategies to sustain ethical collaboration and further promote ethical practices in research.

2.2 Methodology

In order to meet the objectives outlined in Section 2.1, this thesis followed a mixed methods design.

First, an ethical analysis of the issues of Big Data was conducted by performing two systematic reviews, the first focused on the issue of data discrimination (Chapter 3) and the second related to the ethical issues in digital dentistry (Chapter 4). Both systematic reviews were performed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method.

Second, an interview study was conducted in order to grasp the perspectives of academic scholars involved in Big Data research (Chapters 5, 6, 7 and 8). The interviews were conducted between January 2018 and August 2019. They comprise of 39 semi-structured interviews with academic researchers involved in the fields of sociology and psychology both from Switzerland (n=20) and the United States (n=19) that were selected systematically and through snowballing.

The specific methods used for the different articles are described in detail in the methods sections of the chapters below and they are therefore not presented here.

2.2.1 Individual contributions

The study was conceived and supervised by Prof. Dr. med. Bernice Simone Elger, the Head of the Institute for Biomedical Ethics (IBMB) at the University of Basel. Prof. Elger received funding for the NRP 75 from the Swiss National Science Foundation (SNF, Grant-No: 407540_167211). Dr. T. Wangmo, C. Schneble and F. Zimmerman, both PhD students at the IBMB, prepared the submission to obtain ethical approval from the competent Cantonal Ethics Committee (Ethics Committee northwest/central Switzerland (EKNZ)) and drafted the interview guide. C. Schneble carried out the first two pilot interviews with Swiss scholars to test the study material that was subsequently implemented and modified by the research team (me, C. Schneble, E. De Clercq). The systematic protocol for participant recruitment was devised by me. I also recruited the remaining participants and both conducted and transcribed 37 out of 39 interviews. Qualitative data analysis was carried out by me, T. Wangmo, and C. Schneble for the first four interviews and subsequently by me and E. De Clercq for the remaining interviews (description of the analysis process is described in detail in Chapter 5).

The conceptualization, development and writing for each paper included in this dissertation was devised by me with the revision, supervision and approval of E. De Clercq, B. Elger and the other co-authors.

Chapter 3 – Big Data and discrimination: perils, promises and solutions. A systematic review

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3.1 Abstract

Background: Big Data analytics such as credit scoring and predictive analytics offer numerous opportunities but also raise considerable concerns, among which the most pressing is the risk of discrimination. Although this issue has been examined before, a comprehensive study on this topic is still lacking. This literature review aims to identify studies on Big Data in relation to discrimination in order to (1) understand the causes and consequences of discrimination in data mining, (2) identify barriers to fair data mining and (3) explore potential solutions to this problem. Methods: Six databases were systematically searched (between 2010 and 2017): PsychINDEX, SocIndex, PhilPapers, Cinhal, Pubmed and Web of Science. Results: Most of the articles addressed the potential risk of discrimination of data mining technologies in numerous aspects of daily life (e.g. employment, marketing, credit scoring). The majority of the papers focused on instances of discrimination related to historically vulnerable categories, while others expressed the concern that scoring systems and predictive analytics might introduce new forms of discrimination in sectors like insurance and healthcare. Discriminatory consequences of data mining were mainly attributed to human bias and shortcomings of the law; therefore suggested solutions included comprehensive auditing strategies, implementation of data protection legislation and transparency enhancing strategies. Some publications also highlighted positive applications of Big Data technologies. Conclusion: This systematic review primarily highlights the need for additional empirical research to assess how discriminatory practices are both voluntarily and accidentally emerging from the increasing use of data analytics in our daily life. Moreover, since the majority of papers focused on the negative discriminative consequences of Big Data, more research is needed on the potential positive uses of Big Data with regards to social disparity.

3.2 Introduction

Big Data has been described as a “one-size-fits-all (so long as it’s triple XL) answer” (Crawford, 2013) to solve some of the most challenging problems in the fields of climate change, healthcare, education and criminology. This may explain why it has become the buzzword of the decade. Big data is a very complex and extensive phenomenon that has had fluctuating meanings since its appearance in the early 2010’s (Ward and Barker, 2013). Traditionally it has been defined in terms of four dimensions (the four V’s of Big Data): volume, velocity, variety, and veracity - although some scholars also include other characteristics such as complexity (Perry, 2017) and value (Ishwarappa and Anuradha, 2015) - and it consists of capturing, storing, analyzing, sharing and linking huge amount of data created through computer-based technologies and networks, such as smartphones, computers, cameras, sensors etc. (Howie, 2013). As we live in an increasingly networked world, where new forms of data sources and data creation abound (e.g., video sharing, online messaging, online purchasing, social media, smartphones), the amount and variety of data that is collected from individuals has increased exponentially, ranging from structured numeric data to unstructured text documents such as email, video, audio and financial transactions (SAS-Institute).

Interestingly, due to the fact that traditional computational systems are unable to process and work on Big Data, characteristics of this phenomenon have been described by scholars in strict relation to the technical challenges they raise: volume and velocity, for example, present the most immediate challenge to traditional IT structures since companies do not have the necessary infrastructures to collect, store and process the vast amount of data that is created at increasingly higher speeds; variety refers to the heterogeneity of both structured and unstructured data that is collected from very different sources making storage and processing even more complex; and finally, since Big Data technologies are dealing with high volume, velocity and great variety of qualitatively very heterogeneous data, it is highly improbable that the resulting data set will be completely accurate or trustworthy, creating issues of veracity (Ishwarappa and Anuradha, 2015).

Despite the aforementioned issues, we should not forget that Big Data analytics - understood here as the plethora of advanced digital techniques (e.g. data mining, neural networks, deep learning, profiling, automatic decision making and scoring systems) designed to analyze large datasets with the aim of revealing patterns, trends and associations, related to human behavior - play an increasingly important role in our everyday life: the decision to accept or deny a loan, to grant or deny parole, or to accept or decline a job application are influenced by machines and algorithms rather than by individuals. Data analysis technologies are thus becoming more and more entwined with people's sensitive personal characteristics, their daily actions and their future opportunities. Hence it should not come as a surprise that many scholars have started to scrutinize Big Data technologies and their applications to analyze and grasp the novel ethical and societal issues of Big Data. The most common concerns that arise regard privacy and data anonymity (Francis and Francis, 2014; Daries et al., 2014), informed consent (Ioannidis, 2013), epistemological challenges (Floridi, 2012), and more conceptual concerns such as the mutation of the concept of personal identity due to profiling (de Vries, 2010) or the analysis of surveillance in an increasing "datafication" or "data-fied" society (Ball et al., 2016).

One of the most worrying but still underresearched aspects of Big Data technologies is the risk of potential discrimination. Although "there is no universally accepted definition of discrimination" (Vandenhole, 2005), the term generally refers to acts, practices or policies that impose a relative disadvantage on persons because of their membership of a salient social or recognized vulnerable group based on gender, race, skin color, language, religion, political opinion, ethnic minority etc. (Charter of Fundamental Rights of the European Union, 2000). For the scope of our study we adhere to the aforementioned general conception of discrimination and only distinguish between *direct discrimination* (i.e. procedures that discriminate against minorities or disadvantaged groups on the basis of sensitive discriminatory attributes related to group membership such as race, gender or sexual orientation) and *indirect discrimination* (i.e. procedures that might intentionally or accidentally discriminate against a minority, while not explicitly mentioning discriminatory attributes) (Hajian and Domingo-Ferrer, 2013). We also acknowledge the close connection between discrimination and inequality, since a disadvantage caused by discrimination necessarily leads to inequality between the considered groups (Shin, 2009).

Although research on discrimination in data mining technologies is far from new (Romei and Ruggieri, 2013), it has gained momentum recently, in particular after the publication of the White House report of 2014 which firmly warned that discrimination might be the inadvertent outcome of Big Data technologies (Podesta, 2014). Since then, possible discriminatory outcomes of profiling and scoring systems have increasingly come to the attention of the general public. In the United States, for example, a system technology used for the assessment of future risk of re-offending among defendants was found to discriminate against black people (Courtland, 2018). Likewise, in the United Kingdom, an algorithm used to make custodial decisions was found to discriminate against people with lower incomes (Burgess, 2018). But more citizen-centered applications, such as the Boston's Street Bump App, which is developed to detect potholes on roads are also potentially discriminatory. By relying on the use of a smartphone, the App, risks increasing the social divide between neighborhoods with a higher number of older or less affluent citizens and those more wealthy areas with more young smartphone owners (Reich, 2013).

The proliferation of these cases explains why discrimination in Big Data technologies has become a hot topic in a wide range of disciplines, ranging from computer science and marketing to philosophy, resulting in a scattered and fragmented multidisciplinary corpus that makes it difficult to fully access the core of the issue. Our literature review therefore aims to identify relevant studies on Big Data in relation to discrimination from different disciplines in order to (1) understand the causes and consequences of discrimination in data analytics; (2) to identify barriers to fair data-mining and (3) explore suggested solutions to this problem.

3.3 Methods

A systematic literature review was performed by searching the following six databases: PsycINFO, SocINDEX, PhilPapers, Cinhal, Pubmed and Web of Science (see Table 3-1).

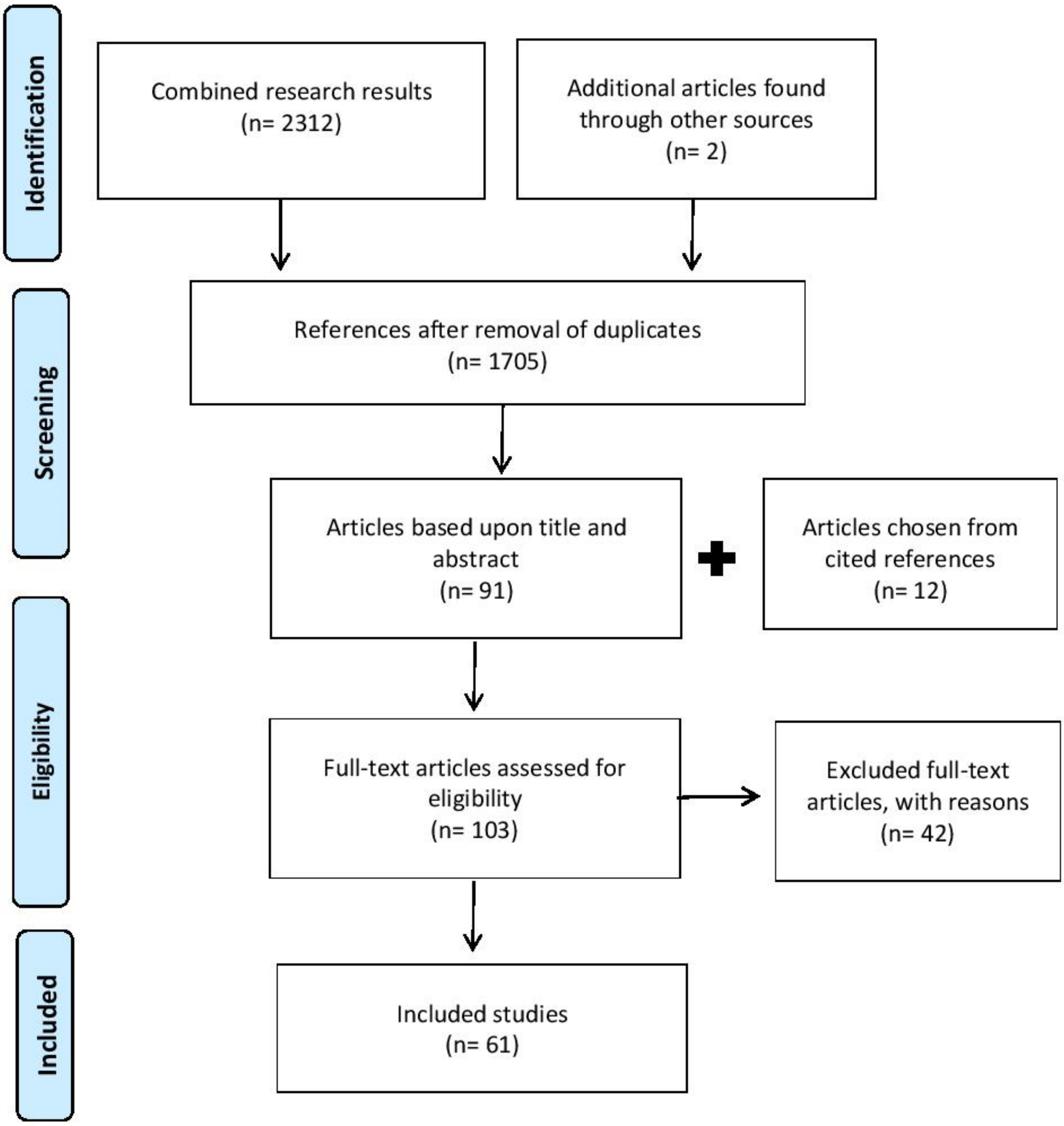
Table 3-1: *Search Terms*

No.	Matches search terms	PsychInfo	PhilPapers	SocIndex	CINHAL	PubMed	Web of Science
1	"big data" OR "digital data" OR "data mining" OR "data linkage"	2385	179	507	944	13214	23740
2	discriminat* OR *equality OR vulnerab* OR *justice OR ethic* OR exclusion	69435	46349	46624	38096	245604	414661
3	1 AND 2	156	67	88	55	769	1177

The following search terms were used: “big data”, “digital data”, “data mining”, “data linkage”, “discriminat*”, “*equality”, “vulnerab*”, “*justice”, “ethic*” and “exclusion””. The terms were combined using Boolean logic (See Table 1). The inclusion criteria were: (1) papers published between 2010 and December 2017 and (2) written in English. A relatively narrow publication window was chosen as “Big Data” has become a buzzword in academic circles only over the last decade and because we wanted to target only those articles that focus on the latest digital technologies for profiling and predictive analysis. In order to obtain a broader understanding of discrimination and inequality related to Big Data, no restriction was placed on the discipline of the papers (medicine, psychology, sociology, computer science etc.), or on the type of methodology (quantitative, qualitative, mixed methods or theoretical). Books (monographs and edited volumes), conference proceedings, dissertations, literature reviews and posters were omitted.

The search protocol from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method (Moher et al., 2015) was followed and resulted in 2312 papers (see Figure 3-1). Two papers were added that were identified through other sources. The results were scanned for duplicates (609) and 1705 remained. In this phase, we included all articles that mentioned, discussed, enumerated or described discrimination, the digital divide or social inequality related to Big Data (from data mining and predictive analysis to profiling). Therefore, papers that focused mainly on issues of autonomy, privacy and consent were excluded, together with those that merely described means to recognize or classify individuals using digital technologies without acknowledging the risk of discrimination. Disagreements between the first

Figure 3-1: PRISMA Flowchart



and second authors were evaluated by a third reviewer who determined which articles were eligible based on their abstracts. In total, 1559 records were excluded.

The first author subsequently scanned the references of the remaining 91 articles to identify additional relevant studies. 12 papers were added through this process. The final sample included 103 articles. During the next phase, the first author read the full texts. After thorough evaluation, 42 articles were excluded because (1) they did not or only superficially referred to discrimination or inequality in relation to Big Data technologies and focused more on risks related to privacy or consent; (2) they discussed discrimination but not in relation to the development of Big Data analytic technologies; (3) they focused on the growing divide between organizations that have the power and resources to access, analyze and understand Big Datasets ("the Big Data rich") and those that do not ("the Big Data poor") (Andrejevic, 2014) instead of on the concept of Digital Divide, which is defined as the gap between individuals who have easy access to internet-based technologies and those who do not; or (4) they assessed disparities affecting participation in social media. The subsequent phase of the literature review involved the analysis of the remaining 61 articles. The following information was extracted from the papers: year of publication, country, discipline, methodology, type of discrimination/inequality fostered by data mining technologies, suggested solutions to the discrimination/inequality issue, beneficial applications of Big Data to contrast discrimination/inequality, reference to the digital divide, reference to the concept of the Black Box as an aggravator of discrimination, evaluation of the human element in data mining, mention of the shift from individual to group harm, reference to conceptual challenges introduced by Big Data, and mention of legal shortcomings when confronted with Big Data technologies.

3.4 Results

Among the 61 papers included in our analysis, 38 were theoretical papers that critically discussed the relation between discrimination, inequality and Big Data technologies. Of the remaining 23 articles, 7 employed quantitative methods, 3 qualitative methods and 13 computer science methodologies that used a theory to combat or analyze discrimination in data mining and then empirically tested this theory on a data set. To distinguish the latter approach from the more traditional empirical research methods, we classified such studies as "other" (experimental) methods. Most of the papers were published after 2014 (*n*= 44), the year of the publication of the White House report on the promises and challenges of Big Data (Podesta, 2014). Almost one third of the studies (n=22) were from the United States, 6 came from the

Netherlands, 3 from the United Kingdom and the remaining ones were from Belgium, Spain, Germany, France, Australia, Ireland, Italy, Canada, or Israel. Ten papers were from more than one country (see table). Regarding the scientific discipline, 20 papers were published in papers from the field of Social Sciences, 14 from Computer Science, 14 from Law, 9 from Bioethics and only 2 from Philosophy and Ethics. As to the field of application, a considerable number of papers (n=24) discussed discriminatory practices in relation to *various* aspects of daily living such as employment, advertisement, housing, insurance, credit scoring etc., while others focused on *one* specific area.

The majority of the studies (n= 38) did not provide a definition of discrimination, but instead treated the word as self-explanatory and frequently linked it to others concepts such as inequality, injustice and exclusion. A few defined discrimination as "disparate impact", "disparate treatment", "redlining", "statistical discrimination", while others gave a more "juridical" definition and referred to the unequal treatment of "legally protected classes", or directly referred to existing national or international legislation. Only one article discussed the difference between direct and indirect discrimination (see Table 3-2).

Table 3-2: *List of included articles*

Author, Year, Country	Design	Participants	Discipline	Field of Application	Definition of Discrimination	Reference to Legislation/Regulatory text
Ajana (2015), UK	Theoretical		Social Sciences	Migration	Unequal Treatment	
Ajunwa et al. (2016), USA	Theoretical		Bioethics	Employment	Not Given - Self Explanatory	
Bakken & Reame (2016), USA	Theoretical		Bioethics	Healthcare Research	Not applicable - Digital Divide	
Barocas & Selbst (2016),USA	Theoretical		Law	Employment	Disparate Treatment/Disparate Impact	
Berendt & Preibusch (2014), Belgium-UK	Other		Computer Science	Various	Juridical - Legally protected classes	
Berendt & Preibusch (2017), Belgium-UK	Other		Computer Science	Various	Illegitimate Discrimination on grounds of four protected attributes	
boyd & Crawford (2012), Australia-USA	Theoretical		Social Sciences	Digital Divide in Research	Not applicable – Digital Divide	
Brannon (2017), USA	Theoretical		Social Sciences	Social Disparity	Not Given - Inequality	
Brayne (2017), USA	Qualitative	A sample of Employees of LAPD (Officers and Civilians)	Social Sciences	Policing/Criminology	Not Given - Inequality	
Calders & Verwer (2010), Netherlands	Other		Computer Science	Various	Not Given – Self Explanatory	
Casanas i Comabella, & Wanat (2015), UK	Theoretical		Bioethics	Digital Divide in Research	Not applicable – Digital Divide	
Cato et al. (2016), USA	Theoretical		Bioethics	Healthcare	Not Given - Injustice	Belmont Report; 1976
Chouldechova (2017), USA	Other	A sample of Caucasian/African American US Defendants	Computer Science	US Criminal Justice System	Disparate Impact	

Citron & Pasquale (2014), USA	Theoretical		Law	Credit Scoring	Not Given - Reference to protected classes	
Cohen et al. (2014), USA	Theoretical		Bioethics	Healthcare	Not Given - Inequality	
d'Alessandro et al. (2017), USA	Theoretical		Computer Science	Various	Disparate treatment/Disparate Impact	
de Vries (2010), Belgium	Theoretical		Philosophy	Various	Unwarranted Discrimination	
Francis & Francis (2017), USA	Theoretical		Law	Healthcare and Healthcare research	Not Given - Stigmatization and Harm	
Hajian & Domingo-Ferrer (2013), Spain	Other		Computer Science	Various	Not Given – Self Explanatory	
Hajian et al. (2014), Spain	Other		Computer Science	Various	Unfair or Unequal Treatment	Australian Legislation 2008; European Union Legislation 2009
Hajian et al. (2015), Italy-Spain	Other		Computer Science	Various	Unfair or Unequal Treatment	Australian Legislation 2014; European Union Legislation 2014
Hildebrandt & Koops (2010), USA	Theoretical		Law	Ambient Intelligence	Unlawful/Unfair Discrimination	
Hirsch (2015), USA	Theoretical		Law	Various	Not Given - Elusive Concept	
Hoffman (2016), USA	Theoretical		Social Sciences	Employment	Unlawful Discrimination on basis of Disability	Americans with Disabilities Act (ADA), 1990; Genetic Information Nondiscrimination Act (GINA), 2003; Health Insurance Portability and Accountability Act (HIPAA), 1996
Hoffman (2017), USA	Theoretical		Social Sciences	Employment	Unlawful Discrimination on basis of Disability	Americans with Disabilities Act (ADA), 1990; Genetic Information Nondiscrimination Act (GINA), 2003; Health Insurance Portability and Accountability Act (HIPAA), 1996
Holtzhausen (2016), USA	Theoretical		Social Sciences	Various	Not Given – Self Explanatory	
Kamiran and Calders (2012), Netherlands-UK	Other		Computer Science	Various	Unfair and Unequal Treatment	Australian Sex Discrimination Act, 1984; US Equal Pay Act, 1963; US Equal Credit Opportunity Act, 1974; European Council Directive, 2004
Kamiran et al. (2013), Netherlands-Saudi Arabia-UK	Other		Computer Science	Various	Unfair and Unequal Treatment	Australian Sex Discrimination Act, 1984; US Equal Pay Act, 1963
Kennedy & Moss (2015), UK	Theoretical		Social Sciences	Society and Culture	Not Given - Self Explanatory	
Kroll et al. (2017), USA	Theoretical		Law	Various	Not Given - Opposite of Fair Treatment	
Kuempel (2016), USA	Theoretical		Law	Various	Not Given – Self Explanatory	
Le Meur (2015), France	Quantitative	A sample of Pregnant Women	Bioethics	Healthcare	Not Given	
Leese (2014), Germany	Theoretical		Ethics	Aviation/Migration	Principle of Equality and Non Discrimination	Charter of Fundamental Rights of the European Union, 2000; European

						Convention on Human Rights, 1953; Treaty on the Functioning of the European Union, 1958
Lerman (2013), USA	Theoretical		Law	Digital Divide in Social Participation	Social Marginalization/ Exclusion	
Lupton (2015), Australia	Theoretical		Social Sciences	Society	Not Given - Stigmatization	
MacDonnell (2015), Ireland	Theoretical		Social Sciences	Insurance	Not Given	
Mantelero (2016), China-Italy	Theoretical		Social Sciences	Various	Unjust or Prejudicial Treatment	
Mao et al. (2015), USA	Quantitative	A sample of Citizens from Cote D'Ivoire	Social Sciences	Economic Development	Not Given - Related to social and economic disparity	
Newell and Marabelli (2015), UK-USA	Theoretical		Social Sciences	Various	Not Given - Harm towards vulnerable individuals	
Nielsen at al. (2017), Brasil-USA	Quantitative	A sample of Twitter users in Brazil	Social Sciences	Public Health	Not Given - Self Explanatory	
Pak et al. (2017), Belgium	Quantitative	Citizens of Brussels using "Fix My Street" App	Social Science	Urban and social involvement	Not Given - Social Exclusion/Disparity	
Peppet (2014), USA	Theoretical		Law	Various	Illegal or Unwanted Discrimination	
Ploug & Holm (2017), Denmark	Theoretical		Bioethics	Society	Differential Treatment and Stigmatization	
Pope and Sydnor (2011), USA	Other	Full sample of UI Claimants from the State of New Jersey between 1995 and 1997	Computer Science	Employment	Not Given - Self Explanatory	
Romei et al. (2013), Italy	Quantitative	Italian Female Researchers	Computer Science	Academia	Unjustified distinction of individuals based on their membership	European Union Legislation, 2010
Ruggieri et al. (2010), Italy	Other		Computer Science	Various	Juridical	Australian Legislation, 2010; European Union Legislation, 2010; United Nations Legislation, 2010; U.K. Legislation, 2010; U.S. Federal Legislation, 2010
Sharon (2016), Netherlands	Theoretical		Bioethics	Healthcare and Healthcare Research	Not Given - Self Explanatory	
Schermer (2011), Netherlands	Theoretical		Social Sciences	Not Defined	Not Given - Self Explanatory/Stigmatization	
Susewind (2015), Germany	Quantitative	Selected Asian Countries	Social Sciences	Various	Not Given - Self Explanatory	
Taylor (2016), Netherlands	Qualitative	West Africa Population (Cote d'Azur)	Social Sciences	Surveillance	Not Given - Self Explanatory	
Taylor (2017), Netherlands	Theoretical		Social Sciences	Various	Disparity/Inequality/Exclusion	
Timmis (2016), UK	Theoretical		Social Sciences	Education	Not Given - Social Exclusion/Disparity	
Turow at al. (2015), USA	Theoretical		Social Sciences	Marketing	Social Discrimination	
Vaz et al. (2017), Canada	Quantitative		Social Sciences	Urban Development	Social Inequalities	
Veale & Binns (2017), UK	Theoretical		Social Sciences	Various	Not Given - Opposite of fairness and equality	
Voigt (2017), Canada	Theoretical		Social Sciences	Healthcare	Inequality	
Zarate et al. (2016), USA	Qualitative	Participants of the PGP (Personal Genome Project)	Bioethics	Various	Not Given - Self Explanatory	

Zarsky (2014), Israel	Theoretical	Law	Various	Illusive concept - Unfair or Unequal Treatment of the individual	
Zarsky (2016), Israel	Theoretical	Law	Credit Scoring	Unfairness and Inequality	
Zilobaite & Custers (2016), Finland-Netherlands	Other	Computer Science	Various	Juridical	Race Equality Directive (2000/43/EC), Employment Equality Directive (2007/78/EC), Gender Recast Directive (2006/54/EC), Gender Goods and Services Directive (2006/113/EC)
Zilobate (2017), Finland-Netherlands	Other	Computer Science	Various	Adversary Treatment of people based on belonging to some group	Race Equality Directive (2000/43/EC), Employment Equality Directive (2007/78/EC), Gender Recast Directive (2006/54/EC), Gender Goods and Services Directive (2006/113/EC)

3.4.1 Discrimination and data mining

In order to explore whether and how Big Data analysis and/or data mining techniques can have discriminatory outcomes, we decided to divide the studies according to a) the possible discriminatory outcomes of data analytics and b) some of the most commonly identified causes of discrimination or inequality in Big Data technologies.

Forms, targets and consequences of discrimination

Numerous papers assessed the possible various discriminative and unfair outcomes that might result from data technologies (See table 3-3).

Table 3-3: *Discriminatory outcomes of Big Data*

Discriminatory Outcomes		Paper reference
A. Forms of Discrimination	Accidental/Involuntary discrimination	(Barocas and Selbst, 2016; Brayne, 2017; Calders and Verwer, 2010; Citron and Pasquale, 2014; d'Alessandro et al., 2017; Holtzhausen, 2016; Kroll et al., 2017; Mantelero, 2016; Schermer, 2011; Zarsky, 2014; Chouldechova, 2017)

	Direct Voluntary discrimination		(Holtzhausen, 2016; Ajana, 2015; Kuempel, 2016)
B. Victims/Targets of Discrimination	Vulnerable groups/populations		(Kuempel, 2016; Leese, 2014; Newell and Marabelli, 2015)
	Larger groups		(de Vries, 2010; Francis and Francis, 2017; Kennedy and Moss, 2015; Mantelero, 2016)
C. Discriminatory Consequences	Social marginalization and stigma		(Lupton, 2015; Ploug and Holm, 2017; Barocas and Selbst, 2016; Francis and Francis, 2017; Pak et al., 2017; Taylor, 2017; Kennedy and Moss, 2015; Susewind, 2015; Lerman, 2013; Sharon, 2016; Casanas i Comabella and Wanat, 2015)
	Exacerbation of existing inequalities		(Brayne, 2017; Brannon, 2017; Pak et al., 2017; Taylor, 2017; Timmis et al., 2016; Voigt, 2017)
	New forms of discrimination	Economic discrimination	(Hildebrandt and Koops, 2010; Turow et al., 2015; Peppet, 2014)
		Health prediction discrimination	(Ajunwa et al., 2016; Cohen et al., 2014; Hoffman, 2017; Hoffman, 2010)

Among these, a considerable number of papers highlighted the two main forms of discrimination introduced by data mining. In this context, some authors stressed the fact that the aforementioned algorithmic mechanisms might result in involuntary and accidental discrimination (Citron and Pasquale, 2014; Mantelero, 2016; Zarsky, 2014; Barocas and Selbst, 2016; Holtzhausen, 2016; Brayne, 2017; d'Alessandro et al., 2017; Calders and Verwer, 2010; Kroll et al., 2017; Schermer, 2011). Barocas and Selbst (2016), for example, claimed that "when it comes to data mining, unintentional discrimination is the more pressing concern because it is likely to be far more common and easier to overlook" (Barocas and Selbst, 2016: 693) and expressed concern about the possibility that classifiers in data mining could contain unlawful and harmful discrimination towards protected classes and or vulnerable groups. Holtzhausen (2016), along the same lines, argued that "algorithms can have unintended consequences"

(Holtzhausen, 2016: 25) and might cause real harm to individuals, ranging from differences in pricing, to employment practices, to police surveillance. Some other studies instead highlighted that data mining technologies could result in direct and voluntary discrimination (Kuempel, 2016; Holtzhausen, 2016; Hajian and Domingo-Ferrer, 2013). Here we follow the aforementioned definition of direct discrimination offered by Hajian and Domingo-Ferrer (2013) that describes it as discrimination against minorities or disadvantaged groups on the basis of sensitive discriminatory attributes related to group membership such as race, gender or sexual orientation. Holtzhausen (2016), for instance, warned against the discriminatory use of ethnic profiling in housing and surveillance; and Ajana (2015) discussed potentially oppressive and discriminatory outcomes of data mining on migration and profiling that impose an automatic and arbitrary classification and categorization upon supposedly risky travelers.

Some papers also defined the potential targets of data mining technologies. Newell and Marabelli (2015) and Kuempel (2016) discussed the increased exploitation of the vulnerable as one of the most worrying consequences of data mining; they claimed that algorithms might identify those who are less capable, such as elder individuals with gambling habits, and prey on them with targeted advertisements or by persuading them "to take out risky loans, or high-rate instant credit options, thereby exploiting their vulnerability"(Newell and Marabelli, 2015: 8). Leese (2014) claimed that discrimination is one of the harms that derives from the massive scale of the profiling of society and that the risk is even higher for vulnerable populations. Four of the reviewed papers also noticed how profiling and data mining technologies are causing a shift in harm from single profiled and classified individuals to larger groups. The papers argued that decisions taken on the aggregation of collected information might have harmful consequences for a) the entire collectivity of the people involved in the data set (Mantelero, 2016), b) for people who were not in the original analyzed dataset (Francis and Francis, 2017), and c) for the general public due to the penetration of data mining practices into each of our every day's activity thanks to big companies like Facebook, Twitter, Google (Kennedy and Moss, 2015). de Vries (2010), has taken this concept a step further and argued that the increased use of machine profiling and automatic classification could lead to a general increase of discrimination in many sectors to a level that might make discrimination perceived as a legitimate practice in a constitutional democracy.

Regarding the consequences of the use of Big Data technologies, social exclusion, marginalization and stigmatization were mentioned in 11 articles. Lupton (2015) argued that the disclosure of sensitive data, specifically sexual preference and heath data related to fertility and sexual activity could result in stigma and discrimination. Ploug and Holm (2017) described how health registries for sexual transmittable diseases risk singling out and excluding minorities, Barocas and Selbst (2016), Pak and colleagues (2017), and Taylor (2017) argued that some individuals will be marginalized and excluded from social engagement due to the digital divide.

According to the literature, Big Data technologies might also perpetuate existing social and geographical historical disparities and inequalities, for example by increasing the exclusion of ethnic minorities from social engagement, worsening the living conditions of the economically disadvantaged, widening the economic gap between poor and rich countries, excluding some minorities from healthcare (Brayne, 2017; Brannon, 2017; Pak et al., 2017; Taylor, 2017; Timmis et al., 2016; Voigt, 2017), and/or delivering a fragmented and incomplete picture of the population through data mining technologies (Brannon, 2017).

Some papers also highlighted how new means of automated decision making and personalization could create novel forms of discrimination that transcend the historical concept of unlawful discrimination and that are not related to historically protected classes or vulnerable categories. According to Newell and Marabelli (2015), individuals could be inexplicably and unexpectedly excluded from certain opportunities, exploited on the basis of their lack of capacities, and be unfairly treated through targeted advertisement and profiling. The reviewed literature pinpointed two main new forms of discrimination: first, economic or marketing discrimination, that is, the unequal treatment of different consumers based on their purchasing habits or inequality in pricing and offers that are given to costumers based on profiling, such as insurance or housing (Hildebrandt and Koops, 2010; Turow et al., 2015; Peppet, 2014); secondly, discrimination based on health prediction, that is the unequal treatment or discrimination of individuals based on predictive, and not actual, health data (Ajunwa et al., 2016; Cohen et al., 2014; Hoffman, 2017; Hoffman, 2010).

Causes of discrimination

Many papers highlighted the main elements that might cause discrimination or inequality in Big Data technologies (See table 3-4).

Table 3-4: *Causes of Discrimination in data analytics*

Causes of Discrimination		**Related Articles**
Algorithmic Causes	**Definition of the Target Variable**	(Barocas and Selbst, 2016); (d'Alessandro et al., 2017).
	Data issues ➔ Training data (Historically biased data sets)	(Brayne, 2017; Barocas and Selbst, 2016; d'Alessandro et al., 2017; Kamiran and Calders, 2012)
	Data issues ➔ Training Data (manual assignment of class labels)	(Barocas and Selbst, 2016; d'Alessandro et al., 2017)
	Data issues ➔ Data collection (Overrepresentation and underrepresentation)	(Barocas and Selbst, 2016; d'Alessandro et al., 2017)
	Proxies	(Barocas and Selbst, 2016; d'Alessandro et al., 2017; Zliobaite and Custers, 2016; Schermer, 2011; Kamiran and Calders, 2012)
	Feedback Loop	(Brayne, 2017; d'Alessandro et al., 2017; Mantelero, 2016)
	Overfitting	(Kamiran and Calders, 2012; Mantelero, 2016)
	Feature Selection	(Barocas and Selbst, 2016)
	Cost Function ➔ Error by omission	(d'Alessandro et al., 2017)
	Masking ➔ Proxies	(Barocas and Selbst, 2016; Kroll et al., 2017; Peppet, 2014; Zarsky, 2014; Zliobaite and Custers, 2016)
Digital Divide	Skills	(Boyd and Crawford, 2012; Casanas i Comabella and Wanat, 2015)
	Resources	(Barocas and Selbst, 2016; Pak et al., 2017)
	Geographical Location	(Barocas and Selbst, 2016; Pak et al., 2017; Casanas i Comabella and Wanat, 2015)
	Age	(Casanas i Comabella and Wanat, 2015)
	Income	(Barocas and Selbst, 2016; Pak et al., 2017)
	Gender	(Boyd and Crawford, 2012)
	Education	(Boyd and Crawford, 2012)
	Race	(Sharon, 2016; Bakken and Reame, 2016)
Data Linkage		(Cato et al., 2016; Ploug and Holm, 2017; Susewind, 2015; Zarate et al., 2016)

Algorithmic causes of discrimination

Ten papers focused on how algorithmic and classificatory mechanisms might make data mining, classification and profiling discriminatory. These studies underlined that data mining technologies always involve a form of statistical discrimination. Adverse outcomes against protected classes might occur involuntarily due to the classification system. Barocas and Selbst (2016) and d'Alessandro (2017), for example, pointed out that while the process of locating statistical relationships in a dataset is automatic, computer scientists still have to personally set both the target variable or outcome of interest ("what data miners are looking for") and the "class labels" ("that divides all the possible outcomes of the target variable in binary and mutually exclusive categories") (Barocas and Selbst, 2016: 678). Insofar the data scientist needs to translate a problem into formal computer coding, deciding on the target variable and the class labels is a subjective process. Another algorithmic cause of discrimination is related to biased data in the model. In order to develop automatization, data mining models need datasets to train on, since they learn to make classifications on the basis of given examples. Schermer (2011) argued that if the training data is contaminated with discriminatory or prejudiced cases, the system will assume them as valid examples to learn from and reproduce discrimination in its own outcomes. This contamination could derive from historically biased datasets (Brayne, 2017) or from the manual assignment of class labels by data miners (Barocas and Selbst, 2016). An additional issue with the training data might be the data collection bias (Barocas and Selbst, 2016) or sample bias (d'Alessandro et al., 2017). Bias in the data collection can present itself as an *underrepresentation* of specific groups and/or protected classes in the data set, which might result in unfair or unequal treatment, or also an *overrepresentation* in the data set which might result in a "disproportioned attention to a protected class group, and the increased scrutiny may lead to a higher probability of observing a target transgression" (d'Alessandro et al., 2017: 126). Within this context, Kroll and colleagues mentioned the phenomenon of "overfitting" where "models may become too specialized or specific to the data used for training" and, instead of finding the best possible decision rule overall, they simply learn the most suited rule to the training data thus perpetrating its bias (Kroll et al., 2017: 633). Another possible algorithmic cause of discriminatory outcomes is proxies for protected characteristics such as race and gender. A historically recognized proxy for race, for example, is ZIP or post-code and "redlining" is defined as the systematic disadvantaging of specific, often racially associated, neighborhoods or communities (Schermer, 2011). On this note, Zliobate and Custers (2016) highlighted how, in data mining, the elimination of sensitive attributes from the data set does not help to avoid discriminative outcomes as the algorithm could automatically identify unpredictable proxies for protected attributes. Two papers discussed feedback loop and systematic loop as a possible cause of unfair predictions (d'Alessandro et al., 2017; Brayne, 2017). These involve the creation of a negative vicious cycle where certain inputs in the data set induce statistical deviations that are learned and perpetuated by the algorithm in a self-fulfilling loop of cause and consequence. An example might help to clarify this mechanism: police crime notification in certain urban areas will increase police patrol activity since crime notification is considered predictive of increased criminal activity. However, intensive paroling will result in an increasingly higher rate of criminal activity reports in that area, irrespective of the true crime rate of that neighborhood with respect to others. “Feature selection” is another possible cause of discrimination identified by Barocas and Selbst (2016). This is a process that is used by those who collect and analyze the data to decide what kind of attributes or features they want to observe and take into account in their decision making processes. The authors argued that the selection of attributes always involves a reductive representation of the more complex real world object, person, or phenomena that it aims to portray insofar as it cannot take into account all the attributes and all the social or environmental factors related to that individual (Barocas and Selbst, 2016: 688).

d’Alessandro identified two additional possible causes of discrimination lined to model misspecification, that is “the functional form of feature set of a model under study not being reflective of the true model” (d'Alessandro et al., 2017: 126). These are “cost function” misspecification and “error by omission”. “Cost function” misspecification is defined as the failure to consider the additional weight given to the event or attribute of interest (eg. criminal record) by the data scientist. d’Alessandro argued that since “discrimination is enforced when a protected class receives an unwarranted negative action”, if a “false positive error could cause significant harm to an individual in a protected class”, the weight of the attribute, namely its asymmetry with respect to others, has to be taken into account (d'Alessandro et al., 2017: 127). “Error by omission” is another form of cost function misspecification that occurs when terms that penalize discrimination are ignored or left out from the model. Simply put, it means that the model does not take into account the differences in how the algorithm classifies protected and non-protected classes (d'Alessandro et al., 2017: 127-128).

Finally, the reviewed articles also highlighted how algorithmic analysis can become an excellent and innovative tool for direct voluntary discrimination. This practice, defined as “masking”, involves the intentional exploitation of the mechanisms described above to perpetrate discrimination and unfairness. The most common practice of masking is the intentional use of proxies as indicators of sensitive characteristics (Barocas and Selbst, 2016; Zliobaite and Custers, 2016; Kroll et al., 2017; Peppet, 2014; Zarsky, 2014).

Digital Divide

We identified 9 papers that discussed the digital divide, that is, the gap between those who have continuous and ready access to internet, computer and smartphones and those who do not, as a possible cause of inequality, injustice or discrimination. Lack of resources or computational skills, older age, geographical location, and low income were identified as possible causes of this digital divide (Pak et al., 2017; Barocas and Selbst, 2016; Casanas i Comabella and Wanat, 2015). Two papers (Sharon, 2016; Lerman, 2013) discussed the "big data exclusions" referring to those individuals "whose information is not regularly collected or analyzed because they do not routinely engage in data-generating practices" (Lerman, 2013: 56). On the same note, Bakken and Reame (2016) argued that data is mainly gathered from white, educated people leaving out racial minorities such as Latinos. Boyd and Crawford discussed the creation of new digital divides, arguing that discrimination may arise due to (1) differences in information access and processing skills - the Big Data rich and the Big Data poor, and due to (2) gender differences insofar most researchers with computational skills are men (Boyd and Crawford, 2012). Lastly, Cohen and colleagues (2014) described how the commercialization of predictive models will leave out vulnerable categories such people with disabilities or limited decision-making capacities and high risk patients.

Data linkage and aggregation

Four papers discussed data linkage, that is, the possibility of automatically obtaining, linking, and disclosing personal and sensitive information as an important cause of discrimination. Two articles (Cato et al., 2016; Zarate et al., 2016) described how the use of electronic health records could result in the automatic disclosure of sensitive data without the patient's explicit agreement or to re-identification. Others (Ploug and Holm, 2017; Susewind, 2015) also highlighted that discrimination is not created by a data collection system (such as social and health registries) in itself, but is made easier by the linkage and aggregation potentiality embedded in the data.

3.4.2 Suggested solutions

The literature has suggested several different strategies to prevent discrimination and inequality in data analytics, ranging from computer based and algorithmic solutions to the incorporation of human involvement and supervision (See table 3-5).

Table 3-5: *Suggested solutions to discrimination in Big Data*

Suggested Solutions		Paper Reference
Computer Science and Technical Solutions	Pre-processing	(Kamiran et al., 2013; Kamiran and Calders, 2012; Hajian and Domingo-Ferrer, 2013; Hajian et al., 2014)
	In-processing	(Zliobaite and Custers, 2016; Pope and Sydnor, 2011; Kamiran et al., 2013; Calders and Verwer, 2010; Kroll et al., 2017)
	Post-processing	(Hajian et al., 2015)
	Mixed Methods	(d'Alessandro et al., 2017)
	Implementation of Transparency	(Schermer, 2011; Citron and Pasquale, 2014; Hildebrandt and Koops, 2010; Kroll et al., 2017)
	Privacy Preserving Strategies	(Hildebrandt and Koops, 2010; Hajian et al., 2015)
	Exploratory fairness analysis	(Veale and Binns, 2017)
Legal Solutions		(Kuempel, 2016; Citron and Pasquale, 2014; Hirsch, 2015; Hoffman, 2017; Hoffman, 2010; Peppet, 2014; Hildebrandt and Koops, 2010)
Human Based Solutions	Human in the Loop	(Zarsky, 2014; Berendt and Preibusch, 2017; d'Alessandro et al., 2017)
	Third Parties	(Mantelero, 2016; Veale and Binns, 2017)
	Multidisciplinary Involvement	(Taylor, 2016a; Taylor, 2017; Cohen et al., 2014)
	Education	(Veale and Binns, 2017; Zarsky, 2014)
	Implementing EHR flexibility	(Hoffman, 2010)

Practical computer science and technological solutions

Some articles authored by IT specialists suggested practical computer science solutions, namely the development of discrimination-aware methods to be applied during the development of the algorithmic models. These techniques include: *pre-processing* methods that involve the sanitization or distortion of the training data set to remove possible bias in order to prevent the new model from learning discriminatory behaviors (eg. (Kamiran et al., 2013; Hajian et al., 2014); *in-processing* techniques that provide for the modification of the learning algorithm through the application of regularization to probabilistic discriminative models (Kamiran et al., 2013) such as the inclusion of sensitive attributes to avoid discriminatory predictions (Zliobaite and Custers, 2016; Pope and Sydnor, 2011) or the addition of randomness to avoid overfitting or hidden model bias (Kroll et al., 2017); *post-processing* methods that involve the auditing of the extracted data mining models for discriminative patterns and eventually their sanitization

(Hajian et al., 2015). Along these lines, (d'Alessandro et al., 2017) suggested the implementation of an overall discrimination-aware auditing process that involves the coherent combination of all pre-, in-, and post-processing methods to avoid discrimination. Many papers indicated how the implementation of transparency of data mining processes could help avoid injustice and harm. Practical suggestions to reinforce transparency in data mining include the development of interpretable algorithms that will give explanations on the logical steps behind a certain classification (Kroll et al., 2017; Schermer, 2011), and the creation of transparent models that will allow individuals to see in advance how their behavior and choices will be interpreted by the algorithm or the infrastructure (Citron and Pasquale, 2014; Hildebrandt and Koops, 2010). Another solution was the enhancement of proper privacy preserving strategies since it’s impossible to eradicate the likelihood of discriminative practices in data mining if discrimination-preventing data mining is not integrated with privacy-preserving data mining models (Hajian et al., 2015). Lastly, one paper suggested the promotion of exploratory fairness analysis that could be used to build up knowledge of the mechanisms and logics behind machine learning decisions (Veale and Binns, 2017).

Legal solutions

Implementation of legislation on data protection and discrimination was another common suggestion among the papers from the USA. Kuempel (2016) suggested that the harmonization of stronger data protection legislation across different sectors in the US, could help contrast discrimination in under regulated areas, such as online marketing and data brokering. One author (Peppet, 2014) argued that policies to constrain data use should be put into place. Such constraints should limit or deny the disclosure of sensitive data in specific contexts (eg. health data in employment) or even deny specific uses of data in contexts where sensitive data is already disclosed if such use might cause harm to the individual (eg. the use of health data to increase premiums in insurance). Finally, one article (Hildebrandt and Koops, 2010) suggested the idea of “code as law”, that is a transition from written-law to computational law, implying the articulation of specific legal norms in digital technologies through the use of software.

Human-centered solutions

Keeping the human in the loop of data mining was another recommendation. According to some papers, human oversight and supervision is critical to improve fairness since humans could notice where important factors are unexpectedly overlooked or sensitive attributes are improperly correlated (d'Alessandro et al., 2017; Berendt and Preibusch, 2017). Other solutions that include human involvement were: a) the participation of trusted third parties to either store sensitive data and rule on their disclosure to companies (Veale and Binns, 2017) or supervise and assess suspicious data mining and classification practices (Mantelero, 2016); b) the engagement of all relevant stakeholders involved in a decision making or profiling process – such as health care institutions, physicians, researchers, subjects of research, insurance companies, and data scientists - in a multidisciplinary discussion towards the creation of a theoretical overarching framework to regulate data mining and promote the implementation of fair algorithms (Cohen et al., 2014); c) the implementation of strategies to educate data scientists in building proper models, such as the creation of a knowledge base platform for fairness in data mining that could be investigated by data scientists in case they stumbled upon problematic correlations; and d) the implementation of flexibility and discretion in EHR disclosing system to avoid stigma from the disclosure of personal and private information (Hoffman, 2010).

3.4.3 Obstacles to fair data mining

Many papers described algorithmic decision making as a black box system where the input and the output of the algorithm are visible but the inner process remains unknown (Brannon, 2017; Citron and Pasquale, 2014; d'Alessandro et al., 2017), resulting in lack of transparency regarding the methods and the logic behind scoring and predictive systems (Hildebrandt and Koops, 2010; Leese, 2014; Mantelero, 2016; Zarsky, 2016). Reasons behind the opacity of automated decision making are multiple: first, algorithms might use enormous and very complex data sets that are uninterpretable to regulators (d'Alessandro et al., 2017), who frequently lack the required computer science knowledge to understand algorithmic processes (Schermer, 2011); second, automatic decision making might intrinsically transcend human comprehension since algorithms do not make use of theories or contexts as in regular human based decision-making (Newell and Marabelli, 2015); and finally, algorithmic processes of firms or companies might be subject to intellectual property rights or covered by trade secret provisions (Hildebrandt and Koops, 2010). If there is no transparent information on how algorithms and processes work it is almost impossible to (Kennedy and Moss, 2015) evaluate the fairness of the algorithms or discover discriminatory patterns in the system (Kroll et al., 2017).

Human bias was identified as another main obstacle to fair data mining. Human subjectivity is at the very core of the design of data mining algorithms since the decisions regarding which attributes will be taken into account and which will be ignored are subject to human interpretation (Boyd and Crawford, 2012), and will inevitably reflect the implicit or explicit values of their designers (Ajana, 2015).

Algorithmic data mining also poses considerable conceptual challenges. Many papers claimed that automatic decision making and profiling are reshaping the concept of discrimination, beyond legally accepted definitions. In the United States (US), for example, Barocas and Selbst (2016) claimed that algorithmic bias and automatization are blurring notions of motive, intention and knowledge, making it difficult for the US doctrine on disparate impact and disparate treatment to be used to evaluate and persecute causes of algorithmic discrimination. One article (Leese, 2014), discussing European Union (EU) regulation, argued that it is necessary to rethink discrimination in the context of data driven profiling, since the production of arbitrary categories in data mining technologies and the automatic correlation of the individual's attributes by the algorithm differ from traditional profiling, which is based on the establishment of a causal chain developed by human logic. Some articles have also pointed out that concepts like "identity" and "group" are being transformed by data mining technologies. de Vries argued that individual identity is increasingly shaped by profiling algorithms and ambient intelligence in terms of increased grouping created in accordance with algorithms' arbitrary correlations, which sort individuals into a virtual, probabilistic "community " or "crowd" (de Vries, 2010). This typology of "group" or "crowd" differs from the traditional understanding of groups, since the people involved in the "group" might not be aware of (1) their membership to that group, (2) the reasons behind their association with that group and, most importantly, (3) the consequences of being part of that group (Mantelero, 2016). Two other concepts are being reshaped by data technologies. The first is the concept of border (Ajana, 2015), which is no longer a physical and static divider between countries but has become a pervasive and invisible entity embedded in bureaucratic processes and the administration of the state due to Big Data surveillance tools such as electronic passports and airport security measures. The second is the concept of disability, which needs to be broadened to include all diseases and health conditions, such as obesity, high blood pressure and minor cardiac conditions, which might result in discriminatory outcomes from automatic classifiers through algorithmic correlation with more serious diseases (Hoffman, 2017; Hoffman, 2010).

The final barrier that was pinpointed in the literature is of a legal nature. According to some authors, current antidiscrimination and data protection legislation, both in the EU and in the US, are not well equipped to address cases of discrimination stemming from digital technologies (Barocas and Selbst, 2016). Kroll and colleagues (2017) claimed that current antidiscrimination laws might legally prevent users of algorithms from revising and inspecting algorithms after the discriminatory fact has happened, making the development of ex-ante anti-discriminatory models even more pressing. Kuempel (2016) argued that data protection legislation is too sectorial and does not provide sufficient safeguards from discrimination in sectors like marketing. Some papers focused on the implications of the implementation of European data protection regulations, specifically the new General Data Protection Regulation (GDPR) of May 2018. The authors emphasized that data protection requirements, such as data gathering minimization and the limitation of use of personal data, might result in barriers into the development of antidiscrimination models that demand the inclusion of sensitive data in order to avoid discriminatory outcomes (Zliobaite and Custers, 2016; Hildebrandt and Koops, 2010) (See table 3-6).

Table 3-6: *Barriers to fair data analytics*

Obstacles to fair data analytics	**Paper Reference**
Black Box	(Berendt and Preibusch, 2014; Brannon, 2017; Brayne, 2017; Citron and Pasquale, 2014; Cohen et al., 2014; d'Alessandro et al., 2017; Hildebrandt and Koops, 2010; Turow et al., 2015; Kennedy and Moss, 2015; Kroll et al., 2017; Leese, 2014; Mantelero, 2016; Newell and Marabelli, 2015; Ruggieri et al., 2010; Schermer, 2011; Taylor, 2017; Zarsky, 2016; Zarsky, 2014)
Human Bias	(Ajana, 2015; Ajunwa et al., 2016; Barocas and Selbst, 2016; Brayne, 2017; Berendt and Preibusch, 2017; Boyd and Crawford, 2012; Citron and Pasquale, 2014; d'Alessandro et al., 2017; Kamiran and Calders, 2012; Veale and Binns, 2017; Voigt, 2017; Zarsky, 2014)
Conceptual Challenges	(Ajana, 2015; Barocas and Selbst, 2016; de Vries, 2010; Francis and Francis, 2017; Hirsch, 2015; Hoffman, 2010; Hoffman, 2017; Kroll et al., 2017; Kuempel, 2016; Mantelero, 2016; Leese, 2014; Lerman, 2013; MacDonnell, 2015; Taylor, 2017; Zarsky, 2014)
Inadequate Legislation	(Barocas and Selbst, 2016; Citron and Pasquale, 2014; Hildebrandt and Koops, 2010; Hoffman, 2017; Hoffman, 2010; Kuempel, 2016; Lerman, 2013; Ruggieri et al., 2010; Zliobaite, 2017; Zliobaite and Custers, 2016; Peppet, 2014)

3.4.4 Beneficial adoption of Big Data technologies

Finally, many papers also described how data mining technologies could be an important practical tool to counteract or prevent inequality and discrimination (See table 3-7).

Table 3-7: *Beneficial adoption of data analytics*

Beneficial Adoption of Big Data		**Paper Reference**
Promotion of Objectivity in Classification		(Barocas and Selbst, 2016; Brayne, 2017; MacDonnell, 2015; Zarsky, 2014)
Uncover and assess discriminatory practices		(Berendt and Preibusch, 2014; Romei et al., 2013; Ruggieri et al., 2010)
Integration of data for promotion of equality and social integration	Healthcare	(Bakken and Reame, 2016; Le Meur et al., 2015)
	Economic growth and urban development	(Mao et al., 2015; Vaz et al., 2017; Voigt, 2017)
	Migration	(Taylor, 2016b; Ajana, 2015)
Beneficial use of Social Media		(Nielsen et al., 2017; Casanas i Comabella and Wanat, 2015)

Data mining is said to promote objectivity in classification and profiling because decisions are made by a formal, objective and constant algorithmic process with a more reliable empirical foundation than human decision-making (Barocas and Selbst, 2016). This feature of objectivity could limit human error and bias. According to some of the literature, automatic data mining could also be used to discover and assess discriminatory practices in classification and data mining. Through the construction of discrimination-aware algorithmic models (eg. (Ruggieri et al., 2010; Berendt and Preibusch, 2014)), individuals who suspect that they are being discriminated against could be helped to identify and assess direct/indirect discrimination, favoritism or affirmative action, and decision makers (such as employers, insurance companies managers and so on) could be protected against wrongful discrimination allegations. Some of the papers also highlighted that the potential of Big Data technologies to integrate socioeconomic data, mobile data and geographical data could promote equitable and beneficial implementations in various sectors. In healthcare, for example, the integration of healthcare data with spatial contextual information might help identifying areas and groups that require health promotion (Le Meur et al., 2015); moreover the use of big data, profiling and classification could foster equity with regard to health disparities in research, since it could promote the implementation of tailored strategies that take into account an individual's ethnicity, living conditions and general lifestyle (Bakken and Reame, 2016). Economic and urban development is another area in which data mining could help foster equity. The integration of analysis from mobile phone activity and socio-economic factors within geographical data could help monitoring and assessment of social structural inequalities to promote the implementation of more equitable city development and growth (Mao et al., 2015; Vaz et al., 2017; Voigt, 2017). Migration could also benefit from the use of Big Data technologies, as it can provide scholars and activists with more accurate data regarding migration flows and thus prepare and enhance humanitarian processes (Ajana, 2015). Finally, two papers also discussed the positive influence of social media. Nielsen et al. (2017) analyzed how text mining could be used to assess the level and diffusion of discrimination related to people affected by Human Immunodeficiency Virus Infection (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in popular social media like Facebook and at the same time implement awareness-raising campaigns to spread tolerance. Another article (Casanas i Comabella and Wanat, 2015) claims that social media could be used to enhance the participation of people receiving pediatric palliative care, a particularly vulnerable group, in research.

3.5 Discussion

The majority of the reviewed papers (49 out of 61) date from the last 5 years. This shows that although Big Data has been a trending buzzword in the scientific literature since 2011 (Burrows and Savage, 2014), the problem of algorithmic discrimination has become of prime interest only recently, in conjunction with the publication of the White House report of 2014 (Podesta, 2014). Hence, scholarly reflection on this issue has appeared rather late, leaving potentially discriminatory outcomes of data mining unaddressed for a long time. Moreover, in line with other studies (Mittelstadt and Floridi, 2016), our review indicates that while a theoretical discussion on this topic is finally emerging, empirical studies on discrimination in data mining, both in the field of law and social sciences, are largely lacking. This is highly problematic especially in light of the new forms of disparate treatment that arise with the increased "datafication" of society. Price and health prediction discrimination (e.g. in insurance policies), for example, are not illegal but might become ethically problematic if persons are denied access to essential goods or services based on their income or lifestyle. More evidence-based studies on the possible harmful use of these practices are urgently needed if we want to understand the complexity of this problem in depth. In addition, it is interesting to notice that no paper examined discrimination in relation to the four V's of Big Data, as they focused more on the classificatory and algorithmic issues of data analytics. It is thus important that future studies also take into account the issue of harmful discrimination related to the specific problems related to the unique characteristic of Big Data, such as the veracity of the data sets and the constraints related to the high volume of data, and the velocity of their production.

Although the majority of papers were theoretical in nature, the term discrimination was presented as self-explanatory and linked to other notions such as injustice, inequality and unequal treatment, with the exception of some papers in law and computer science. This overall lack of a working definition in the literature is highly problematic, for several reasons. First, given that data mining technologies are purposely created to classify, discern, divide and separate individuals, groups or actions (Barocas and Selbst, 2016), discussing the problem of unfair discrimination in absence of a clear definition is creating confusion. The discrimination operated in data-mining, in fact, is not in itself illegal or ethically wrong as long as it limits itself to making a distinction between people with different characteristics (Hildebrandt and Koops, 2010). For example distinguishing between minors and adults is a socially and legally accepted practice of "neutral discrimination"; based on a straightforward distinction of age (in most countries set at 18 years old) individuals are dissimilarly treated: adults have different rights and duties than minors, they can drive and vote, they are judged differently in a court of law and so on. Moreover, even efforts to achieve social equality sometimes imply a sort of differential treatment; for example in the case of gender equality, divergent treatment of individuals based on gender is allowed if such treatment is adopted with the long term goal of evening out social disparities (Weisbard, 2001). Hence, if researchers want to discuss the problem of discrimination in data-mining, a distinction between harmful or unfair versus neutral or fair discrimination is of utmost importance.

Second, without an adequate definition of discrimination, it is difficult for computer scientists and programmers to appropriately implement algorithms. In fact, to avoid unfair practices, measure fairness and quantify illegal discrimination (Kamiran et al., 2013), they need to translate the notion of discrimination into a formal statistical set of operations. The need for this expert knowledge may explain why, compared to other researchers in the field, computer scientists have been at the forefront of the search for a viable definition.

Still, despite the need for a working definition of discrimination, we should not forget that it remains an elusive ethical and social notion which cannot and should not be reduced to a "petrified" statistical measurement. As seen in our review, data-mining has given rise to novel forms of differential treatment. To properly understand the implications of these new discriminatory practises, a reconceptualization of the notion of fair and unfair discrimination might be needed. To keep the debate on discrimination in Big Data open it is important to keep humans in the loop.

Practices of automatic profiling, sorting and decision making through data mining have been introduced with the prima facie concept that Big Data technologies are objective tools capable of overcoming human subjectivity and error resulting in increased fairness (Anderson, 2008). However, data mining can never be fully human-free, not only because humans always risk undermining the presumed fairness and objectivity of the process with subconscious bias, personal values or inattentiveness, but also because they are crucial in order to avoid improper correlations and thus to ensure fairness in data mining. It thus seems that Big Data technologies are deeply tied to this dichotomous dimension where humans are both the cause of its flaws and the overseers of its proper functioning.

One way of keeping the human in the loop is through legislation. Our results, however, show that although legal scholars have tried to address possible unfair discriminatory outcomes of new forms of profiling, Big Data poses important challenges to "traditional" antidiscrimination and privacy protection legislation because core notions, such as motive and intention, are no longer in place (Barocas and Selbst, 2016). A recurring theme in many papers was that legislation always lacks behind technological developments and that while gaps in legal protection are somehow systemic (Hildebrandt and Koops, 2010), an overarching legal solution to all unfair discriminatory outcomes of data mining is not feasible (Kroll et al., 2017).

In our review, very few papers offered a pragmatic legal solution to the problem of unfair discrimination in data-mining: for example one study advocated for a generally applicable rule (Kuempel, 2016), while another suggested the production of a set of precedents built in time through a case by case adjudication (Hirsch, 2015). Both solutions are incompatible with the reality and needs of data management because they are either too rigid (Kuempel, 2016) or too specialized and protracted (Hirsch, 2015).

This poor outcome is probably the result of the technically complex nature of data mining and the intrinsically tricky legal designation of what represents unfair discrimination that should be prohibited by law. The new European *General Data Protection Regulation (GDPR)* is exemplary in this regard. Two key features of the GDPR are: data minimization (i.e. data collection and processing should be kept to a minimum) and purpose limitation (i.e. data should be analysed and processed only for the purpose it was collected for). Since both these principles are inspired from data privacy regulations established in the 1970s, they fail to take into account two crucial points that have been reiterated by many computer science, technical and legal scholars in the past few years (Goodman, 2016): first, with Big Data technologies, information is not collected for a specific, limited and specified purpose, rather it is gathered to discover new and unpredictable patterns and correlations (Lyon, 2014); second, antidiscrimination models require the inclusion of sensitive data in order to detect and avoid discriminatory outcomes (Zliobaite and Custers, 2016).

The difficulties encountered in adequately regulating discrimination in Big Data, especially from a legal point of view, could be partly related to a diffuse lack of dialogue among disciplines. The reviewed literature in fact pinpointed that while on the one hand, unfair discrimination is a complex philosophical and legal concept that stores difficulties for trained data scientists (Chouldechova, 2017), Big Data, on the other, is quite a technological field so philosophers, social scientists and lawyers do not always fully understand the implications of algorithmic modelling for discrimination (Schermer, 2011).

This mutual lack of understanding highlights the urgent need for a multidisciplinary collaboration between fields, such as philosophy, social science, law, computer science and engineering. The idea of collaboration between disciplines due to the spreading of digital technologies is not new. An example of this can be found in the conception of "code as law" first proposed by both Reidenberg and Lessing in the late 1990s, which implies the design of digital technologies to support specific norms and laws such as privacy and antidiscrimination (Reidenberg, 1997; Lessing, 1999). As shown by our results (eg. (d'Alessandro et al., 2017; Kamiran and Calders, 2012; Kamiran et al., 2013)), the "code as law" proposal has been steadily implemented in computer science practice by many scholars who want to implement antidiscrimination rules in algorithmic models to avoid unfair harmful outcomes. Some papers, however, recommended a broader and overarching dialogue among disciplines (Cohen et al., 2014; Goodman, 2016; Kroll et al., 2017). Nonetheless, concrete means to put this multidisciplinarity into practice were lacking in the literature.

Finally, a few studies highlighted that Big Data technologies may tackle discrimination and promote equality in various sectors, such as healthcare and urban development (Bakken and Reame, 2016; Casanas i Comabella and Wanat, 2015; Le Meur et al., 2015). Such interventions, however, might have the opposite effect and create other types of social disparities by widening the divide between people who have access to digital resources and those who do not, on the basis of income, ethnicity, age, skills, and geographical location. The significant number of papers that identified the digital divide as a major cause of inequality indicates how, despite all the efforts made to enhance digital participation across the globe (Yu et al., 2018b), social disparities due to lack of access to digital technologies are increasing in many sectors including health (Weiss et al., 2018), public participation/engagement (Bartikowski et al., 2018) and public infrastructure development (Pak et al., 2017; Taylor, 2017). Scholars are rather sceptical about finding a solution to this problem due to the ever-changing technological landscape that creates new inclusion difficulties (Yu et al., 2018a). Still, due to the potential promising beneficial applications of Big Data technologies, more studies should focus on the analysis and implementation of such fair uses of data-mining while considering and avoiding the creation of new divides.

In conclusion, more research is needed on the conceptual challenges that Big Data technologies raise in the context of data mining and discrimination. The lack of adequate terminology regarding digital discrimination and the possible presence of latent bias might mask persistent forms of disparate treatment as normalized practices. Although a few papers tackled the subject of a possible conceptual revision of discrimination and fairness (Taylor, 2017), no study has done so in an exhaustive way.

3.6 Limitations

A total of 61 peer-reviewed articles in English qualified for inclusion and were further assessed. It might thus be possible that studies in other languages and relevant grey literature have been overlooked. Aside from these limitations, this is the first study to comprehensively explore the relation between Big Data and discrimination from a multidisciplinary perspective.

3.7 Conclusions

Big Data offers great promise but also poses considerable risks. The literature review highlights that unfair discrimination is one of the most pressing, but at the same time an often underestimated issue in data mining. A wide range of papers proposed solutions on how to avoid discrimination in the use of data technologies. Though most of the suggested strategies were practical computational/algorithmic methods, numerous papers recommended human solutions. Transparency was a commonly suggested solution to enhance algorithmic fairness. Improving algorithmic transparency and resolving the black box issue might thus be the best course to undertake when dealing with discriminatory issues in data analytics. However, our study results identify a considerable number of barriers to the proposed strategies, such as technical difficulties, conceptual challenges, human bias and shortcomings of legislation, all of which hamper the implementation of such fair data mining practices. Due to the risk of discrimination in data mining and predictive analytics and the strikingly shortage of empirical studies on the topic that our review has brought to light, we argue that more empirical research is needed to assess how discriminatory practices are deliberately and accidentally emerging from their increased use in numerous sectors such as healthcare, marketing and migration. Moreover, since most studies focused on the negative discriminatory consequences of Big Data, more research is needed on how data mining technologies, if properly implemented, could also be an effective tool to prevent unfair discrimination and promote equality. As more reports from the press are emerging on the positive use of data technologies to assist vulnerable groups, future research should focus on the diffusion of similar beneficial applications. However, since even such practices are creating new forms of disparity between those who can access digital technologies and those who do not, research should also focus more on the implementation of practical strategies to mitigate the Digital Divide.

3.8 Abbreviations

US: United States; **EU:** European Union; **HIV:** Human Immunodeficiency Virus; **AIDS:** Acquired Immunodeficiency Syndrome.

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Chapter 4 - Big Data and digitalization in dentistry: a systematic review of the ethical issues

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4.1 Abstract

Big Data and Internet and Communication Technologies (ICT) are being increasingly implemented in the healthcare sector. Similarly, research in the field of dental medicine is exploring the potential beneficial uses of digital data both for dental practice and in research. As digitalization is raising numerous novel and unpredictable ethical challenges in the biomedical context, our purpose in this study is to map the debate on the currently discussed ethical issues in digital dentistry through a systematic review of the literature. Four databases (Web of Science, Pub Med, Scopus and Cinahl) were systematically searched. The study results highlight how most of the issues discussed by the retrieved literature are in line with the ethical challenges that digital technologies are introducing in healthcare such as privacy, anonymity, security, and informed consent. In addition, image forgery aimed at scientific misconduct and insurance fraud was frequently reported, together with issues of online professionalism and commercial interests sought through digital means.

4.2 Introduction

The sophistication and increased use of ICT, the rise of Big Data and algorithmic analysis, and the origin of the Internet of Things (IOT) are a plethora of interconnected phenomena that is currently having an enormous impact on today's society and that is affecting almost all spheres of our lives. In recent years we have seen an exponential growth in the generation, storage and collection of computational data and the digital revolution is transforming an increasing number of sectors in our society (Lynch, 2008; Boyd and Crawford, 2012).

In the biomedical context, for instance, digital technologies are finding numerous novel applications to improve healthcare, cut costs for hospitals, and maximize treatment effectiveness for patients. Examples of such implementations include the development of electronic health records (EHR) and smarter hospitals for increased workflow (Mertz, 2014), personalized medicine and linkage of health data (Cohen et al., 2014), clinical decision support for novel treatment concepts (Lee and Yoon, 2017), and deep learning and artificial intelligence for diagnostic analysis (Liu et al., 2019). In addition, the implementation of mobile technologies into the medical sector is fundamentally altering the ways in which healthcare is perceived, delivered and consumed. Thanks to the ubiquity of smartphones and wearable technologies, mobile health (mHealth) applications are currently being explored by healthcare providers and companies for remote measurement of health and provision of healthcare services (Nilsen et al., 2012).

Dentistry, as a branch of medicine, has not remained unaffected by the digital revolution. The trend in digitalization has led to an increased production of computer-generated data in a growing number of dental disciplines and fields – for example oral and maxillofacial pathology and surgery, prosthodontics and implant dentistry, and oral public health (Fasbinder, 2010; Joda et al., 2018b; Finkelstein et al., 2020). For this reason, research in the field of dental medicine is currently focusing on exploring the numerous potential beneficial applications of digital and computer-generated data both for dental practice and in research. Population-based linkage of patient-level information could expand new approaches for research such as assisting with the identification of unknown correlations of oral diseases with suspected and new contributing factors and furthering the creation of new treatment concepts (Joda et al., 2018a). Artificial Intelligence (AI) applications could help enhance the analysis of the relationship between prevention and treatment techniques in the field of oral health (Joda et al., 2019). Digital imaging could promote accurate tracking of the distribution and prevalence of oral diseases to improve healthcare service provisions (Hogan et al., 2018). Finally, the creation of the digital or virtual dental patient, through the application of sophisticated dental imaging techniques (such as 3D con-beam computed tomography (CBCT), 3D printed models, etc.) could be used for precise pre-operative clinical assessment and simulation of treatment planning in dental practice (Joda et al., 2018b; Vandenberghe, 2018). As these technologies are still at the early phases of implementation, technical issues and disadvantages might also emerge. For instance, data collection for the implementation of Big Data applications and AI must be done systematically according to harmonized and inter-linkable data standards otherwise it causes issues of data managing and garbage data accumulation (Hashimoto et al., 2014). AI for diagnostic purposes are still in the very early phases where their accuracy is being assessed and although they are revealing themselves to be valuable for image-based diagnoses, analysis of diverse and massive EHR data still remains challenging (Liang et al., 2019). Finally, with regards to the simulation of a 3D virtual dental patient, dataset superimposition techniques are still experimental and none of the currently available imaging techniques are sufficient to capture the complete dataset needed to create the 3D output in a single-step procedure (Joda et al., 2018b).

In the past few years, however, alongside the ambitious promises of digital technologies in healthcare, the research community has also highlighted many of the potential ethical issues that Big Data and ICT are raising for both patients and other members of society. In the biomedical context, data technologies have been claimed to exacerbate issues of informed consent for both patients and research participants (Ioannidis, 2013; Martani et al., 2019a), and to create new issues regarding privacy, confidentiality (Francis and Francis, 2014; Schneble et al., 2018; Schneble et al., 2020), data security and data protection (McMahon et al., 2019), and patient anonymization (Choudhury et al., 2014) and discrimination (Favaretto et al., 2019; Geneviève et al., 2020; Martani et al., 2019b). In addition, recent research has also emphasized on additional pressing challenges that could emerge from the inattentive use of increasingly sophisticated digital technologies, such as issues of accuracy and accountability in the use of diagnostic algorithms (Martin, 2019) and the exacerbation of healthcare inequalities (Geneviève et al., 2020).

As dentistry is also undergoing the digital path, similar ethical issues might emerge from the application of ICT and Big Data technologies. To the best of our knowledge, there is currently no systematic evaluation of the different ethical issues raised by Big Data and ICT in the field of dentistry, as most of the literature on the topic focuses generally on non-dental medicine and healthcare (Mittelstadt and Floridi, 2016). As timely ethical evaluation is a consistent part of appropriate health technology assessment (Esfandiari and Feine, 2011) and since recent literature has focused on the ethical issues related to health related Big Data (Mittelstadt and Floridi, 2016), it is of the outmost importance to map the occurrence of the ethical issues related to the application of heterogeneous digital technologies in dental medicine and to investigate if specific ethical issues for dental Big Data are emerging.

We thus performed a systematic review of the literature. The study has the following aims: 1) mapping the identified ethical issues related to the digitalization of dental medicine and the applications of Big Data and ICT in oral healthcare; 2) investigating the suggested solutions proposed by the literature; and 3) understanding if some applications and practices in digital dentistry could also help overcome some ethical issues.

4.3 Materials and methods

We performed a systematic literature review by searching four databases: PubMed, Web of Science, Scopus, and Cinahl. The following search terms were used: "big data", "digital data", "data linkage", "electronic health record *", "EHR", "digital *", "artificial intelligence", "data analytics", "information technology", "dentist *", "dental *", "oral health", "orthodont *", "ethic *", and "moral *". No restriction was placed on the type of methodology used in the paper (qualititative, qualitative, mixed methods or theoretical). No time restriction was used. In order to enhance reproducibility of the study we only included original research articles from peer-reviewed journals, therefore grey literature, books (monographs and edited volumes), conference proceedings, dissertations and posters were omitted. English was selected as it is the designated language of the highest number of peer-reviewed academic journals. The search was performed on 24 of January 2020 (see Table 4-1).

Table 4-1: *Search terms*

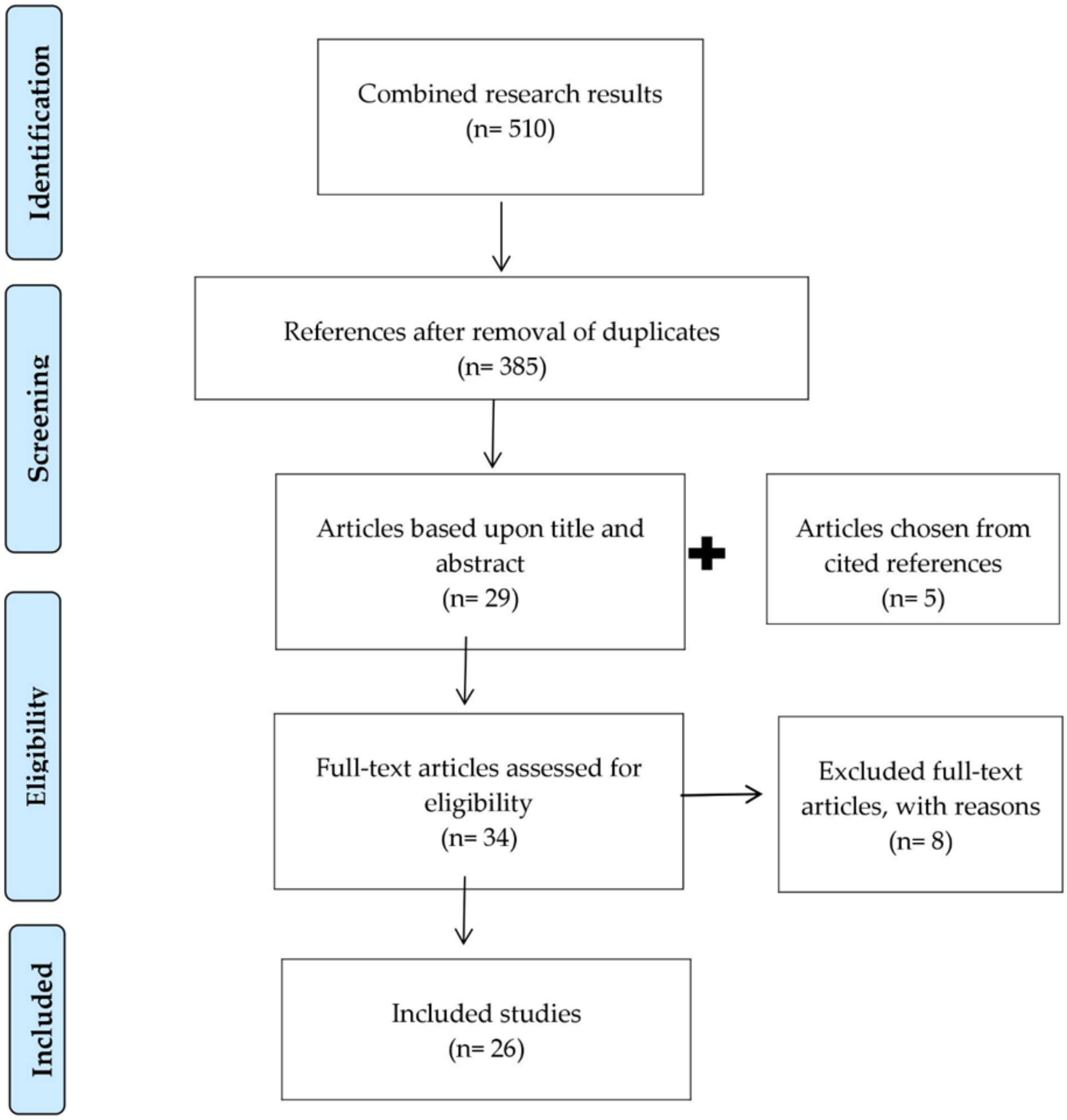
No.	Match search terms	Pub Med	Web of Science	Scopus	Cinahl
1	(“big data” OR “digital data” OR “data linkage” OR “electronic health record*” OR “EHR” OR “digital*” OR “artificial intelligence” OR “data analytics” OR “information technology”)	251,004	4,682,526	1,750,766	67,116
2	(“dentist*” OR “dental*” OR “oral health” OR “orthodont*”)	827,547	1,409,796	613,348	158,231
3	(“ethic*” OR “moral*”)	334,537	582,299	528,738	98,246
4	1 AND 2 AND 3	190	186	71	63

We followed the protocol from the Preferred Reporting Item for Systematic Reviews and Meta-Analyses (PRISMA) method (Moher et al., 2015) which resulted in 510 papers. We scanned the results for duplicates (125) and 385 papers remained. In this phase we included all articles that focused on digitalization of dentistry or on one specific digital technology in the field of dentistry and that mentioned, enumerated, discussed or described one or more ethical challenges related to digitalization. Papers that only described a technology from a technical point of view, that did not focus on dentistry or focused generally on medical practice, or that did not relate to the ethical challenges of digitalization, were excluded. Additional papers (27) were excluded because they were book sections, posters, conference proceedings or not in English. In total, 356 papers were excluded.

We subsequently scanned the references of the remaining 29 articles to identify additional relevant studies. We added five papers through this process. The final sample included 34 articles. During the next phase, the first author read the full texts in their length. After thorough evaluation, eight articles were excluded for the following reasons: 1) they did not discuss or mention any ethical issue related to the technology discussed in the study; and 2) they did not refer to any digital implementation in dentistry (See Figure 4-1).

The subsequent phase of the study involved the analysis of the remaining 26 articles. Regarding data analysis, we carried out a narrative synthesis of included publications (Popay et al., 2006). Therefore, we extracted the following information relevant to the aim of the present study and to the research question from the papers: year and country of publication; methodology; type of technology or digital application discussed; field of application of the article; ethical issues that emerge from the use of the technology; technical issues that might exacerbate the ethical issues discussed; suggested potential solutions to the issue(s); and ethical issues that the technology could help overcome.

Figure 4-1: *PRISMA Flowchart*



4.4 Results

Among the 26 papers included in our analysis, 22 were theoretical papers that critically discussed the impact of digitalization in the field of dentistry or that discussed a specific technology highlighting its promises and some of its ethical challenges. Among the remaining papers, three applied empirical methods and one was a feasibility study. The majority of papers (n=20) were published after 2010, five were published between 2008 and 2010 and one of them was from 1996. Half of the articles (n=13) were from the United States, five came from the UK and four from India. The remaining ones came from Belgium, Brazil, Germany and South Africa. Regarding the type of technological application they discussed, almost one third of the papers (n=8) analyzed digital photography, radiology and computed imaging; six papers discussed the impact of digital communication and social media in dentistry; three articles focused on electronic health records (EHRs) and patient records; another three discussed the promises and challenges of mobile Health and teledentistry; an additional three records focused on data linkage and personalized medicine. In addition, two papers broadly discussed the challenges and promises of ICT and digital implementations in dentistry while one paper focused on search engine optimizations in dental practices. Finally, concerning the field of application of the different papers, 10 articles discussed the ethical issues of digitalization regarding dental practice, nine discussed digitalization and digital application for dentistry without a specific focus, five focused on education and dental school, and two discussed applications in research (See table 4-2).

Table 4-2: *Retrieved Papers*

Author, Year, Country	Design	Participants	Technology Discussed	Field of Application	Ethical Issues
Boden (2008), USA	Theoretical		Digital transfer of patient records	Dental practice	Justice and autonomy- high charges for the patient prevent beneficial use of records for future patient treatment
Calberson et al. (2008), Belgium	Theoretical		Digital radiography	General	Fraudulent use of radiographs
Cederberg and Valenza (2012), USA	Theoretical		EHRs (in dental schools)	Dental school	Justice, patient privacy and security, shift in doctor patient relationship, misconduct from students
Chambers (2012), USA	Theoretical		Digital Communication	Dental practice	Shift in doctor patient relationship, patient privacy and security, professionalism
Cvrker (2018), USA	Theoretical		mHealth	General	Patient access, data ownership, patient privacy and security, bystanders
da Costa et al. (2012), Brazil	Theoretical		Teleorthodontics	General	Patient privacy and security

Day et al. (2018), UK	Feasibility Study	Birth cohort in the UK	Data linkage	Research	Anonymization, data ownership
Eng et al. (2012), USA	Theoretical		Personalized dentistry	General	Discrimination, confidentiality
Gross et al. (2019), Germany	Theoretical		Digitalization in dentistry	General	Shift of doctor patient relationship, data literacy, responsibility and accountability for AI, digital footprint.
Indu et al. (2015), India	Empirical	A sample of postgraduate students and teaching faculties of oral pathology in India	Digital photography	General	Anonymity and security
Jampani et al (2011), India	Theoretical		Teledentistry	General	Confidentiality, patient privacy, security, consent
Kapoor (2015), India	Empirical		Digital photography and radiology	General	Fraudulence, scientific misconduct
Khelemsky (2011), USA	Theoretical		CBCT	Dental practice	Harm to the patient, consent
Knott (2013), UK	Theoretical		ICT	Dental practice	Anonymity, data security, patient privacy
Luther (2010), UK	Theoretical		Digital forensics	Research	Scientific misconduct, fraudulence
Neville and Waylen (2015), UK	Theoretical		Social Media	Dental practice	Shift of doctor patient relationship, patient confidentiality, privacy, anonymity,
Oakley and Spallek (2012), USA	Theoretical		Social Media	Dental School	Shift of doctor patient relationship, patient privacy and confidentiality, miscommunication, boundary violation
Peltier and Curley (2013), USA	Theoretical		Social Media	Dental practice	Dishonest/ unlawful advertising, patient confidentiality
Rao et al. (2010), India	Empirical	A sample of randomly selected clinicians in India	Digital photography	General	Scientific misconduct, fraudulence

Spallek er al. (2015), USA	Theoretical	Social Media	Dental School	Shift of doctor patient relationship, patient privacy and confidentiality, miscommunication, boundary violation
Stieber et al. (2015), USA	Theoretical	Electronic media and digital photography	Dental School	Patient privacy and confidentiality, autonomy and consent
Swirsky at al. (2018), USA	Theoretical	Search engine optimization	Dental practice	Beneficence, autonomy, consent, conflict of interest and undue influence
Sykes et al (2017), South Africa	Theoretical	Social Media	Dental practice	Patient privacy, anonymity confidentiality and consent, professionalism, shift of patient doctor relationship, misleading advertisement
Szekely et al. (1996), USA	Theoretical	EHRs	Dental practice	Patient privacy and confidentiality, security
Wenworth (2010), USA	Theoretical	Digital Radiography	Dental practice	Patient privacy and confidentiality, misleading advertisement
Zijlstra-Shaw and Stokes (2018), UK	Theoretical	Big Data analytics (in dental education)	Dental school	Consent and data ownership

4.4.1 Implementation of digital technologies in dentistry

Two papers generally discussed the ethical implications that ICT and digitalization are introducing in dentistry (Gross et al., 2019a; Knott, 2013). According to Gross et al. (Gross et al., 2019a), digitalization of dentistry is influencing the patient doctor relationship as the integration of digital technologies could distract attention away from the patient during the visit. Issues of data literacy can arise for both the dentist – who will need to constantly be updated on the latest technologies – and the patient – who will need to understand how new technologies work, possibly disfavoring people with poor computer literacy such as the elderly. The application of AI for diagnostic purposes could create issues of responsibility and accountability. A shift might occur towards overtreatment of the patient due to increased demand for the use of digitized systems. In addition, the constant use, refurbishment and replacement of increasingly new technology leaves a remarkable digital footprint and aggravates digital pollution. Finally, digital technologies create issues of data security, data falsification, and privacy issues regarding identifiable patient information (Knott, 2013).

4.4.2. Big Data and data analytics

Nine papers discussed the increased employment of Big Data and data analytics in dentistry related to different applications such as data linkage (Day et al., 2018), data analytics in dental schools (Zijlstra-Shaw and Stokes, 2018), personalized medicine (Eng et al., 2012), EHR (Boden and Amer Dent Assoc Council, 2008; Cederberg and Valenza, 2012; Szekely et al., 1996) and mHealth and teledentistry (da Costa et al., 2012; Cvrkel, 2018; Jampani et al., 2011).

Electronic Health Records (EHRs)

Three papers focused on the implementation of EHRs both in private practices and in dental education (Boden and Amer Dent Assoc Council, 2008; Szekely et al., 1996; Cederberg and Valenza, 2012). Ethical issues that arise from this technology are data security, since sensitive patient information could be more easily accessed by unauthorized third parties, resulting in breach of patient privacy and confidentiality (Cederberg and Valenza, 2012; Cederberg et al., 2015).

In addition, Cederberg and Valenza (Cederberg and Valenza, 2012) argue that the use of digital records might compromise the doctor patient relationship in the future, as easy access to all relevant information through digital means and forced focus on the computer screen could accustom students to becoming more detached from patients.

Suggested solutions for privacy and security issues related to EHR are: a) the implementation of a three zone confidentiality model of medical information for databases both linked (networked) and non-linked (network), where different levels of access and security are put in place for different areas – from a more secured inner area that holds the highest sensitive information about the patients (e.g. HIV status and psychiatric care) to an outer, less secured, area containing generally publicly available information (Boden and Amer Dent Assoc Council, 2008).

mHealth and teledentistry

Ethical concerns related to mHealth and teledentisry – that is the use of information technologies and telecommunications to provide remotely dental care, education and raise oral health awareness – were raised by three articles (Cvrkel, 2018; da Costa et al., 2012; Jampani et al., 2011). As for other Big Data technologies, issues of data security and patient anonymity

(Cvrkel, 2018; da Costa et al., 2012) and confidentiality (Jampani et al., 2011) were the most mentioned as networked transfer through unsecure means could enable unwarranted third parties to obtain more easily access to sensitive patient data.

mHealth might also have an impact on consent both for the patient who might not have been appropriately informed about all of the risks that teledentistry implies (Jampani et al., 2011) and for non-consenting bystanders, whose data might be collected by the device the patient is using (Cvrkel, 2018).

Furthermore, Cvkrel (Cvrkel, 2018), argued that first, mHealth creates additional vulnerability as smartphones gathers additional data that is usually not collected by healthcare practitioners (e.g. fitness data, sleep patterns) and, as it is an object of everyday use it might be easily accessible to unauthorized people. Second, easy access through the smartphone to raw data including data related to dental care, could be counterproductive and harmful for patients who might self-adjust the prescription given by the practitioner.

Among the suggested solutions are: a) the establishment of secured networking communication such as the development of state of the art firewalls and antiviruses to mitigate security concerns in telecommunications (da Costa et al., 2012); b) the formulation of high quality consent processes that appropriately make the user aware of the risks and all relative factors (Cvrkel, 2018); and c) the implementation of information and education about the specific issues that such technology raises for dentists who want to employ teledentistry in their practice.

Personalized medicine and data linkage

In the context of data linkage in dental practices, personalized medicine, and dental schools, the analyzed articles reported how consent issues might arise concerning data usage when the student or the patient cannot be completely informed about the ways in which the collected data is used (Zijlstra-Shaw and Stokes, 2018). Data anonymization (Day et al., 2018) and patient confidentiality (Eng et al., 2012) were again both mentioned as issues of data linkage. Finally, Eng et al. (2012) highlighted how discrimination based on higher risk for specific diseases might appear from the linkage of different databases in personalized medicine.

In order to overcome these issues, Eng et al. (2012) suggested to develop protective measures at both at a legal and a clinical level to ensure patient data confidentiality and security.

4.4.3 Digital communication and social media in dentistry

Seven papers discussed the impact that the employment of digital communication and social media could have upon dental practices and the dentist-patient relationship (Chambers et al., 2012; Neville and Waylen, 2015; Oakley and Spallek, 2012; Peltier and Curley, 2013; Spallek et al., 2015; Sykes et al., 2017; Swirsky et al., 2018).

According to the retrieved studies, one of the main issues is the possibility that commercial values might creep into the management of private practices' websites and official social media pages (Chambers et al., 2012). For instance, digital media broadcasts might deliver a distorted image of the practice resulting in misleading or dishonest advertisement of state-of-the-art dental technologies or dental practices thus exercising an undue influence on patients (Peltier and Curley, 2013; Sykes et al., 2017). In addition, Swirsky (Swirsky et al., 2018) also raised concern regarding unethical search engine optimization, an aggressive marketing technique aimed at making your own website appear before others in popular search engines. This practice creates conflict of interest between, the dental profession and the patient/public.

Furthermore, the introduction of digital communication in dental practices has heavy effects on the dentist-patient relationship. Neville and Waylen (2015) indicate how the use of social media pages is blurring the personal and professional divide. Via social media, patients might have access to information about their dental providers that could compromise the doctor patient relationship and create issues of trust between the two parties. For instance, shared posts and messages of doctors might be misinterpreted by the users (patients) and be considered unprofessional. Likewise, privacy issues might occur in the case where a dentist visits the personal social media page of their patient and uncovers information that the patient did not want to share with them (Oakley and Spallek, 2012; Spallek et al., 2015). In addition, doctor-patient confidentiality could be breached by dentists both willingly and inadvertently, if information about a patient is disclosed online, such as identifiable patient photographs, or sensitive treatment details (Peltier and Curley, 2013; Sykes et al., 2017).

Suggested practices to avoid such issues are the development of adequate social media policies for the use of social media in dental practices and increased education for dental practitioners regarding online professionalism in social media – such as awareness of the ethical issues and of the rules of conduct to be used while using social media (Sykes et al., 2017; Spallek et al., 2015).

4.4.4 Digital photography and radiography

The technology discussed by eight of the collected papers was digital photography and digital radiography (Calberson et al., 2008b; Indu et al., 2015; Kapoor, 2015; Khelemsky, 2011; Luther, 2010; Rao et al., 2010; Stieber et al., 2015; Wentworth, 2010). Among them, four articles (Calberson et al., 2008a; Kapoor, 2015; Luther, 2010; Rao et al., 2010) highlighted that image modification, made easier by digitalization of both dental photography and radiography could result in misconduct in science and fraudulent use of modified pictures. Practitioners could be tempted to modify radiographs to deceive insurance companies (Calberson et al., 2008a) and researchers might do the same to falsify the results of their research (Luther, 2010).

Three papers correlated the ethical issues of digital imagery to digital sharing and storage of images (Stieber et al., 2015; Indu et al., 2015; Wentworth, 2010). For instance, issues of security of data and patient privacy and confidentiality might arise owing to inattentive storage of images (if digital photographs are stored for too long on an SD-card or if images are shared via electronic means such as using emails and smartphones or networking apps as Whatsapp (Indu et al., 2015). In addition, Stieber et al. (2015) indicate how even patient autonomy and consent might be breached if the images are used in an unauthorized manner, such as posting them on a public forum.

Finally, one paper that discussed the ethical issues of digital dental imaging focused on a particular diagnostic technology: cone beam computed tomography (CBCT) (Khelemsky, 2011). Highlighted issues related to this particular technology are related to its routine use potentially causing harm to patients, especially children and adolescents, owing to the excessive exposure to radiation and consent if patients are not appropriately informed about the health risks they are exposed to when undergoing this diagnostic exam.

Some papers also highlighted some potential solutions. Regarding image modification, the application of state of the art anti-forgery techniques was suggested (Calberson et al., 2008a), and also the development of appropriate guidelines to set an acceptable standard for image modification in dentistry (Kapoor, 2015). As for image sharing issues, Stieber et al. (Stieber et al., 2015) suggested the implementation of a privacy compliant framework where informed consent is enhanced in order to give patients more control over how their images are used, while Indu et al. (2015) proposed the use of only custom apps built exclusively for medical data sharing.

4.4.5 Digital dentistry might solve ethical issues

Finally, almost one third of the papers discussed not only ethical issues but also mentioned how some of these technologies could be of assistance to solve ethical issues in dentistry and oral health. For instance, the application of digital technologies could result in empowerment of patients and democratization of oral health knowledge owing to increased and widespread information that could be easily retrieved on the Internet (Gross et al., 2019a; Gross et al., 2019b). mHealth and teledentistry were argued to be powerful tools to a) fight known inequalities in healthcare and provide better treatment and patient care in vulnerable populations thanks to the increased saturation of mobile phones and communication technologies that will allow them easier access to health information and remote treatment (Cvrkel, 2018); b) overcome cultural and geographic barriers in oral health (da Costa et al., 2012); and c) help eliminate the disparities in oral health care between rural and urban communities (Jampani et al., 2011). Provision of information about health care prevention and oral health issues through social media could positively influence and promote oral healthcare (Oakley and Spallek, 2012; Sykes et al., 2017). While the implementation of research through correlation and data linkage between birth cohorts in the UK and oral health habits could ameliorate public oral health issues such as caries prevention for children and adolescent (Day et al., 2018). Finally, digital forensics, that is the digital analysis of images, could help with the recognition of scientific misconduct in dental research (Luther, 2010).

4.5 Discussion

The analyzed literature raised a plethora of intertwined ethical issues across different technologies and practices in dentistry. Numerous issues are in line with the commonly mentioned ethical challenges that digital technologies are introducing in healthcare – privacy anonymity, security and so on. On the other hand, additional aspects emerged for dental medicine – such as commercialization and image forgery – that are usually less associated with digitalization of healthcare and Big Data (Mittelstadt and Floridi, 2016).

The most frequently mentioned ethical issues related to the increased digitalization of dentistry are those related to patient privacy, which is often associated with anonymization and confidentiality. This is in line with a study by Mittelstadt and Floridi (Mittelstadt and Floridi, 2016) that highlighted how this cluster of issues related to patient privacy is the one that is most correlated by scholarly research with Big Data technologies such as data analytics, IOT and social media use. In the era of digitalization, with increased implementation of EHRs and digital data management, issues of privacy become among the most paramount, notably also in dentistry on account of the opportunities for patient treatment development and research offered by data linkage. Important ethical issues could be overlooked if it is assumed that dental health data are less sensitive than, for example, mental health or stigmatizing infectious disease data. On the contrary, dental health data are sensitive for a number of specific reasons. For example, economic or marketing discrimination, that is inequality in pricing and offers that are given to costumers based on profiling, such as insurance or housing (Peppet, 2014), or discrimination based on health data and health prediction (Hoffman, 2010) are practices that are creeping out of the exploitation of digital records and might be exacerbated by the analysis of dental records and the use of mHealth in dentistry.

Informed consent was another issue that was often mentioned by the selected papers, although surprisingly not in relationship to the reuse of EHR data. From an ethical and legal point of view, consent needs to be specific concerning three different activities: use for clinical care; clinical trials where new Big Data technologies are used in dental patients; and secondary use of data for research or other purposes (such as marketing). For use in the clinical setting, issues of informed consent are not so prominent as the EHR would function as a substitute for a paper patient chart, leaving more concerns in the area of data security and patient privacy. However, as Big Data applications for secondary use of EHR data are becoming an increasingly implemented research practice and issues of consent for EHR and Big Data are quite often discussed for the biomedical context (Mittelstadt and Floridi, 2016), more research should be spent in this area for the dental field. In fact, only three retrieved papers focused on EHR, they mostly targeted clinical care, and two of them were from before 2010 - which may explain why they did not consider the implications of Big Data and secondary use of data from health records that are currently causing dilemmas of consent from both an ethical and a regulatory point of view (Ioannidis, 2013; Starkbaum and Felt, 2019). Consent was also briefly mentioned by the retrieved papers in relation to data linkage and personalized medicine, but overall the literature has not sufficiently analyzed the issue data linkage and secondary use of data for dentistry. In fact, electronic dental records increasingly include sensitive and complementary data about the patient, such as automatic tooth charting, general patient health information, development of treatment plans, radiographic captures of the mouth and intraoral photography (Cederberg et al., 2015), that could be linked and analyzed for research and app development purposes without obtaining the appropriate patient’s approval. Cvrkel, (Cvrkel, 2018), in the context of mHealth, suggested deflecting the discussion from privacy concerns to the development of high quality consent practices both for clinical but also for secondary research use. Based on a recent study by Valenza et al. (Valenza et al., 2014), that assessed the benefits of "Smart consent" strategies that take into account patients' preferences and desires regarding both treatment and the use of their dental data, we argue that the implementation of better consent policies and strategies could also be beneficial to electronic dental records in order to face not only privacy issues related to clinical care but also issues of consent related to secondary use of data.

As might be expected, considerable space was given to digital photography and radiology in dentistry. Ethical issues were raised in two directions. First, concerns of patient privacy and anonymity and of data security were highlighted in relation to the storage and sharing of digital images (Stieber et al., 2015; Indu et al., 2015; Wentworth, 2010). These issues are of a comparable nature to those enumerated for EHR, mHealth and teledentistry, which principally have to do with possible access to sensitive patient information by unwarranted parties and interception of digital communications. Interestingly, substantial weight was given to the topic of image forgery. According to the literature, image modification for fraudulent purposes such as insurance fraud and scientific misconduct is described as an expanding practice within dentistry (Rao et al., 2010; Luther, 2010). The main problem is that the introduction of digital imagery in our society has exponentially increased the ease with which digital photographs can be manipulated and changed, both in the early and late stages of image production to a point where essential information about the subject of the image might be falsified (Benovsky, 2014). As a consequence, numerous scholars who focused on the epistemic status of photographs and digital imaging have tried to analyze the challenges that digital imaging poses to the epistemic consistency of images (Benovsky, 2014; Hopkins, 2012; Alcarez, 2015). The question is, in our opinion, whether in the case of image modification in dentistry, a well-defined line can be settled on acceptable modifications that prevent misinterpretation or misreading by the observer, and modifications that would let the image fall in the category of image forgery. Following clear guidelines on the ethics of image modification (Cromey, 2010) could assist practitioners in making the right choices, but might not be enough. Well-intentioned image modification, such as changing the background, modifying light sources, over and under exposure, cropping, color modification and so on might unintentionally alter the epistemic consistency of an image, as the limit of acceptable alterations that digital images can endure while maintaining their epistemic value is vague and undetermined (Benovsky, 2014).

Another interesting finding of this study is that numerous articles – almost one third of the total and all theoretical papers – rather than expanding on the ethical issues that derive from the application of a medical/dental digital technology, focused on how digital communication could have an impact on the practice of dental care itself and on the doctor-dentist relationship. Some of the retrieved papers (Neville and Waylen, 2015; Oakley and Spallek, 2012; Peltier and Curley, 2013; Spallek et al., 2015; Sykes et al., 2017; Chambers et al., 2012), in fact, highlighted how the inappropriate use of social media by dentists could compromise trust between dental practitioners and patients either owing to leakage of confidential information about patients, such as treatment outcomes or identifiable pictures, or displays of inappropriate behavior on their private social media pages. As the use of social media is permeating our everyday life, blurring the line between private and public, social media and online professionalism are topics that have been increasingly addressed in other areas of healthcare as well (Greysen et al., 2010; Ventola, 2014). The ethical challenge here seems to be twofold. First, education regarding the professional use of social media for dental practitioners could be enhanced by the implementation of rules and social media policies that clearly state the dos-and-don'ts of managing a social media page – such as: do not post identifiable pictures of patients without their consent; don't discuss patient treatment on the page and so on (Spallek et al., 2015). However, if breach of confidentiality should occur through inattentiveness, the reach of the leaked information would be greater than in face to face exchanges, expanding exponentially the scale of the mistake (Greysen et al., 2010). Second, it becomes more challenging to implement strategies to appropriately educate dental practitioners about their private social media behavior. It has been argued by Greysen et al. (Greysen et al., 2010) that some online content that might be flagged as unprofessional – such as posts concerning off-duty drinking and intoxication or the advertisement of radical political ideals that might question their professionalism – do not clearly violate any existing principle of medical professionalism, as they are done in the private sphere. In addition, even the interactions that a health practitioner might have with the private social media page of a patient become an intricate matter that might raise ethical dilemmas. By only accessing the page of their patient, the doctor could access private information such as their marital status, sexual orientation, or political orientation that might have an impact, either conscious or unconscious, on the practitioner's personal perception of the patient (FitzGerald and Hurst, 2017). Things become even more complicated if the healthcare professional retrieves posts or photos on social media sites that depict patients participating in risk-taking or health-averse behaviors (Greysen et al., 2010). All of this information might create a fracture in the patient doctor relationship, as implicit bias and conflict of interests might prevent medical practitioners from providing the patient with the best care (Garrison and Ibañez, 2016; FitzGerald and Hurst, 2017).

In addition, another interesting challenge raised by almost all of the papers that discussed digital communication in dentistry was the issue of commercialization and conflict of interest that interfere with patient care. A strong focus of some of the papers was on the possible exertion of undue influence on the patient by producing misleading advertisement for private practices and state of the art dental procedures. As Chambers et al. (Chambers et al., 2012) argue, the dentist-patient relationship should never shift to one of customer-provider and commercial interests should always be in a subordinate position to that of oral health, as the well-being of the patient should always come first. In addition according to the American Dentist Associations' (ADA) Code of Conduct:

> Dentists who, in the regular conduct of their practices, engage in or employ auxiliaries in the marketing or sale of products or procedures to their patients must take care not to exploit the trust inherent in the dentist-patient relationship for their own financial gain […] and no dentist shall advertise or solicit patients in any form of communication in a manner that is false or misleading in any material respect. (McCarley, 2011)

Doing so would negate the patient's right to self-determination and accurate information (Swirsky et al., 2018). As additional technological developments are being increasingly introduced in dental practices, it is of the utmost importance that strong measures are taken to limit commercial interests for dental practice.

In addition, while a substantial number of papers focused on digital photography and radiography, as well as the impact of digital communication for dental practice, this systematic review highlighted some gaps regarding some of the applications that data technologies have in dentistry and the possible ethical issues that might emerge as a consequence. For instance, the implementation of AI applications for diagnostic purposes in dentistry (Joda et al., 2019) or the sophistication of 3D imaging technologies for pre-operative clinical assessment (Joda et al., 2018b) were not discussed in the retrieved literature. In addition, very few of the retrieved papers focused on the increased application of Big Data analytics and data linkage of health-related data. Shetty et. al (Shetty et al., 2018) highlighted how the debate on digital dentistry is reflective of the traditional dental delivery model and usually focuses on micro trends in technology development such as technology-assisted services (e.g., CAD/CAM), digital radiography and electronic patient records. However, trends in the implementations of Big Data technologies such as mHealth, social media, AI and the like, are transforming oral healthcare through social and technical influences from outside the dental profession as it has been seen in relation to the social media use by dental providers. In addition, it has recently been argued that current literature on the topic of digital dentistry has a tendency to focus on its beneficial potentials or on the technical challenges of the discussed technology without appropriately addressing the ethical issues that these technologies might raise (Gross et al., 2019a). Also, our review indicates that while a theoretical discussion on this topic is emerging, empirical studies on the ethical issues of digital implementations in dentistry are largely lacking. As a consequence, owing to the sensitive nature of data included in electronic dental records, the specific digital implementations in dental practice and research, and the gaps in the literature regarding the ethical analysis of some dental applications, it is of the outmost importance to conduct additional research, and especially more evidence-based studies, on the possible specific ethical issues related to the field of digital dentistry in order to appropriately understand and confront these issues.

Finally, only a few papers mentioned ethical issues that could be solved by digital dentistry. In addition to those mentioned in Section 4.4, there are two other contenders for useful applications of Big Data research. It has historically been very difficult to conduct epidemiological research on the relationship (if any) between the public health measure of adding fluoride to water supplies and the incidence of dental fluorosis in children owing to the very high number of variables and confounders involved in such research. Big Data analytics could make sense of this difficult area of research, helping to address the public health ethics of water fluoridation (Shaw, 2012) . Similarly, antibiotic prophylaxis before dental treatment in patients who have undergone heart surgery remains a contentious area, with dentists tending to recommend against it despite heart surgeons supporting the prescription of antibiotics (Shaw and Conway, 2010). Big Data research could help to shed some light on this difficult ethical dilemma.

4.6 Conclusions

Our study highlighted how most of the issues presented for digital dental technologies such as electronic dental records, mHealth and Teledentistry, and developments in personalized medicine, are in line with those mostly discussed in the debate regarding the application of ICT in healthcare, namely patient privacy, confidentiality and anonymity, data security, and informed consent. In addition to those issues, image forgery aimed at scientific misconduct and insurance fraud was frequently reported in the literature. Moreover, the present review identified how major concerns in the field of dentistry are related to the impact that an improper use of ICT could have on the dental practice and the doctor patient relationship. In this context, issues of online professionalism were raised together with issues of aggressive or misleading social media or web. Finally, additional research should be conducted to properly assess the ethical issues that might emerge from the routine applications of increasingly novel technologies.

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Chapter 5 – What is your definition of Big Data? Researchers’ understanding of the phenomenon of the decade

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5.1 Abstract

The term Big Data is commonly used to describe a range of different concepts: from the collection and aggregation of vast amounts of data, to a plethora of advanced digital techniques designed to reveal patterns related to human behavior. In spite of its widespread use, the term is still loaded with conceptual vagueness. The aim of this study is to examine the understanding of the meaning of Big Data from the perspectives of researchers in the fields of Psychology and Sociology in order to examine whether researchers consider currently existing definitions to be adequate and investigate if a standard discipline centric definition is possible.

Methods: Thirty-nine interviews were performed with Swiss and American researchers involved in Big Data research in relevant fields. The interviews were analyzed using thematic coding.

Results: No univocal definition of Big Data was found among the respondents and many participants admitted uncertainty towards giving a definition of Big Data. A few participants described Big Data with the traditional "Vs" definition – although they could not agree on the number of Vs. However, most of the researchers preferred a more practical definition, linking it to processes such as data collection and data processing.

Conclusion: The study identified an overall uncertainty or uneasiness among researchers towards the use of the term Big Data which might derive from the tendency to recognize Big Data as a shifting and evolving cultural phenomenon. Moreover, the currently enacted use of the term as a hyped-up buzzword might further aggravate the conceptual vagueness of Big Data.

> "Big Data is like teenage sex: everyone talks about it, nobody really knows how to do it, everyone thinks everyone else is doing it, so everyone claims they are doing it..."
>
> @Dan Ariely, 2013

5.2 Introduction

Big Data is a term that has invaded our daily world. From commercial applications to research in multiple fields, Big Data holds the promise of solving some of the world's most challenging problems. Also within academics, Big Data is popular in most disciplines, from the social sciences (Salganik, 2019), to psychology (Harlow and Oswald, 2016), geography (Kitchin, 2013), humanities (now also called digital humanities (Ewing et al., 2016)), and healthcare (Andreu-Perez et al., 2015).

The possibility of using increasingly big datasets that have the potential to reveal patterns of individual and group behavior together with the promising beneficial application of data analytics (Mikal et al., 2016) have attracted many researchers. Examples include the development of *smarter hospitals* where predictive analysis of Electronic Health Records (EHR) can identify in real time patients at higher risks for health deterioration or cardiac arrest (Mertz, 2014), and the design of smarter cities projects that involve the use of aggregated data from social media, GPS, radio frequencies and consumer data to improve various sectors of urban living such as transportation, education and energy (Hashem et al., 2016).

Hence, Big Data has become a frequently utilized term in the academic environment as a novel and sophisticated apparatus for research. But this raises the important question: what exactly is meant with "Big Data"?

This study aims to explore how researchers working with state of the art digital research projects in psychology and social sciences understand the term Big Data, in order to a) explore the main characteristics that researchers attribute to Big Data; b) examine whether researchers consider currently existing definitions of Big Data to be adequate; c) investigate if an overarching and straightforward discipline centric definition of Big Data in psychological and sociological research is actually possible and desirable.

The term Big Data is not a recent one. Although Diebold admits that it "probably originated in the lunch-table conversations at Silicon Graphics in the mid-1990s" (Diebold, 2012: 4), its first appearance in the academic literature dates back to the early 2000 in statistics and econometrics, where Big Data was used to describe "the explosion in the quantity (and sometimes, quality) of available and potentially relevant data, largely the result of recent and unprecedented advancements in data recording and storage technology" (Diebold, 2003: 5). Attributed characteristics of Big Data were: *volume* (huge amounts), *velocity* (high-speed processing) and *variety* (heterogeneous data), the so-called 3Vs of Big Data (Laney, 2001).

In the following years, as larger quantities of data became readily available, additional definitions of Big Data were developed, that expanded on the traditional three attributes (Ward and Barker, 2013): from additional Vs such as *veracity* (IBM), *value* (Ishwarappa and Anuradha, 2015) and *variability* (Fan and Bifet, 2013) to other qualities including *exhaustivity* (Mayer-Schönberger and Cukier, 2013), *extensionality* (Marz and Warren, 2015), and *complexity* (Perry, 2017).

Despite their differences, these definitions all highlight that Big Data consists in large amounts of data coming from different sources. The European Commission defines Big Data as:

> large amounts of different types of data produced from various types of sources, such as people, machines or sensors. This data includes climate information, satellite imagery, digital pictures and videos, transition records or GPS signals. Big Data may involve personal data: that is, any information relating to an individual, and can be anything from a name, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer IP address (EU Commission, 2016).

Similarly, in the United States, the National Science Foundation (NSF) refers to Big Data as:

> large, diverse, complex, longitudinal, and/or distributed data sets generated from instruments, sensors, Internet transactions, email, video, click streams, and/or all other digital sources available today and in the future" (NSF-12-499) (National Science Foundation, 2012),
>
> or
>
> data that challenge existing methods due to size, complexity, or rate of availability (NSF-14-543) (National Science Foundation, 2014).

Despite the consensual focal point of these definitions, Big Data continues to be surrounded with conceptual vagueness due to the heterogeneous ways in which the term is used in various contexts (De Mauro et al., 2015). To solve this issue, scholars have tried to propose a standard or mutually agreed upon definition of Big Data. For example De Mauro and colleagues proposed a consensual formal definition where Big Data "represents the Information assets characterized by such a High Volume, Velocity and Variety to require specific Technology and Analytical Methods for its transformation into Value" (De Mauro et al., 2015: 103). In the biomedical context, Baro et al. (2015) define it exclusively by its volume and propose a threshold to over which a dataset qualifies as Big Data.

Other scholars, like Floridi for example, have criticized these traditional "attributes" definitions because they are vague and obscure and do not clarify what the term Big Data exactly means or refers to (Floridi, 2012). Some scholars within the social sciences have suggested to discard the "V features" definitions altogether as these attributes predominantly come from data science and data analytics and are considered too technical. Among them, one has proposed to replace them with 13 "P features" such as *portentous*, *perverse*, *personal*, *political*, *predictive*, etc. (Lupton, 2015). Kitchin and McArdle, argue that V-words and P-words "are often descriptive of a broad set of issues associated with Big Data, rather than characterizing the ontological traits of data themselves" (Kitchin and McArdle, 2016: 2). The authors also claim that volume and variety are not key characteristics of Big Data – only velocity and exhaustivity are – and that the V definition is somewhat false and misleading as there are multiple forms of Big Data that do not share all the same characteristics. Moreover, it has also been argued that, as computational capacities of systems are exponentially increasing with time, it would be "impractical to define a specific threshold for Big Data volumes, because they are relative and they vary by factors, such as time and the type of data" (Gandomi and Haider, 2015: 138), leaving the threshold to be a non-definitive and suggestive measure that is not suitable for a coherent definition.

So despite scholarly effort to narrow down the debate on the definition of Big Data and despite the existence of definitions employed by policymaking and academic bodies, such as the aforementioned definitions from the European Commission and the NSF, there is still no consensus in the literature on a proper definition of Big Data. Moreover, it is unclear to what extent academic researchers working in disciplines that embrace Big Data as a research methodology are aware of and agree with these existing definitions.

The definition of Big Data is an important topic given that Institutional Review Boards (IRBs) and regulatory bodies worldwide are struggling to regulate Big Data research and research projects involving Big Data methods and analytics. The use of growing amounts of personal data and the lack of appropriate guidelines and laws in fact raise important ethical issues (Vayena et al., 2015; Kaplan, 2016). In psychology and sociology in particular, privacy concerns are particularly pressing. For instance the literature has highlighted the issues of linking different digital datasets that on the one hand might lead to valuable research insights but on the other reveal sensitive information about research participants (Boyd and Crawford, 2012); some scholars have underlined the intrinsic tension between ensuring anonymity of research participants and the quality of the data set especially in light of increasingly applied policies for open data sources in academic research (Daries et al., 2014); others have questioned the acceptability of using data from digital spaces (for instance social media) for research purposes without the subjects' explicit consent or awareness (Henderson et al., 2013). Scandals such as Cambridge Analytica (Schneble et al., 2018) and the Facebook Emotional Contagion Experiment (Fiske and Hauser, 2014) have put under the spotlight how poorly regulated research practices might jeopardize public perception of research. Public outrage that followed such scandals has led towards the development of strategies to protect both private users and research participants, both in industry and academic contexts (Schroeder, 2014). However, researchers are still pointing to the lack of support from regulatory bodies when it comes to evaluating increasingly computational research proposals (Vitak et al., 2017; Vitak et al., 2016).

As long as definitions are unclear, laws, regulations and guidelines that are bound to govern Big Data research in these two fields of research are unlikely to be effective, especially if researchers are unaware of the regulatory framework or refrain from defining their research as Big Data research out of fear for regulatory restrictions as it happened with the buzzword "nano" when referring to nanotechnology (Satalkar et al., 2016).

Furthermore, we should not forget that the growing datafication and digitalization of society requires researchers to work together in multidisciplinary teams in order to address the technical, ethical and legal challenges that Big Data research poses (Bone et al., 2016). As communication challenges might arise in collective networks and among different stakeholders if each has their own definition or understanding of the discussed technology, like it happened in other scientific fields (Satalkar et al., 2016), the lack of a shared definition of Big Data might aggravate multidisciplinary communications. For instance if a researcher in the social sciences does not recognize that they are working with Big Data, as they have a particular definition in mind, they might be less likely to promptly and spontaneously approach expert researchers in the field of data protection and data ethics to plan improved strategies for the protection of research subjects that are in line with the standards asked by the specific privacy issues embedded in Big Data research.

For this purpose, we have conducted interviews with researchers from high standing universities both in Switzerland, and the United States. The present study offers an important contribution to the existing literature since it is one of the first studies to examine the opinions of academic researchers on the definition of Big Data in the fields of sociology and psychology.

5.3 Methods

5.3.1 Sampling

The data for this manuscript was collected as part of a larger research project on the ethics of Big Data research. The aim of the overall project was to investigate the ethical and regulatory challenges of Big data academic research in the fields of psychology and sociology in Switzerland. These two disciplines were selected not only because they are at the forefront of using Big Data methodologies in projects that involve human research subjects both directly and indirectly (Metcalf and Crawford, 2016) but also because they are among the most under regulated research fields (Vayena et al., 2015; Fiske and Hauser, 2014). This is especially true for Switzerland, the home country of the project, where Big Data research is challenging the current regulatory framework of academic research projects such as the Federal Act of Data Protection (Weber, 2010) and the Human Research Act (Baeriswyl, 2013).

We conducted 39 semi-structured interviews – 20 in Switzerland (CH) and 19 in the United States (US) – with researchers (professors, senior researchers, or postdocs) involved in research projects using Big Data methodologies in the field of psychology and sociology.

The United States were chosen as a comparative sample country where advanced Big Data research is taking place in the academic context. This instance is supported by the numerous grants that federal institutions, such as the NSF and the National Institute of Health (NIH) have been placing for Big Data research projects for several years (National Science Foundation, 2012; National Science Foundation, 2014; National Institute of Health, 2019)

Participants were selected based on their involvement in Big Data research. For this purpose, we compiled a list of keywords linked to Big Data. The list was compiled by two of the authors while performing a systematic review on Big Data that assisted the identification of the main terms related to Big Data research and technology (Favaretto et al., 2019). The first author then systematically browsed the professional pages of all professors affiliated to the departments of psychology and sociology of all twelve Swiss Universities (ten Universities and two Federal Institutes of Technology) and the top ten US Universities according to the Times Higher Education University Ranking 2018 (accessed on 13.12.2018) and selected those that had these specific keywords appearing in their personal page (See Table 5-1).

Table 5-1: *Keywords for Candidate Selection*

Keywords for Systematic Web Search
1. Big Data
2. Internet
3. Social Media
4. (Data) Linkage
5. Neural Networks
6. Machine Learning
7. Computational/Computer Based
8. Prediction
9. Data Mining
10. Algorithms
11. Data Analytics
12. Deep Learning
13. Profiling
14 Scoring System
15. (Algorithmic) Modelling
16. Network Analysis
17. Informatics/ Bioinformatics

For Switzerland the selection was carried out throughout January/February 2018 and for the US during January/February 2019. Other participants were identified through snowballing. Selection of the sample both through systematic selection and snowballing identified a consistent number of data scientists working on research projects involving data from human subjects in sociology, psychology and similar fields (political science, behavioral science, neuropsychology). They were therefore included in the sample as their profile matched the selection criteria. As this is not a representative sample, since it includes participants only related to the fields of psychology and sociology, we do not seek to generalize from the findings. Instead we are trying to raise awareness about the possible challenges that the use of the term Big Data is generating for research practices internationally.

A total of 194 interview invitations – 50 for Switzerland and 144 for the US – were sent via email. They contained information on the purpose of the study, participant rights, and the significance of the study. If no reply was received, a reminder was sent a week after the first invitation email. A 40% positive response rate for Switzerland and a 13.2% positive response rate for the US was obtained. We reached a sample size of 39 researchers. Regarding saturation, we define it as the point in the analysis where no new codes or themes emerge from the analysis, but only mounting instances of the same codes (Given, 2015; Urquhart, 2012). Our interviews stopped producing new codes after analyzing the seventeenth interview of the Swiss sample and the fifteenth for the US sample, thus reaching saturation. The analysis was carried out until the end of the sample.

5.3.2 Data collection

Interviews were carried out by the first and third author between January 2018 and August 2019. At the time of the interviews, the two authors were doctoral students with respectively a background in philosophy and empirical ethics and geography and computer science. Before starting the interviews, both authors were trained on interviewing skills and took formal methodological courses as part of their PhD education. Once the first pilot interviews were completed, both students received constructive feedback on their performance from two senior researchers in order to ensure the high quality of collected data.

Interviews with Swiss researchers were performed at a time and place chosen by the interviewee (usually at their home University) or via telephone, according to the participants' preference and availability. Interviews with American researchers were carried out via Skype or telephone.

Oral informed consent was sought from all participants prior to the start of the interview and registered upon consent. From an ethical point of view, for minimal risk research involving interviews studies with experts whose data (transcripts or questionnaires) are anonymized, oral consent and active participation are ethically considered sufficient and proportionate. Furthermore, prior to the beginning of the interview phase, we asked for ethics approval to the Ethics Committee northwest/central Switzerland (EKNZ) and we received an exemption letter stating that since in Switzerland interviews with experts (not patients) are outside of the Human Research Act, they do not require ethics committee approval. To make sure that our experts were clearly informed, at the beginning of the discussion the interviewer briefly restated the purpose of the overall study, their role in the project, the confidential nature of the interview and allowed the participants to ask questions.

A semi-structured interview guide was used to conduct the interview, that was built on the experiences of the research team during prior phases of the overall project. The guide was designed through discussion and consensus within the research team after they had the time to gain familiarity with the literature and studies on Big Data research in the fields of the social sciences and psychology, and on the knowledge gained through the conduction of a systematic literature review (Favaretto et al., 2019).

Questions included information about (a) the research projects conducted by the interviewee either prior to or at the time of the interview, (b) the participant's opinion on the use of social media or commercial data for academic research, (c) the researcher's attitude towards Big Data research, (d) the participant's personal understanding of Big Data, (e) perceived ethical, regulatory or technical barriers while conducting the research project, (f) institutional regulatory practices and experiences with Institutional Review Boards (IRBs) or Cantonal Review Boards (ECs) – the latter only for the Swiss participants, (g) the researcher's opinion on data driven research as opposed to theory driven research. Most of the data presented in this paper comes from the questions related to topics (c) and (d), as they deal with the conceptualization, definition and understanding of Big Data. The other topics will be analyzed elsewhere. Table 5-2 illustrates the relevant interview questions for this article.

Table 5-2: *Relevant questions from the interview guide*

Sample questions
Are you currently working on any Big Data research project?
Which one(s) of your research project(s) would you consider as involving Big Data methods or related to Big Data?
What do you think is the main difference between Big Data research and more traditional research in your field?
How would you define Big Data?

The interviews lasted between 35-90 minutes. All interviews were performed in English, being the language commonly used in academia, both for Swiss and American participants. Interviews were tape-recorded and subsequently transcribed verbatim to facilitate qualitative analysis. If participants requested, transcripts were returned to them to check the accuracy of the transcription. Only one participant asked for their transcript back and found no inconsistencies.

The transcripts were successively transferred into the qualitative analysis software MaxQDA (Version 2018) to support the analytic process (Guest et al., 2011).

5.3.3 Data analysis

Applied thematic analysis was used for data analysis. This method aims at analyzing and reporting thematic elements and patterns within the data in order to organize, describe and interpret the dataset in rich detail (Braun and Clarke, 2006). The transcripts were therefore read in full length and independently analyzed by at least two of the members of the research group. This first step of analysis consisted of open ended coding to explore the thematic elements in the interviews. Later on the members of the team came together to confront the independent open ended coding, discuss and sort the identified themes.

Several major themes were identified from this analysis including: regulation of Big Data research, new emerging challenges, collaboration and interdisciplinary approach in digital studies, the understanding of the term Big Data, and attitudes towards Big Data studies.

Understanding and definition of Big Data were chosen to explore since the participants gave many different interpretations of the term. Subsequently, all interviews were analyzed for units of text that related both to the definition of Big Data or to expressions of attitudes or opinions towards the understanding of the term. The units were then sorted into sub-codes referring to different ways of defining or interpreting the term Big Data. This phase was carried out by the first author and checked for consistency and accuracy by the second author. Through constant discussion and comparison between the two researchers the themes were refined and systematically sorted.

5.4 Results

For the study, a total of 39 interviews were performed including 21 sociologists (9 from CH and 12 from the US), 11 psychologists (6 from CH and 5 from the US), and 7 data scientists (5 from CH and 2 from the US). Among them, 34 were professors while 5 were postdocs or senior researchers at the time of the interview.

Of the 39 researchers, 27 explicitly stated that they were working on Big Data research projects or on projects that involve Big Data methodologies. Four participants replied that they were not involved in Big Data research and eight were unsure whether their research could be described as Big Data research (See table 3). A significant difference was found between American and Swiss researchers: among the former, all but one confirmed their affiliation to Big Data research compared to slightly more than half (12 out of 20) of the Swiss respondents. Nevertheless, overall, no significant divergence was found between the two countries with regard to the definition of Big Data. In addition, no considerable dissimilarity was found in the answers based on the research field of the participants, with similar definitions and attitudes equally distributed over psychologists, sociologists and data scientists.

All, but one, participant gave an answer to the question: how would you define Big Data.

Table 5-3: *Demographics*

	Sociology (S)	Psychology (P)	Data Science (D)	Total
CH Researchers	9	6	5	20
US Researchers	12	5	2	19
Professors	20	9	5	34
Postdocs/Senior researchers	1	2	2	5
Participants' self-involvement in a Big Data Project				
Yes	15	6	6	27
No	1	3	0	4
Uncertain	2	5	1	8

5.4.1 Definitions of Big Data

First, some of our respondents initially admitted of not having a definition.

> I don't think anybody really knows but I guess for me I would think that it's…. (P3US-S).
>
> I define it as a...dataset of many features, you know, of...yeah, I don't really…It's funny, I don't really have a definition (P13US-P).

A consistent minority of researchers adopted an “essential definition” of Big Data, one based on attributes or properties, while the majority of respondents supported a more “practical definition”, one that is grounded in the practices or processes related to Big Data such as data collection, data source and data processing.

Table 5-4 illustrates the type of definitions given by our respondents. Some overlaps occur as some participants expressed more than one key definitional trait for Big Data.

Table 5- 4: *Definitions*

Type of definition	Summary/Explanation	Participants
1. Essential definition based on attributes/properties		
1.1 Several Vs definition	Definition based on the traditional attributes of Big Data (Volume, Velocity, Variety, Veracity …)	P27CH-D; P29CH-D; P32CH-D; P33CH-S; P35CH-S.
1.2 Volume	Vast amounts of data	P39CH-S; P2US-S; P9US-S; P13US-P; P14US-P; P17US-P; P20US-S
1.3 Variety	Heterogeneous data, both structured and unstructured	P30CH-S; P34CH-D
1.4 Complexity	Very complex data compared to data that is traditionally collected in research	P5CH-S; P19US-S
1.5 Impact	Data that has a huge impact and value for society	P21US-S
2. Practical Definitions		
2.1 Source of Data	Data that comes from digital technologies	P25CH-P; P26CH-P; P23CH-S; P2US-S; P22US-P
2.1.1 The Human Component	Data that is generated from people	P22CH-P; P24CH-P; P37CH-S; P38CH-S P11US-P; P12US-S; P17US-P; P19US-S;
2.3 Collection	Data collected with no purpose or with no informed consent	P9CH-P; P24CH-P; P26CH-S P30CH-S; P31CH-D; P38CH-S; P3US-S; P4US-P; P5US-S;
2.4 Data Processing	Data that needs sophisticated computational processes to be analyzed	P30CH-S; P37CH-S; P2US-S; P6US-S; P16US-S; P18US-D; P19US-S; P34CH-D
2.5 Problem Solving Tool	Method that is capable of answering questions	P28CH-S; P29CH-D; P30CH-S; P31CH-D; P8US-D;

Essential definition based on attributes/properties

Only a few respondents referred to the traditional “several Vs” definition of Big Data: “We have big volume, we have big velocity, right? We have this kind of three V: Volume, Velocity and Variety” (P29CH-D). Some of them, used these dimensions to illustrate the many technical challenges that Big Data technologies raise.

> I like the definition of the several Vs to sum it up. Big Data is simply all those data issues for which you cannot use a standard database. Right so whenever you have a problem with data and it cannot be solved with a relational database than it's a Big Data problem. (P27CH-D)

There was no agreement among the interviewees on the number of dimensions to attribute to Big Data. One respondent acknowledged that it is uncertain how many dimensions are actually attributed to Big Data: “You know, there are always these different Vs, the 3 Vs, the 5 Vs, the 7 Vs, or whatever the 15 Rs. I don't know there's so many definitions…” (P23CH-S).

Some participants chose to describe Big Data by referring to only one of its dimensions. Of these, volume was mentioned most often, with “Big Data as being a big sample size” (P13US-P) or “Huge amounts of data usually from multiple sources” (P14US-P). Some researchers expressed the idea of a sort of undefined threshold which needs to be crossed in order for the Big Data status to be conferred: “I mean one definition is like, it's data that's too big to fit on one hard drive, or too big to be loaded on the RAM of a single machine.” (P17US-P).

However, a couple of respondents pointed out that volume or size alone are not enough to define a dataset as Big Data: “I think of Big Data studies...I realize the term focuses on the size of the dataset but I actually think of it more as the way the data are...how the data come about” (P26CH-S)

While volume was mentioned most frequently, some respondents highlighted other key characteristics such as variety or complexity :

> Actually the very big part of practical work with Big Data in our context is what is sometimes referred to the variety characteristic of Big Data. So you have many sources, data comes in all kind of different formats, forms. (P30CH-S)

> Data that…complex data that you find out there compared to data that you have collected for a specific observation or experiment or so. (P5US-S)

Finally, one participant circumscribed the definition of Big Data to its overall impact or value on research and society.

> Big Data, I think to me it's more related to how big is the impact of that data. I know that is controversial. Like in research you have certain definitions that are different. I feel that's very fluid, you could have tons of data and then this data has almost no impact and the researchers do not call that Big Data. (P21US-S)

Practical definitions

Most respondents, instead of focusing on the attributes ascribed to Big Data, identified some of the practical processes, such as data collection and data processes, as determinant components for the definition of Big Data.

Source of data

For some participants the source of data was a key factor of the definition. Some spoke for example of digital data coming from technological devices:

> […] but then my internal definition is that...it has to be...it has to draw on some kind of digital data and the analysis has to be digital in some kind of way" (P2US-S)

> Well, so Big Data are data that are generated by people when they use different technological devices" (P25CH-P).

The human component of Big Data sources

A consistent number of researchers highlighted the human component and defined Big Data as data generated by people during their daily activities:

> What I would probably say more classical Big Data as that when you have like a lot of... people with a lot of data points coming out of...observed situations, so...like computer behavior or like the step counts from your iPhone or the sort of that...that's more the macro perspective perhaps (P22CH-P).

One researcher directly referred to a specific "official" definition delivered by an academic body:

> I go with the definition that is advanced here in the United States by the National Science Foundation, that Big Data is the accumulation, use, assimilation and synthesis of multi-modal, multi-leveled, multiple types of data in real-time so as to allow deep and vast analytics that are both current, retro- as well as prospective. (P11US-P)

Within this context, some participants stated that Big Data offers traces of the real world or mirrors reality because it shows how people spontaneously behave. Others however argued that Big Data only gives a limited and sometimes incorrect representation of reality:

> We try to understand the reality. And data is just one aspect of the reality, it does not reflect all reality. A typical example is that people have two phones. And so if you try to estimate the number of people travelling somewhere and you actually calculate the number of phones you need to correct for that. And if you talk to people in machine learning they just don't care about it. For their analysis the universe is the dataset. You see? (P38CH-S)

A couple of researchers downplayed the human component by stating that Big Data is just another data structure, and not necessarily linked to the individuals producing that kind of data:

> I've never done a Big Data project that I've did the data collection on. […] So by the time the data gets to me it just looks like data. So yeah, it's Big Data but it's data that I … you know, it's big in that sense and it has a lot of rows, a lot of columns...but it's you know, to me it's you know, it just looks like data. […] So yeah, for me it's just another...another data structure. (P3US-S)

One researcher waned against understanding of Big Data as just "data" and expressed the need for critical reflection in the humanities to safeguard the people behind the dataset:

The data are also about people (…) This is really a fundamental ethical challenge to all of the social sciences and also social science history and the humanistic, digital humanities as well...the challenges for a deep rethinking, not one that refuses these new tools...but really takes on board the fact that this kind of data organizes, potentially reorganizes the entirety of the academic fields, and beyond actually. […] This is a big issue. (P19US-S)*Collection*

Another key feature linked to the definition of Big Data were the procedures of data collection, in particular to the absence of purpose or informed consent.

> And it's often the case with Big Data, right? You're often analyzing data that weren't originally generated for the purpose of research and now you want to use it for that purpose (P4US-P).
>
> In my view Big Data is datasets which are generated from people's behavior without their informed consent (P9CH-P).

Data processing

A substantial number of respondents mentioned the typology of data analysis procedures as one of the components of the definition of Big Data. Within this view, Big Data was seen as challenging data that necessitate specific algorithmic or computational processes.

> I've been defining it in sort of practical terms as data that require, you know that are in such as scale that they require some algorithmic operation on them to reduce the complexity in a format that makes it possible for you to analyze them. (P6US-S)
>
> I would define it data which is hard to handle. Very generally. For the practitioner. (P30CH-S)

Problem-solving tool

Finally, some researchers expressed the opinion that one of the key components of the definition of Big Data is its pragmatic capacity of acting as a tool for answering questions and solving problems in a timely manner:

> How easy it is to ask any question to the data that you have available. And ... the more...your approach, (…) is a Big Data approach, the easier it is to answer all kinds of questions with your approach. So a good Big Data approach helps you find answers with your own data. (P31CH-D).
>
> Well I guess Big Data is this belief in the possibility of answering old questions or maybe new questions by just … well, by aggregating and then analyzing newly available large data sources. (P28CH-S)

5.4.2 Attitudes towards Big Data

Some of the respondents, also expressed an attitude towards the concept of Big Data either in addition to the definition or as a replacement of it.

The problem of conceptual confusion

Various respondents pointed to the conceptual unclarity that surrounds the term Big Data. Especially with regards to the research environment, a couple of researchers attributed this to the various ways in which the notion is used across disciplines

> I think that every discipline would think of it differently so... in (*specific subfield of physics*) we always thought that we work with Big Data in the sense of very large datasets that need to be managed, you know, with a lot of resources. And we have a lot of complexity in that sense, right? The term though, seems to be more often applied

> to datasets that come from society...come from new tools and applications and instruments and society, that are just collected constantly, right? (laughs) So… it's a little bit different to the way that we were thinking about it from (*specific subfield of physics*) point of view. (…) it [the definition] depends on the context, you might refer to something different… (P5US-S).

Due to this lack of conceptual clarity, a few researchers were reluctant to use the term Big Data: "I think it isn't a useful term because I think it confuses people (P13US-P)".

Rather than something "useful", various participants considered Big Data to be a popular buzzword, a cultural product of our life-world rather than a material entity:

> This fuzziness is kind of interesting in itself because it kind of says something about the cultural moment we live in where everything potentially can be described, not everything, but many things can be described as Big Data, right? (…) it says some things about how present these new technologies or new ways of analyzing the world are in our daily life. (P2US-S).

On this note, a few researchers highlighted how, especially within academics, Big Data is used to draw attention of funding agencies or research institutes:

> There's also like a cynical answer about what Big Data is: whatever gets you funding (P17US-P)
>
> You see it in different levels, you also see it when you have positions advertised. Because Universities and departments see it as a drawback if they don't have anyone doing kind of Big Data research. Very often new positions advertised will include that we're specifically looking for somebody who's doing this kind of research. How this research is being done...that's not something they're interested in. They just see the need to be part of the hype as it were. (P37CH-S)

One participant believed that the conceptual confusion surrounding the term could be overcome if researchers stopped calling their work "Big Data" and started using specific subcategories (e.g. crowd sourcing, social media etc.).

> I think it's important to not look at Big Data as ah "ok, you're working on Big Data". Because it's still like a huge world, that you are working on. So I understand the application is Big Data but it's nice that one goes beyond that. And like for example when talking with people who really work on crowd sourcing or social media, I think it would be really helpful when it comes to this kind of topic. (P29CH-D)

One of the researchers, however believes that compared to the past, the meaning of Big Data is becoming clearer thanks to its increased use both by experts and laypeople. To explain what he meant the participant referred to the philosophical concept of "language games", developed by Ludwig Wittgenstein, for whom the meaning of a word is conferred by its use within the activity of spoken and written language (Wittgenstein, 2009):

> So like anything else, sort of a "Wittgenstein word game", you know? … as we use the word more, the meaning of the word becomes more apparent and also evolves given the actuality of this use. So, when we started to talk about Big Data ten years ago, twelve years ago, … it was relatively amorphous and there were certain vagaries of what actually constituted a Big Data approach (P11US-P).

Another participant expressed this increasing understanding of what Big Data is as follows: "I think it's like pornography, you know it when you see it." (P6US-S).

However, only one researcher expressed the belief that there is consensus among researchers in the way that the term is used and understood.

> I think there's becoming more of a general consensus of an operational definition of Big Data as the term is being used more frequently. We understand what Big Data means. I mean I think there are a number sub-definitions that are possible. But I think that an overarching or undergirding definition of Big Data is probably pretty uniform at this point. (P11US-P)

A couple of participants even asserted that Big Data is not a new concept, but that researchers have been dealing with the technical challenges of Big Data for many years:

> But the concept of Big Data has been around forever. As I said it depends on your resources. You know, so when you have more information than you have resources that's Big Data. So from the very beginning we've been working on problems with Big Data. (P8US-D)

Still, one of the researchers pointed out that, despite its longevity, Big Data is still a concept that brings novelties that need to be grasped by those working in the field:

> But again it's not because they put new names on existing concepts that there is nothing new in what they do, right? (P38CH-S)

5.5 Discussion

Due to the regulatory and multidisciplinary challenges that Big Data is introducing in academic research, there is currently the need to explore the meaning of Big Data to facilitate the development of regulatory frameworks and that of collective research networks. This study aims to contribute to the debate on the definition of Big Data by offering a unique insight into the understanding of and attitudes towards Big Data among American and Swiss based researchers in psychology and sociology. As both Swiss and US research institutions fulfill high internationally recognized standards, we argue that their answers reflect current international discussions in this field

The study results show that, although there was no consensus among the participants on the interpretation or definition of Big Data, some important overlaps among different definitions could be found. Taking these into consideration there was substantial agreement among researchers in defining Big Data as huge amounts of digital data produced from technological devices that that necessitate specific algorithmic or computational processes in order to answer relevant research questions.

In spite of this agreement, researchers also reported a high amount of uncertainty and uneasiness in pinning down the term Big Data with an overarching standard definition. In the following discussion we will analyze the adequacy of the different definitions and attitudes given by our respondents in light of the literature and the issues related to ambiguities of the definition of Big Data.

Despite the fact that in the academic literature (Ishwarappa and Anuradha, 2015; Gandomi and Haider, 2015; De Mauro et al., 2015; Oussous et al., 2018; Ward and Barker, 2013) and popular media (IBM; Perry, 2017; SAS Institute) Big Data is often referred to by the several Vs definition, most of the participants in our sample did not consider this definition to be really adequate as few participants used such a definition.

In addition, even the respondents that did do so, struggled in circumscribing Big Data to a precise number of characteristics either giving a generic answer related to the "several Vs" or mentioning just one specific characteristic. This difficulty to narrow down the attributes of Big Data might come from the fact that, as the phenomenon grew in popularity, an exponentially increasing number of different features were attributed to it – "*versatility*, *volatility*, *virtuosity*, *vitality*" (Uprichard, 2013), *exhaustivity* (Mayer-Schönberger and Cukier, 2013), *extensionality*

(Marz and Warren, 2015) to quote just a few – leading to confusion regarding to what are the essential characteristics of Big Data.

This may explain why most of the participants preferred a definition that was grounded in practice (e.g. data source, data collection, data processing etc.). Some of these more "practical" definitions were similar to those described in the literature. For instance, the ones that focused on data processing, showing how some of the participants associated the definition of Big Data with the purpose for which the data is used, namely Big Data analytics (Katal et al., 2013), are in line with studies that emphasize the computational needs behind the processing of large amounts of data as one of the components of the definition (Ward and Barker, 2013; Dumbill, 2013). On the other hand, responses that focused on data sources are the ones that are closer to the official definition of the European Commission (2016) and the National Science Foundation (2012), that identify Big Data as large amounts of different type of data from different sources – emails , sensors, credit cards etc.

However, only one researcher explicitly referred to a definition of an official body, namely that of the National Science Foundation (2012; 2014).

The wide variety of definitions found among researchers of our sample is probably due to the fact that the term Big Data has not undergone a linear and systemic evolution but has found its meaning as a consequence of its heterogeneous utilizations in different contexts, both academic and industry related (De Mauro et al., 2015).

The existence of several different definitions has led to conceptual uncertainty which in turn has caused some of our respondents to reject the term altogether. This skepticism is reflected in our data as several participants admitted not having an appropriate definition for Big Data or avoided the term as much as possible – although many of them stated that they were involved in Big Data research.

This reluctance to pin down a definition or to use the term Big Data, highlights the *implicit* need to adopt a more flexible understanding of the concept of Big Data. Some researchers in fact associated Big Data with a socio-culturally evolving concept rather than with a precise fixed entity or referred to the various different disciplines in which the term is currently used. Being a culturally driven buzzword, it might not be in the nature of Big Data to have a standard definition.

Moreover, it is especially thanks to the fact that Big Data is a flexible and cluster concept that it has been able to attract researchers from various disciplines. However, due the lack of a unanimous definition, researchers might have a different understanding of Big Data, thus deteriorating the state of interdisciplinary collaboration. Although this concern was voiced by one of the participants, it was not confirmed by our research results as there were no big differences among the answers of researchers from psychology, sociology and data science with regard to the definition of Big Data. Even though the commonality of responses across the various disciplines might be attributed to the fact that most researchers were from the social sciences and other very similar disciplines, it might highlight a presumed (rather than an actual) incommensurability among disciplines.

However, as policymaking bodies are currently struggling in properly developing guidelines and regulations for Big Data (Vayena et al., 2015; Kaplan, 2016), the lack of clarity in definitions might aggravate the endeavors of IRBs worldwide as it might become difficult to strategize overarching research guidelines and regulations that could support researchers in conducting their work especially in our field of investigation namely psychology and the social sciences.

As digital technologies are becoming more and more entwined with people's personal characteristics, their daily actions and future opportunities, Big Data research creates pressing ethical and societal issues such as privacy and data anonymity (Daries et al., 2014; Francis and Francis, 2014), respect for personhood and personal identity (de Vries, 2010), discrimination (Barocas and Selbst, 2016; Favaretto et al., 2019), and informed consent (Ioannidis, 2013; Xafis, 2015). It is therefore of the utmost importance that scholars and regulatory bodies are aware of the harm that could be inflicted on research participants and that sustainable regulations are put in place. This might explain why the human component has become one of the main focusses of definitions of Big Data given by policymaking bodies (e.g. EU Commission 2016) (EU Commission, 2016) and academic researchers (Hoover et al., 2016).

A finding that is very relevant for policy making is that many of the researchers in our sample described Big Data as personal data, or, in general, data that keeps some sort of bond with the person from whom the data was gathered. Only two researchers pointed out that they were working just with data and not with research subjects.

The acknowledgment that Big Data are personal data shows that our participants are aware of and attentive to the possible harms that could come to research if their data is not analyzed or collected properly. In fact, two researchers explicitly identified Big Data with a concern about the lack of informed consent.

Our participants' focus on data as personal data and their awareness of the need for strategies to protect research subjects in Big Data research shows that the avoidance of the term Big Data cannot be attributed to the fear of over-regulation but seems to come exclusively from the feeling of conceptual vagueness surrounding the term. This finding is in contradiction with other studies on the definition of newly developed research technologies such as nanotechnology and biobanks which have shown that avoidance of the term is often associated with scholars fears of stricter regulations upon their research (Satalkar et al., 2016; Shaw et al., 2014). In our study we found no indication of such an attitude.

Finally, a couple of researchers also highlighted that within the academic milieu Big Data is often used to attract funding from external agencies for research purposes. It is important to remember that computational social sciences (Lazer et al., 2009) and digital humanities (Ewing et al., 2016) were born thanks to the increased digitalization of society and that Big Data has constituted an important methodological challenge for a large number of "traditional" disciplines in the past years (Uprichard, 2013). While we highly recognize the potential opportunities that Big Data methods are offering to multiple research fields (Harlow and Oswald, 2016; Kitchin, 2013; Mikal et al., 2016; Mertz, 2014; Hashem et al., 2016; Salganik, 2019), the exaggerated hype for Big Data research might have also negative consequences. On the one hand, it might detract from the pressing ethical concerns that Big Data is introducing both in society and in research (Francis and Francis, 2014; Barocas and Selbst, 2016; Rothstein, 2015; Mittelstadt and Floridi, 2016; Mittelstadt et al., 2016) because of the increasingly bigger promises of beneficial applications that it is offering. On the other, such hype might also aggravate the ambiguity of the term, as it is used as a catch-all to grab the attention of the listener.

In conclusion, the current flexible cultural meaning of Big Data that researchers in the fields of sociology and psychology are making use of might exacerbate the difficulty of clearly defining the term. As Kitchin and McArdle (2016) interestingly note, not all Big Data share the same characteristics and there are multiple forms of Big Data – as there are of small data. This is an instance highlighted also by a couple of our respondents who argued that Big Data in its current cultural meaning it's a tremendously vast concept that includes different subcategories and specifics that are characterized by different technical and regulatory challenges.

5.6 Limitations

First, since our respondents were mainly from the fields of psychology and sociology, the study has overlooked the perspectives of other disciplines relevant for Big Data research, for instance medicine, nursing sciences, statistics, geography, architecture and so on. In addition, the researchers from the field of data sciences that we interviewed were strictly connected to research projects in the fields of the social sciences and psychology. Moreover, due to the interdisciplinary nature of Big Data research, it has been difficult to straightforwardly pinpoint the background of some of the researchers, as many of them have gone through a multidisciplinary academic carrier that qualifies them as experts in more than just one field of research (for instance both social sciences and data science). Finally, it must be acknowledged that the findings from this analysis are not generalizable to the understanding of Big Data of researchers in general, as they are based on only a small portion of researchers from only two disciplines. We therefore argue that more research that takes into account additional disciplines might contribute in delivering a more general picture of what is the researchers' understanding of Big Data. However, as this is, to the best of our knowledge, one of the first studies that analyses this topic from the perspective of expert academics working in the field, we feel that it is an important contribution towards the conceptual clarification of the term Big Data.

5.7 Conclusions

Big Data is an interdisciplinary field that requires the connection of different disciplines and the involvement of heterogeneous research skills in order to carry out projects that fully exploit the methodological novelties that Big Data is bringing to the academic environment (Hu and Zhang, 2017). The traditional V's definition of Big Data was not deemed adequate by our research participants who preferred a more practical definition.

Even though most of the researchers used the term Big Data to describe their research projects, we identified an overall uncertainty or uneasiness towards the term itself. This finding might be a symptom of the tendency to recognize Big Data as a shifting and evolving cultural and scholarly phenomenon - or a cluster concept that include a plethora of sophisticated and evolving computing methodologies – rather than a clearly defined and single entity, or methodology.

We argue that assuming Big Data as a cultural evolving concept, and therefore the lack of a formal definition, does not come without issues. As Big Data is currently raising many important ethical concerns, conceptual clarity of the term Big Data would be of the outmost importance in order to strategize appropriate guidelines to protect research subjects in Big Data research in different disciplines. The use of the term Big Data as a hyped-up buzzword that is currently enacted in the academic and commercial environment might further aggravate the conceptual vagueness of Big Data.

In order to correctly capture the essence and characteristics of Big Data, it might be necessary to deconstruct or unfold the term into its different constituents, thus shifting from broad generalities to specific qualities relevant not only for scientists, but also for ethics committees an regulators. However, since to the best of our knowledge, only Kitchin and McArdle (2016) have proposed this shift to a more nuanced analysis of the concept of Big Data aimed at unpacking its characteristics, we claim that more research should urgently go into this direction to gain conceptual clarity about what Big Data actually means.

5.8 Abbreviations

EHR (electronic health record) – EU (European Union) – NSF (National Science Foundation) – IRB (Institutional Review Board) – CH (Switzerland) – US (United States) – EC (Cantonal Review Board) – HRA (Human Research Act) – NIH (National Institute of Health).

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Chapter 6 – First do no harm: an exploration of researchers' ethics of conduct in Big Data behavioral studies

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6.1 Abstract

Research ethics has traditionally been guided by well-established documents such as the Belmont Report and the Declaration of Helsinki. At the same time, the introduction of Big Data methods, that is having a great impact in behavioral research, is raising complex ethical issues that make protection of research participants an increasingly difficult challenge. By conducting 39 semi-structures interviews with academic scholars in both Switzerland and the United States, our research aims at exploring the code of ethics and research practices of academic scholars involved in Big Data studies in the fields to psychology and sociology to understand if the principles set by the Belmont Report are still considered relevant in Big Data research. Our study shows how scholars generally find traditional principles to be a suitable guide to perform ethical data research but at the same time they recognized and elaborated on the challenges embedded in their practical application. In addition, due to the growing introduction of new actors in scholarly research, such as data holders and owners, it was also questioned whether responsibility to protect research participants should fall solely on investigators. In order to appropriately address ethics issues in Big Data research projects, education in ethics, exchange and dialogue between research teams and scholars from different disciplines should be enhanced. In addition, models of consultancy and shared responsibility between investigators, data owners and review boards should be implemented in order to ensure better protection of research participants.

6.2 Introduction

Big Data methods have a great impact in behavioral sciences (Lazer et al., 2009; Salganik, 2019; Chen and Wojcik, 2016), but challenge the traditional interpretation and validity of research principles in psychology and sociology by raising new and unpredictable ethical concerns. Traditionally, research ethics have been guided by well-established reports and declarations such as the Belmont Report and the Declaration of Helsinki (Department of Health Education, 2014; World Medical Association, 2001; Paxton, 2020). At the core of these documents are three fundamental principles – *respect for persons*, *beneficence*, and *justice* – and their related interpretations and practices, such as the acknowledgment of participants' autonomous participation and the need to obtain informed consent, minimization of harm, risk benefit assessment, fairness in distribution and dissemination of research outcomes, and fair participant selection (e.g. to avoid additional burden to vulnerable populations) (Hargittai, 2015).

As data stemming from human interactions is more and more available to scholars, thanks to a) the increased distribution of technological devices, b) the growing use of digital services, and c) the implementation of new digital technologies (Boyd and Crawford, 2012; Lynch, 2008), researchers and institutional bodies are confronted with novel ethical questions. These encompass harm, that might be caused by the linkage of publicly available datasets on research participants (Mittelstadt and Floridi, 2016), the level of privacy users expect in digital platforms such as social media (Buchanan et al., 2011), the level of protection that investigators should ensure for the anonymity of their participants in research using sensing devices and tracking technologies (Daries et al., 2014), and the role of individuals in consenting in participating in large scale data studies (Ioannidis, 2013).

Consent is one of the most challenged practices in data research. In this context subjects are often unaware of the fact that their data is collected and analyzed and lack the appropriate control over their data, preventing them the possibility to withdraw from a study, that allows for autonomous participation (Xafis, 2015; Henderson et al., 2013). When it comes to the principle of *beneficence*, Big Data brings about issues with regard to the appropriate risk-benefit ratio for participants as it becomes more difficult for researchers to anticipate unintended harmful consequences (Boyd and Crawford, 2012). For example, it is increasingly complicated to ensure anonymity of the participant as risks of re-identification abound in Big Data practices (Daries et al., 2014). Finally, interventions and knowledge developed from Big Data research might benefit only part of the population thus creating issues of *justice* and fairness (Mittelstadt and Floridi, 2016); this is mainly due to the deepening of the digital divide between people who have access to digital resources and those who do not, on the basis of a significant number of demographic variables such as income, ethnicity, age, skills, geographical location and gender (Hargittai, 2019; Mittelstadt and Floridi, 2016).

There is evidence that researchers and regulatory bodies are struggling to appropriately address these novel ethical questions raised by Big Data. For instance, a group of researchers based at Queen's Mary University in the UK used a model of geographic profiling on a series of publicly available datasets in order to reveal the identity of famous British artist Banksy (Hauge et al., 2016). The study was criticized by scholars for being disrespectful of the privacy of a private citizen and their family and a deliberate violation of the artist's right of and preference for remaining anonymous (Metcalf and Crawford, 2016). Another example is the now infamous case of the Emotional Contagion study. Using a specific software, a research team manipulated the News Feeds of 689,003 Facebook users in order investigate how "emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without their awareness" (Kramer et al., 2014). Ethics scholars and the public criticized this study because it was performed without obtaining the appropriate consent from Facebook users and it could have cause psychological harm by showing participants only negative feeds on their homepage (Shaw, 2016; Caplan and Seife, 2014).

Given these substantial challenges, it is legitimate to ask whether the principles set by the Belmont Report are still relevant for digital research practices. Scholars advocate for the construction of flexible guidelines and for the need to revise, reshape and update the guiding principles of research ethics in order to overcome the challenges raised in data research and provide adequate assistance to investigators (Vitak et al., 2016; Anabo et al., 2018; Markham and Buchanan, 2012).

As ethics governance of Big Data research is currently at debate, researchers' own ethical attitudes influence significantly how ethical issues are presently dealt with. As researchers are experts on the technical details of their own research, it is also useful for research ethicists and members of ethical committees and Institutional Review Boards (IRB) to be knowledgeable of these attitudes. Therefore, this paper aims to explore the code of ethics and research practices of behavioral scientists involved in Big Data studies in the behavioral sciences in order to investigate perceived strategies to promote ethical and responsible conduct of Big Data research. We have conducted interviews with researchers in the fields of sociology and psychology from eminent universities both in Switzerland and the United States, where we asked them to share details about the type of strategies they develop to protect research participants in their projects; what ethical principles they apply to their projects; their opinion on how Big Data research should ideally be conducted and what ethical challenges they have faced in their research. The present study aims to contribute to the existing literature on the code of conduct of researchers involved in digital research in different countries and the value of traditional ethical principles (Vitak et al., 2016; Xafis, 2015; Anabo et al., 2018) in order to contribute to the discussion around the construction of harmonized and applicable principles for Big Data studies. This manuscript aims at investigating the following research questions: 1) what are the ethical principles that can still be considered relevant for Big Data research in the behavioral sciences; 2) what are the challenges that Big data methods are posing to traditional ethical principles; 3) what are the investigators' responsibilities and roles in reflecting upon strategies to protect research participants.

6.3 Methods

This study is part of a larger research project that investigated the ethical and regulatory challenges of Big Data research. We decided to focus on behavioral sciences, specifically phycology and sociology, for two main reasons. First, the larger research project aimed at investigating the challenges introduced by Big Data methods for regulatory bodies such as Research Ethics Committees (RECs) and Institutional Review Boards (IRBs) (Favaretto et al., 2020a). Both in Switzerland and the United States, Big Data research methods in these two fields are questioning the concept of human research subject – due to the increased distance and detachment between research subjects and investigators brought by digitalized means for data collection (e.g. social media profiles, data networks, transaction logs etc.) and analysis (Metcalf and Crawford, 2016). As a consequence current legislation in charge of regulating academic research, such as the Human Research Act (HRA) (2015), the Federal Act of Data Protection (Weber, 2010) and the Common Rule (Metcalf and Crawford, 2016), is being increasingly challenged. Second, especially in Switzerland, behavioral studies using Big Data methods are at the moment among the most underregulated types of research projects (Rothstein, 2015; Vayena et al., 2015; 2015). In fact, the current definition of human subject leaves many Big Data projects out of the scope of regulatory overview despite the possible ethical challenges they pose. For instance according to the HRA research that involves anonymized data from research participants does not need ethics approval (2015).

In addition we selected Switzerland and the United States to recruit participants: Switzerland, where Big Data research is a quite recent phenomenon, was chosen because the study was designed, funded and conducted there. The United States were selected as a as a comparative sample, where advanced Big Data research has been taking place for several years in the academic environment, as evidenced by the numerous grants placed for Big Data research projects by federal institutions, such as the NSF (2012; 2014) and the National Institute of Health (NIH) (2019).

For the purpose of our study we defined Big Data as an overarching umbrella term that designates a set of advanced digital techniques (e.g. data mining, neural networks, deep learning, artificial intelligence, natural language processing, profiling, scoring systems) that are increasingly used in research to analyze large datasets with the aim of revealing patterns, trends and associations about individuals, groups and society in general (Favaretto et al., 2020b). Within this definition we selected participants that conducted heterogeneous Big Data research projects: from internet based research and social media studies, to aggregate analysis of corporate datasets, to behavioral research using sensing devices (see table 3 for an overview of the data used by our participants). Participant selection was based on their involvement in Big Data research and was conducted systematically by browsing the professional pages of all professors affiliated to the departments of psychology and sociology of all twelve Swiss Universities and the top ten American Universities according to the Times Higher Education University Ranking 2018. Other candidates were identified through snowballing. Through our systematic selection we also identified a consistent number of researchers with a background in data science that were involved in research projects in behavioral sciences (in sociology, psychology and similar fields) during the time of their interview. Since their profile matched the selection criteria we included them in our sample.

We conducted 39 semi structured interviews with academic scholars involved in research projects that adopt Big Data methodologies. Twenty participants were from Swiss universities and 29 came from American institutions. They comprised of a majority of professors (n=34) and a few senior researchers or postdocs (n=5). Ethics approval was sought from the Ethics Committee northwest/central Switzerland (EKNZ) who deemed our study exempt. Oral informed consent was sought prior the start of each interview. Interviews were administered using a semi-structured interview guide developed, through consensus and discussion, after the research team had the time to familiarize with the literature and studies on Big Data research and data ethics. The questions explored topics like: ethical issues related to Big Data studies in the behavioral sciences; ethics of conduct with regards to Big Data research project; institutional regulatory practices; definition and understanding of the term Big Data; and opinions towards data driven studies (Table 6-1).

Table 6-1: *Relevant interview questions*

Sample questions
Was it clear to you which kind of ethical guidelines you would have to apply to your research? Are there any specific guidelines that you applied to conduct your research?
Do you find the guidelines that you are currently using useful? Anything that bothers you about them? Do you have any suggestion on how to improve them?
How do you think data research should be ideally ethically regulated?
What are in your opinion the minimal requirements that the law should enact to ensure that data research is carried out with minimal challenges but fulfilling ethical requirements?
What do you think is the main difference between Big Data research and more conventional research in your field? Do you think this has any implications for the guidelines?
Have you encountered any particular (ethical) challenges when conducting your research project?

Interviews were tape recorded and transcribed ad-verbatim. We subsequently transferred the transcripts into the qualitative software MAXQDA (version 2018) to support with data management and the analytic process (Guest et al., 2011). Analysis of the dataset was done using thematic analysis (Braun and Clarke, 2006). The first four interviews were independently read and coded by two members of the research team in order to explore the thematic elements of the interviews. To ensure consistency during the analysis process, the two researchers subsequently confronted the preliminary open-ended coding and they developed an expanded coding scheme that was used for all of the remaining transcripts. Several themes relevant for this study were agreed upon during the coding sessions such as: a) responsibility and the role of the researcher in Big Data research; b) research standards for Big Data studies; c) attitudes towards the use of publically available data; d) emerging ethical issues from Big Data studies. Since part of the data has already been published, we refer to a previous publication (Favaretto et al., 2020b) for additional information on methodology, project design, data collection and data analysis.

Researcher's code of ethics for Big Data studies was chosen as a topic to explore since participants, by identifying several ethical challenges related to Big Data, expressed concerns regarding the protection of the human subject in digital research and expressed shared strategies and opinions on how to ethically conduct Big Data studies. Consequently, all the interviews that were coded within the aforementioned topics were read again, analyzed and sorted into sub topics. This phase was performed by the first author while the second author supervised this phase by checking for consistency and accuracy.

6.4 Results

For this study we conducted 39 interviews with respectively 21 sociologists (9 from CH and 12 from the US), 11 psychologists (6 from CH and 5 from the US), and 7 data scientists (5 from CH and 2 from the US). Among them, 27 scholars (12 from CH and 21 from US) stated that they were working on Big Data research projects or on projects that involve Big Data methodologies, four participants (all from CH) noted that they were not involved in Big Data research and eight (7 from CH and one from the US) were unsure whether their research could be described or considered as Big Data research (Table 6-2).

Table 6-2: *Demographic table*

	Psychology	Sociology	Data Science	Total
CH Researchers	6	9	5	20
US Researchers	5	12	2	19
Professors	9	20	5	34
Postdocs/Senior researchers	2	1	2	5

Respondents, while discussing codes of ethics and ethical practices for Big Data research, both a) shared their personal strategies that they implemented in their own research projects to protect research subjects, and b) generally discussed the appropriate research practices to be implemented in Big Data research. Table 6-3 illustrates the type of Big Data our participants were working with at the time of the interview.

Table 6-3: *Type of data used by participants*

Type of data	**Participant Number***
Data From Companies (anonymized/aggregate purchase data, traffic phone data)	P29CH-D; P35CH-S; P38CH-S; P1US-S; P18US-D.
Sensing Devices and Sensor data (smartphone data, GPS, fitness trackers, Wi-Fi interactions)	P22CH-P; P28CH-S; P38CH-S; P4US-P; P18US-D; P20US-S; P22US-S.
Social Media Data (Twitter, Facebook, GAAB, Telegram, Reddit)	P24CH-P; P28CH-S; P29CH-D; P3US-S; P12US-S; P18US-D; P20US-S; P21US-S; P22US-S.
Physiological Data (EG, eye tracking)	P22CH-P; P8US-D; P22US-S.
Medical Data (neuroimaging, blood samples, x-rays, genetic data)	P1CH-P; P31CH-D; P32CH-D; P34CH_D; P4US-P; P9US-S; P11US-P; P12US-S; P13US-P; P14US-P; P16US-S.
Administrative data (university and state records, federal records, juridical, tax and census data)	P33CH-S; P39CH-S; P4US-P; P6US-S.
Publically available data (newspaper, books, websites, public documents, data on public figures)	P23CH-S; P30CH-S; P35CH-S; P37CH-S; P1US-S; P2US-S; P3US-S; P6US-S; P17US-P; P19US-S; P20US-S.
Interview and Survey Data	P24CH-P; P28CH-S; P29CH-D; P39CH-S; P2US-S; P4US-P; P14US-P; P17US-P.
Crowdsourcing Data (M-Turk, Crowd Flower, Safecast)	P27CH-D; P29CH-S; P20US-S.
Not specified	P5US-S.

* *Legend: P=participant+ID number+country (CH=Switzerland; US=United States)+background (P=Psychology; S=Sociology; D=Data Science). Eg. P1CH-P=Participant 1, Switzerland, Psychology.*

Our analysis identified several themes and subthemes. They were then divided and analyzed within three major thematic clusters: a) ethical principles for Big Data research; b) challenges that Big Data is introducing for research principles; c) ethical reflection and responsibility in research. Table 6-4 reports the themes and subthemes that emerged from the interviews and their occurrence in the dataset. Representative anonymized quotes were taken from the interviews to further illustrate the reported results.

Table 6-4: *Themes and clusters that emerged from the analysis*

Themes and subthemes	**Number of occurrences in the dataset***	**Cluster 1 :** ethical principles for Big Data research	**Cluster 2:** challenges for research principles	**Cluster 3:** ethical reflection and responsibility in research
1. Responsibility	16			x
1.1 Responsibility to protect the research subject lies on the investigators primarily	10			x
1.2 Investigators cannot be the only actors held responsible or Big Data research	6			x
2. Role and importance of ethical reflection and ethical principles	5			x
3. Research Guidelines	3	x		
3.1 Belmont Report	2	x		
3.2 Declaration of Helsinki	1	x		
4. Research Principles	99	x	x	
4.1 Beneficence	5	x		
4.2 Avoiding Harm	4	x		
4.3 Respect for the participant	2	x		
4.4 Consent	40	x	x	
4.4.1 Importance of consent	19	x		
4.4.2 Awareness of participants	4	x		
4.4.3 Consent is challenging in Big Data research	14		x	
4.4.4 Consent is not the most relevant research principle	3		x	
4.5 Right to withdraw and control over one's data	5	x		
4.6 Privacy	34	x	x	
4.6.1 Importance of respecting people's privacy in research	10	x		
4.6.2 Ensuring participants' anonymity	6	x		
4.6.3 Big Data is challenging the concept of privacy	7		x	
4.6.3.1 The public versus private data conundrum	11		x	
4.7 Transparency	9	x		
4.7.1 Clash between transparency and anonymity	1		x	
4.7.2 Importance of evaluation of intent	1	x		x

** By occurrence we refer to the number of times a theme or a subtheme was coded within the data. It is therefore possible that a single participant mentioned the same concept/topic more than one time during the interview. In addition, a single quote could refer to more than one theme.*

6.4.1 Ethical Principles for Digital Research

Belmont principles, beneficence and avoiding harm

First, many of the respondents shared their opinions on what ethical guidelines and principles they consider important to conduct ethical research in the digital era. Table 6-5 illustrates the number of researchers that mentioned a specific ethical principle or research practice as relevant for Big Data research.

Table 6-5: *Mentioned ethical principles*

Research Principles and Practices	Swiss Scholars	American Scholars	Total
Belmont Report/Declaration of Helsinki	1	2	3
Avoiding Harm	1	2	3
Beneficence/Giving Back to the Community	1	3	4
Respect	1	1	2
Informed Consent	9	10	19
Awareness	2	2	4
Right to withdraw/ Control over data	2	2	4
Transparency	5	4	9
Privacy/Anonymity	8	7	15
Evaluation of intent	1	0	1

Three of our participants, generally referred to the principles stated in the Belmont Report and the ones related to the Declaration of Helsinki.

> I think the Belmont Report principles. The starting point so....you know beneficence, respect for the individuals, justice... and applying those and they would take some work for how to apply those exactly or what it would mean translating to this context but that would be the starting point (P18, US – data science).

A common concern was minimization of harm for research participants and the importance of beneficence as prominent components of scholarly research.

> And...on an ethical point of view... and I guess we should be careful that experiment doesn't harm people or not offend people for example if it's about religion or something like that it can be tricky (P25, CH – psychology).

Beneficence, in the context of digital Big Data research, was sometimes associated with the possibility of giving back to the community as a sort of tradeoff for the inconvenience that research might cause to research participants. On this, P9, an American sociologist, shared:

> I mean it's interesting that the ethical challenges that I faced... (pause) had more to do with whether I feel, for instance in working in the developing world...is it really beneficial to the people that I'm working with, I mean what I'm doing. You know I make heavy demands on these people so one of the ethical challenges that I face is, am I giving back enough to the community.

While another American scholar, a psychologist, was concerned about how to define acceptable risks in digital research and finding the right balance between benefit and risks for research projects.

> P17: Expecting benefit from a study that should outweigh the respective risks. I mean, I think that's a pretty clear one. This is something I definitely I don't know the answer to and I'm curious about how much other people have thought about it. Because like what is an acceptable sort of variation in expected benefits and risks. Like, you could potentially say "on average my study is expected to deliver higher benefits than risks"… there's an open question of like, … some individuals might regardless suffer under your research or be hurt. Even if some others are benefitting in some sense.

For two researchers, respect for the participant and their personhood was deemed particularly important irrespective of the type of research conducted. P19, an American sociologist, commented:

> What I would like to see is integrity and personhood of every single individual who is researched, whether they are dead or alive, that that be respected in a very fundamental way. And that is the case whether it's Big Data, and whether is interviews, archival, ethnographic, textual or what have you. And I think this is a permanent really deep tension in wissenshaftlich (*scientific research*) activities because we are treating the people as data. And that's a fundamental tension. And I think it would be deeply important to explicitly sanitize that tension from the get-go and to hang on to that personhood and the respect for that personhood.

Informed consent and transparency

Consent was by far the most prominent practice that emerged from the interviews as three quarters of our participants mentioned it, equally distributed among American and Swiss researchers. Numerous scholars emphasized how informed consent is at the foundation of appropriate research practices. P2, a Swiss psychologist, noted:

> But of course it's pretty clear to me informed consent is very important and it’s crucial that people know what it is what kind of data is collected and when they would have the possibility of saying no and so on. I think that’s pretty standard for any type of data. (…) I mean it all goes down to informed consent.

For a few of our participants, in the era of Big Data, it becomes not really a matter of consent but a matter of awareness. Since research with Big Data could theoretically be performed without the knowledge of the participant, research subjects at least have to be made aware that they are part of a research project as claimed by P38 a Swiss sociologist who said:

> I think that everything comes down to the awareness of the subject about what is collected about them. I mean, we have collected data for ages, right? And I mean, before it was using pen and paper questionnaires, phone interviews or...there’s been data collection about private life of people for, I mean, since social science exists. So, I think the only difference now is the awareness.

Another practice that was considered fundamental by our participants was the right of participants to withdraw from a research study that, in turn, was translated in giving the participants more control over their data in the context of Big Data research. For example, while describing their study with social media, a Swiss sociologist (P38) explained that ”the condition was that everybody who participated was actually able to look at his own data and decide to drop from the survey any time”. Another Swiss sociologist (P37), when describing a study design in which they asked participants to install an add-on on their browser to collect data on their Facebook interactions, underlined the importance of giving participants control over their data and to teach them how to manage them, in order to create a trust based exchange between them and the investigators:

> And there you'd have to be sure that people...it's not just anonymizing them, people also need to have a control over their data, that's kind of very important because you need kind of an established trust between the research and its subjects as it were. So they would have the opportunity of uninstall the...if they're willing to take part, that's kind of the first step, and they would need to download that add-on and they'd also be instructed on how to uninstall the add-on at any point in time. They'd be also instructed on how to pause the gathering of their data at any point in time and then again also delete data that well...at first I thought it was a great study now I'm not so sure about, I want to delete everything I've ever collected.

The same researcher suggested to create regulations that ensure ownership of research data to participants in order to allow them to have actual power over their participation past the point of initial consent.

> And legal parameters then should be constructed as such that it has to be transparent, that it guards the rights of the individual (…) in terms of having ownership of their data. Particularly if it's private data they agree to give away. And they become part of a research process that only ends where their say. And they can always withdraw the data at any point in time and not just at the beginning with agreeing or not agreeing to taking part in that. But also at different other points in time. So that i think the...you have to include them more throughout your research process. Which is more of a hassle, costs more money and more time, but in the end you kind of....it makes it more transparent and perhaps it makes it more interesting for them as well and that would have kind of beneficial effects for the larger public I suppose.

In addition, transparency of motives and practices was also considered a fundamental principle for digital research. For instance, transparency was seen as a way for research participants to be fully informed about the research procedures and methods used by investigators. According to a few participants transparency is key to guarantee people's trust the research system and to minimize their worry and reservations about participating in research studies. On this P14, an American psychologist, noted:

> I think we need to have greater transparency and more.... You know our system, we have in the United States is that...well not a crisis, the problem that we face in the United States which you also face I'm sure, is that...you know, people have to believe that this is good stuff to do (participating in a study). And if they don't believe that this is good stuff to do then it's a problem. And so....so I think that that....and I think that the consent process is part of it but I think that the other part of it is that the investigators and the researchers, the investigators and the institutions, you know, need to be more transparent and more accountable and make the case that this is something worth doing and that they're being responsible about it.

A Swiss sociologist, P38, who described how they implemented transparency in their research project by giving control to participants over the data they were collecting on them, highlighted that the fear individuals might have towards digital and Big Data research might come from lack of information and understanding about what data investigators are collecting on them and how they are using it. In this sense transparency of practices not only ensures that more individuals trust the research systems but it will also assist them in making a truly informed decision about their participation in a study.

> And if I remember correctly the conditions were: transparency, so every subject had to have access to the full data that we were collecting. They had also the possibility to erase everything if they wanted to and to drop from the campaign. I guess it's about transparency. (…) So, I think this is key, so you need to be transparent about what kind of data you collect and why and maybe what will happen to the data. Because people are afraid of things they don't understand so the better they understand what's happening the more they would be actually.... not only they will be willing to participate but also the more they will put the line in the right place. So, this I agree, this I don't agree. But the less you understand the further away you put the line and you just want to be on the safe side. So, the better they understand the better they can draw the line at the right place, and say ok: this is not your business, this I'm willing to share with you.

In addition, one of our participants considered transparency to be an important value also between scholars from different research teams. According to this participant, open and transparent communication and exchange between research would help implement appropriate ethical norms for digital research. They shared:

> But I think part of it is just having more transparency among researchers themselves. I think you need to have like more discussions like: here's what I'm doing...here's what I'm doing...just more sharing in general, I think, and more discussion. (…) People being more transparent on how they're doing their work would just create more norms around it. Because I think in many cases people don't know what other people have been doing. And that's part of the issues that, you know, it's like how do I apply these abstract standards to this case, I mean that can be though. But if you know what everybody is doing it makes a little bit easier. (P3-US, Sociologist)

On the other hand, however, a sociologist from Switzerland (P37), noted that the drive towards research transparency might become problematic for ensuring the anonymity of research participants as more information you share about research practices and methods the more possibilities of backtracking and re-identifying the participants to the study.

> It's problematic also because modern social science, or science anyway, has a strong and very good drive towards transparency. But transparency also means, that the more we become transparent the less we can guarantee anonymity (…) If you say: "well, we did a crawl study", people will ask "well, where are you starting, what are

> your seeds for the crawler?". And it's important to, you know, to be transparent in that respect.

Privacy and anonymity

Respect for the privacy of research participants, and protection from possible identification, usually achieved through anonymization of data, were the second most mentioned standards to be considered while conducting Big Data research. P33, a Swiss sociologist, underlined how "If ever, then privacy has…like it's never been more important than now", since information about individuals is becoming increasingly available thanks to digital technologies, and how institutions now have a responsibility to ensure that such privacy is respected. A Swiss data scientist, P29, described the privacy aspect embedded in their research with social media and how their team is constantly developing strategies to ensure anonymity of research subjects. They told:

> Yeah, there is a privacy aspect of course, that's the main concern, that you basically...if you're able to reconstruct like the name of the person and then the age of the person, the address of the person, of course you can link it then to the partner of the person, right? If she or he has, they're sharing the same address. And then you can easily create the story out of that, right? And then this could be an issue but...again, like we try to reapply some kind of anonymization techniques. We have some people working mostly on that. There is a postdoc in our group who is working on anonymization techniques.

Similarly, an American researcher, P6 Sociologist, underlined how the it should become a routine practice for every research project to consider and implement practices to protect human participants from possible re-identification:

> In the social science world people have to be at least sensitive to the fact that they could be collecting data that allows for the deductive identification of individuals. And that probably…that should be a key focus of every proposal of how do you protect against that.

6.4.2 Challenges introduced by Big Data to research ethics and ethical principles

A consistent number of our researcher, on the other hand, recognized how Big Data research and methods are introducing numerous challenges related to the principles and practices they consider fundamental for ethical research and reflected upon the limits of the traditional ethical principles.

When discussing informed consent, participants noted that that it might not be the main standard to refer to when creating ethical frameworks for research practices as it cannot be ensured anymore in much digital research. For instance, P14, an American psychologist noted:

> I think that that the kind of informed consent that we, you know, when we sign on to Facebook or Reddit or Twitter or whatever, you know, people have no idea of what that means and they don't have any idea of what they're agreeing to. And so, you know the idea that that can bear the entire weight of all this research is, I think...I think notification is really important, you can ask for consent but the idea that that can bear the whole weight for allowing people to do whatever/ researchers to do whatever they want, I think it's misguided.

Similarly, P18, an American scholar with a background in data science, felt that although there is still a place for informed consent in the digital era, this practice should be appropriately revisited and reconsidered as it cannot be applied anymore in the stricter sense, for instance when analyzing aggregated databases where personal identifiers are removed and it would be impossible to trace back the individual to ask them for consent. They shared:

> Certainly, I think there is [space for informed consent in digital research]. And like I said I think we should require people to have informed consent about their data being used in aggregate analysis. And I think right now we do not have informed consent. (…) So, I think again, under the strictest interpretation even to consent to have one's data involved in an aggregate analysis[3] should involve that. But I don't know, short of that, what would be an acceptable tradeoff or level of treatment. Whether simply aggregating the analysis is good enough and if so what level of aggregation is necessary.

As for consent, many of our participants while recognizing the importance of privacy and anonymity, also reflected on some of the challenges that Big Data and digitalization of research are creating for these research standards. First, a few respondents highlighted how in digital research the risk of identification of participants is quite high as anonymized datasets could almost always be de-anonymized, especially if data is not adequately secured.

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[3] Data aggregation is the process of gathering data from multiple sources and presenting it in a summarized format. Through the process of data aggregation, data can be stripped from personal identifiers thus ensuring anonymization of the dataset and analyzing aggregate data should, theoretically not reveal personal information about the user.

On this, P1, an American sociologist explained:

> I understand and recognize that there are limits to anonymization. And that under certain circumstances almost every anonymized dataset can be de-anonymized. That's what the research that shows us. I mean sometimes that requires significant effort and then you ask yourself would someone really invest like, you know, supercomputers to solve this problem to de-anonymise…

A Swiss sociologist (P38) described how anonymization practices towards the protection of the privacy of the research participant could, on the other hand, diminish the value of the data for research as anonymization would destroy some of the information the researcher is actually interested in.

> You know, we cannot do much about it. So... there is a tendency now to anonymize the data but basically ehm...anonymization means destruction of information in the data. And sometimes the information that is destroyed is really the information we need…

Moreover, it was also claimed how digital practices in research are currently blurring the line between private and public spaces creating additional challenges for the protection of the privacy of the research participant and practices of informed consent. A few of our researchers highlighted how research subjects might have an expectation of privacy even in public digital spaces such as social media and public records. In this context, an American sociologist, P9, noted how participants could have a problem in allowing researchers to link together publically available datasets as they would prefer information stemming from this linkage to remain private:

> P9USR: Well because the question is ...even if you have no expectation of privacy in your Twitter account, you know Twitter is public. And even if you have no expectation of privacy in terms of whether you voted or not, I don't know, in Italy maybe it's a public record whether if you show up at the pool or not. Right? I can go to the city government and see who voted in the last elections right? (…) So...who voted is listed or what political party they're member of is listed, is public information. But you might have expectation of privacy when it comes to linking those data. So even though you don't expect privacy in Twitter and you don't expect privacy in your voting records, maybe you don't like it when someone links those things together.

In addition, a sociologist, P19 from the US, noted how even with just linking information of some publically available data, research subjects could be easily identified.

> However, when one goes to the trouble of linking up some of the aspects of these publically available sets it may make some individuals identifiable in a way that they haven't been before. Even though one is purely using publically available data. So, you might say that it kind of falls into an intermediate zone. And raises practical and ethical questions on protection when working with publically available data. I don't know how many other people you have interviewed who are working in this particular grey zone.

Two, of our participants while describing personal strategies to handle matters of expectation of privacy and consent, discussed the increased blur between private and public spaces and how it is becoming increasingly contextual to adequately handle matters of privacy on social media.

> P2USR: So, for example when I study journalists, I assume that their Tweets are public data just because Twitter is the main platform for journalists to kind of present their public and professional accomplishments and so I feel fine kind of using their tweets, like in the context of my research. I will say the same thing, about Facebook data for example. So, some of the journalists kind of... that I interviewed are... are not on Facebook anymore, but at the time we became friends on Facebook and there were postings and I... I wouldn't feel as comfortable, I wouldn't use their Facebook data. I just think that somehow besides the norms of the Facebook platform is that it's more private data, from...especially when it's not a public page so... But it's like... it's fuzzy.

6.4.3 Responsibility and ethical reflection in research

Due to the challenges introduced by digital methods, some of our participants elaborated on their opinions regarding the role of ethical reflection and their responsibility in addressing such challenges in order to ensure the protection of research participants.

Among them, some researches emphasized the importance for investigators to apply ethical standards to appropriately perform their research projects. However, a couple of them recognized how not all researchers might have the background and expertise to acknowledge the ethical issues stemming from their research projects or to be adequately familiar with ethical frameworks. On this, P12, an American sociologist, highlighted the importance of education in ethics for research practitioners:

> I also want to re-emphasize that I think that as researchers in this field we need to have training in ethics because a lot of the work that we're doing (pause) you know can be on the border of infringing on people's privacy.

In addition, self-reflection, ethical interrogation and evaluation about the appropriateness of certain research practices was a theme that emerged quite often during our interviews. For an American psychologist, P4, concerned about issues of consent in digital research, it is paramount that investigator begin to interrogate themselves upon what type of analysis would be ethically appropriate without explicit consent of participants.

> And it is interesting by the way around Big Data because in many cases those data were generated by people who didn't sign any consent form. And they have their data used for research. Even (for the) secondary analysis of our own data the question is: what can you do without consent?

Similarly, P26, a sociologist from Switzerland, reflected upon the difficulties that researchers might encounter in evaluating what type of data investigators can consider unproblematic to collect and analyze even in digital public spaces, like social media:

> Even though again, it's often not as clear cut, but I think if people make information public that is slightly different from when you are posting privately within a network and assume that the only people really seeing that are your friends. I see that this has its own limits as well because certain things...well A: something like a profile image I think is always by default public on Facebook...so... there you don't really have a choice to post it privately. I guess your only choice is not to change it ever. And then the other thing is that…I know it because I study (…) internet skills, I know a lot of people are not very skilled. So, there are a lot of instances where people don't realize they're posting publically. So even if something is public you can't assume people had meant it to be public.

Moreover, reflection and evaluation of the intent behind a research study was considered important by P31, a Swiss data scientist, for ethical research in Big Data. The researcher recognized that this is difficult to put into practice as investigators with ill intent might lie about their motivations and you could have negative consequences even with the noblest of intents.

> I find it really difficult to answer that. I would say, the first thing that comes to my mind is the evaluation of intent... rather than other technicality. And I think that's a lacking point. But also the reason why I don't give that answer immediately is like...intent is really difficult to probe... and it's probably for some people quite easy to know what is the accepted intent. And then I can of course give you a story that is quite acceptable to you. And also with good intent you can do evil things. So, it's difficult but I would say that discussion about the intent is very important. So that would be maybe for me a minimal requirement. At least in the discussions.

In this context, some scholars also discussed their perception regarding responsibility of protecting research participants in digital studies and the role investigators play in overcoming ethical issues.

For a few of them it was clear that the responsibility of protecting the data subjects should fall on the investigators themselves. For instance, an American scholar, P22 sociologist, while discussing the importance of creating an ethical framework for digital research that uses publically available data of citizens shared:

> So, I do think (the responsibility) it's on researchers (…) and I get frustrated sometimes when people say "well it's not up to us, if they post it there then it's public". It's like well it is up to us, it's literally our job, we do it all day, try to decide, you know, what people want known about them and what people don't. So, we should apply those same metrics here.

However, other researchers also pointed out how the introduction of digital technologies and digital methods for behavioral research is currently shifting the perceived responsibility scholars have. P16, an American sociologist, shared some concerns regarding the use of sensor devices for behavioral research and reflected on how much responsibility they, as investigators, have in assuring data protection of their research subjects since the data they work with is owned by the company that provided the device for data collection:

> There's still seems to be this question about...whether....what the Fitbit corporation is doing with those data and whether we as researchers should be concerned about that. We're asking people to wear Fitbits for a study. Or whether that's just a separate issue. And I don't know what the answer to that is, I just know that it seems like the type of question that it's going to come up over and over and over again.

One a similar note, P14, an American psychologist, noted that while researchers actually have a responsibility of preventing harm that might derive from data research, it should be a responsibility in part shared with data holders. They claimed:

> Do I think that the holders of data have a responsibility to try to you know, try to prevent misuse of data? Yeah, I think they probably do. (…) I think there is a notion of stewardship there. Then I think that investigators also have an independent obligation to make sure to think about the data they're analyzing and trying to get and think about what they're using it for. So not to use data in order to harm other people or those kinds of things.

Finally, a few participants hinted at the fact that research ethics boards like Institutional Review Boards (IRBs) and Ethics Committees (ECs) should play a bigger role of responsibility in ensuring that investigators actually perform their research ethically. For instance, P16, an American sociologist, complained that IRBs do not provide adequate follow-up to researchers to ensure that they are appropriately following the approved research protocols.

> There does seem to be kind of a big gap even in the existing system. Which is that a researcher proposes a project, the IRB hopefully works with the researcher and the project gets approved and there's very little follow-up and very little support for sort of making sure that the things that are laid out at the IRB actually in the proposal and the project protocol actually happen. And not that I don't believe that most researchers have good intensions to follow the rules and all of that but there are so many of kind of different projects and different pressures that things can slip by and there's... there's nobody.

6.5 Discussion

As Big Data methodologies are becoming widespread in research, it is important to reach international consensus on whether and how traditional principles for research ethics, such as the ones described in the Belmont Report, are still relevant for the new ethical questions introduced by Big Data and internet research (Vitak et al., 2016; Anabo et al., 2018). Our study offers a relevant contribution to this debate as it investigated the methodological strategies and code of ethics researchers from different jurisdictions - Swiss and American investigators - apply in their Big Data research projects. It is interesting to notice how, despite regional difference, participants shared very similar ethical priorities. This might be due to the international nature of academic research, where scholars share similar codes of ethics and apply similar strategies for the protection of research participants.

Our results point out that in their code of conduct, researchers mainly referred to the traditional ethical principles enshrined in the Belmont report and the Declaration of Helsinki, like respect for persons in the practice of informed consent, beneficence, minimization of harm through protection of privacy and anonymization, and justice. This finding shows that such principles are still considered relevant in behavioral sciences to address the ethical issues of Big Data research, despite the critique of some that rules designed for medical research cannot be applied in sociological research (Kahn et al., 2014). Even before the advent of Big Data, the practical implementation of the Belmont Report principles has never been an easy endeavor as they were originally conceived to be flexible to accommodate a wide range of different research settings and methods. However it has been argued that exactly this flexibility makes them the perfect framework in which investigators can "clarify trade-offs, suggest improvements to research designs, and enable researchers to explain their reasoning to each other and the public" in digital behavioral research (Salganik, 2019).

Our study shows how scholars still place great importance on the practice of informed consent. They considered crucial that participants are appropriately notified of their research participation, are adequately informed about at least some of the details and procedures of the study, and are given the possibility to withdraw at any point in time. A recent study, however, has highlighted that there is currently no consensus among investigators on how to collect meaningful informed consent among participants in digital research (Shilton and Sayles, 2016). Similarly, a few researchers from our study recognized that consent, although preferable in theory, might not be the most adequate practice to refer to when designing ethical frameworks. In the era of Big Data behavioral research, informed consent becomes an extremely complex practice that is intrinsically dependent on the context of the study and the type of Big Data used. For instance, in certain behavioral studies that analyze track data from devices related to a limited number of participants, it would be feasible to ask for consent prior to beginning of the study. However, recombination and reanalysis of the data, possibly across ecosystems far removed from the original source of the data, makes it very difficult to fully inform participants about the range of uses to which their data would be put through, the type of information that could emerge from the analysis of the data, and the unforeseeable harms that the disclosure of such information could cause (Xafis et al., 2019). In online studies and internet-mediated research, consent often amounts to an agreement to unread terms of service or a vague privacy policy provided by digital platforms (Metcalf and Crawford, 2016). Sometimes valid informed consent is not even required by official guidelines when the analyzed data can be considered 'in the public domain' (British Psychological Society, 2017), leaving participants unaware that research is performed on their data. It has been argued however that researchers should not just assume that public information is freely accessible for collection and research just because it is public. Researchers should take into consideration what the subject might have intended or desired regarding the possibility for their data to be used for research purposes (Zimmer, 2010). At the same level, we can also argue that even when information is harvested with consent, the subject might a) not wish for their data to be analyzed or reused outside of the purview of the original research purpose and b) fail to understand what is the extent of the information that the analysis of the dataset might reveal about them.

Matzner and Ochs argue that practices of informed consent “are widely accepted since they cohere with notions of the individual that we have been trained to adopt for several centuries” (Matzner and Ochs, 2017: 46), however they also emphasize how such notions are being altered and challenged by the openness and transience of data-analytics that prevent us from continuing to consider the subject and the researcher within a self-contained dynamic. Since *respect for persons*, in the form of informed consent, is just one of the principles that needs to be balanced when considering research ethics (Gillon, 2015), it becomes of outmost importance to find the right balance between the perceived necessity of still ensuring consent from participants and the reality that such consent is sometimes impossible to obtain properly. Salganik (2019), for instance, suggests that in the context of digital behavioral research “rather than “informed consent for everything,” researchers should, follow a more complex rule: “some form of consent for most things”. This means that, assuming informed consent is required, it should be evaluated on a case by case basis whether consent is a) practically feasible and b) actually necessary. This practice might however leave too much space to the discretion of the investigator who might not have the skills to appropriately evaluate the ethical facets of their research projects (Vitak et al., 2017).

Next to consent, participants from our study also argued in favor of ensuring more control to participants over their own data. In the past years in fact, it has been argued that individuals often lack the control to manage, protect and delete their data (Rothstein, 2015; Shaw, 2016). Strategies of dynamic consent could be considered a potential tool to address ethical issues related to consent in Big Data behavioral research. Dynamic consent, a model where online tools are developed to have individuals engage in decisions about how their personal information should be used and which allows them some degree of control over the use of their data, are currently mainly developed for biomedical Big Data research (Abdul Aziz and Mohd Yusof, 2019; Dankar et al., 2020). Additional research could be performed to investigate if such models can be translated and applied also for behavioral digital research.

Strictly linked to consent is the matter of privacy. Many researchers underlined the importance of respecting the privacy and anonymity of research participants to protect them from possible harm. At the same time, they also recognized the many challenges related to such practice. They highlighted the difficulty of ensuring complete anonymity of the data and prevent re-identification of participants in Big Data research, especially since high level of anonymization could cause the loss of essential information for the research project. The appropriate trade-off between ensuring maximum anonymization for participants while maintaining quality of the dataset is still hotly debated (Daries et al., 2014). Growing research in data science strives towards developing data models to ensure maximum protection for participants (Zhang et al., 2014). On the other hand, our participants also referred to the current debate surrounding the private nature of personal data as opposed to publically available data and how Big Data and digital technologies are blurring the line between private and public spheres. Some respondents expressed concern or reservation towards the analysis of publically available data – especially without informed consent – as it could still be considered an infringement of the privacy of research participants and also cause them harm. This shows how researchers are well aware of the problems of considering privacy a binary concept (private vs public data) and that they are also willing to reflect upon strategies to protect the identity of participants even when handling publically available data. According to Zook et al. (2017), breaches of privacy are the main means by which Big Data can do harm as it might reveal sensitive information about people. Besides the already mentioned "Tagging Banksy" project (Hauge et al., 2016), another distressing example is what happened in 2013, after the New York City Taxi & Limousine Commission released an anonymized dataset of 173 million individual cab rides – including the pickup and drop-off times, locations, fare and tip amount. Many researchers who freely accessed this database showed how easy it was to elaborate the dataset so that it revealed private information about the taxi-drivers, such as their religious belief, average income and even an estimation of their home address (Franceschi-Bicchierai, 2015). It becomes therefore increasingly crucial that investigators in the behavioral sciences recognize how privacy is contextual, situational and changes over time as it depends on multiple factors such as the context in which the data were created and obtained, and the expectations of those whose data is used (Zook et al., 2017; Nissenbaum, 2009; Salganik, 2019; Zimmer, 2018). For instance, as reported by one of our respondents, users might not have expectations of privacy on some publically available information when taken singularly or separately – e.g. social media and voter data, but they might have privacy concerns on the information that the linkage of this data might reveal – e.g. who they voted for. This difficulty, if not impossibility, of defining a widespread single norm or rule for protecting privacy, shows again the intrinsic context dependency of Big Data studies, and highlights how researchers are increasingly called to critically evaluate their decisions on a case by case basis rather than by blindingly applying a common rule.

As new methods of data collection and analysis in behavioral sciences create controversy and appropriately balancing and evaluating ethical principles is becoming a source of difficult decisions for researchers (Salganik, 2019), our participants underlined the importance of ethical reflection and education towards the appropriate development of research projects. They also recognized how investigators are called to critically reflect about the design of their studies and the consequences they might have for research participants (Goel, 2014). However, as claimed by one of our participants, not all researchers, especially those coming from more technical disciplines like data science, might have the expertise and tools to proactively think about ethical issues when designing a research project (Vitak et al., 2016) and might need additional guidance. We therefore argue that education in ethics, exchange and dialogue between research teams and scholars from different disciplines must be implemented. As suggested by Zook et al. (2017) discussion and debate of ethical issues are an essential part of establishing a community of ethical practitioners and integrating ethical reflection into coursework and training can enable a bigger number of scholars to raise appropriate ethical questions when reviewing or developing a project.

Within the current discussion, we have seen how context-dependency, although never spelled out explicitly by our participants, becomes a major theme in the debate over ethical practices in Big Data studies. Our results have in fact highlighted that a one-size fits all approach to research ethics, or a definite overarching set of norms or rules to protect research participants, is not opportune to appropriately handle the multifaceted ethical issues of Big Data. The context-dependent nature of some of the ethical challenges of Big Data studies, such as consent and privacy, might require a higher level of flexibility together with a more situational and dialogic approach to research ethics (Anabo et al., 2018). For instance, the Association of Internet Researchers (AoIR) in the development of their Ethical Guidelines for Internet research agrees that the adequate process approach for ethical internet research is one that is reflective and dialogical "as it begins with reflection on own research practices and associated risks and is continuously discussed against the accumulated experience and ethical reflections of researchers in the field and existing studies carried out" (franzke et al., 2019: 9). As a consequence we argue that applying context specific assessments increases the chances of solving ethical issues and appropriately protecting research participants (Steinmann et al., 2016). Many authors in the field are thus promoting methodological approaches that focus on contextually-driven decision-making for Big Data research. Zimmer, for example, suggests the application of contextual integrity's decision heuristic on different research studies to appropriately assess the ethical impact of the study on the privacy of its participants and consequently overcome the conceptual gaps left by the Belmont Report for Big Data research ethics (Zimmer, 2018). Similarly, Steinmann et al. (Steinmann et al., 2016) provide an heuristic tool in the form of a “privacy matrix” to assist researchers in the contextual assessment of their research projects.

But what should drive investigators’ ethical reflection and decision making? Despite the multifaceted challenges introduced by Big Data and digital research, we argue that the principles stated in the Belmont Report can still be considered a valuable guidance for academic investigators. As argued by Rothstein (Rothstein, 2015), we believe Big Data exceptionalism is no viable option and new challenges should not serve as a catalyst for abandoning foundational principles of research ethics. This is in line with the current best practices suggested by institutional bodies like the American Psychological Association (APA), that claim that the core ethical principles set by the Belmont report should be expanded to address the risks and benefits of today’s data (Paxton, 2020). Numerous research groups are striving towards the design of ethical frameworks in Big Data research that stay true to the foundational principles of research ethics, but at the same time accommodate the needs and changes introduced by Big Data methods. Steinmann et al. (Steinmann et al., 2016), for instance, suggest to consider five principles (non-maleficence, beneficence, justice, autonomy, and trust) as a well-defined pluralism of values that, by having clear and direct utility in designating practical strategies for protecting privacy, should guide researchers in the evaluation of their research projects. Xafis et al. (Xafis et al., 2019), in the development of an ethical framework for Biomedical Big Data research, provide a set of 16 values relevant for many Big Data uses divided in substantive values (such as justice, public benefit, solidarity or minimization of harm) and procedural values (accountability, consistency, transparency and trustworthiness) that should be used by investigators to identify and solve ethical issues within their research project. Vitak et al. (2016) recommend the implementation of the principle of transparency, intended as a flexible principle that finds application in different ethical components related both to intent of research (what you are doing with data and why) and practice (how you’re getting the data – informed consent (disclosing purpose and potential use) and how you are processing the data – data anonymity). Also, according to some of our participants, enhancement of transparency in research practices would be positive on different levels. First, it would assist participants in trusting the research system and minimize their worry about participating in research studies; in addition, enhanced transparency between research teams would assist in building up the knowledge to face the ethical issues that emerge in heterogeneous research projects. Although the principle of transparency is becoming increasingly embedded in research practices as something highly recommended, there is still some uncertainty regarding how this principle would actually translate in practice, in order to overcome challenges posed to ethical practices like consent. At the moment much of the debate on transparency mainly focuses on the implementation of algorithmic transparency with Big Data (Rader et al., 2018), more research should focus on how put research transparency in practice

Finally, a very relevant theme that our participants reflected upon, that it is rarely addressed by the current literature on Big Data studies, was the topic of responsibility. Some of our respondents in fact interrogated themselves whether the introduction of digital technologies and methods implies a shift of responsibility in protecting research participants. Although all those who discussed responsibility admitted that at least part of it should definitely fall on investigators themselves, some pointed that also other actors involved in Big Data research could share some of this responsibility such as data holders, data owners – in case of the use of corporate data. Digital research has in fact changed the traditional research subject/investigator dynamic (Metcalf and Crawford, 2016) by introducing other factors/actors in the process (social media platforms, private firms etc.) and therefore raises ethical challenges for which researchers do not always have the necessary skills to either anticipate or face (Vitak et al., 2017; Favaretto et al., 2020a). To the best of our knowledge, it seems that this aspect of responsibility has not yet entered the ethics debate. This might be due to the practical difficulties that such a debate would necessarily imply such as communication, coordination and compromise between stakeholders with very different goals and interests at stake (Bekelman et al., 2003; Dooley and Kirk, 2007). However our results show that there are relevant questions and issues that should be further addressed such as: who should bear the responsibility of protecting the research subject in Big Data studies? How much should data owners, data holders, ethics committees and even users be involved in sharing such responsibility? We believe that academic investigators should not bear all the responsibility of the ethical design of research projects alone, or singularly confront themselves with the ethical implications of digital research (Raymond, 2019). At the moment, models of consultancy between ethics committees and researchers are advocated to assist investigators foresee ethical issues (Favaretto et al., 2020a; Vitak et al., 2017). These models, together with the implementation of sustainable and transparent collaboration/partnership with data holders and owners (Mitroff and Sharpe, 2017), could assist the creation of appropriate paradigms of shared responsibility that could definitely play a significant role in the development of ethically sound research projects.

6.6 Limitations

First, since our respondents were mainly from the fields of psychology and sociology, the study might have overlooked the perspectives of other relevant fields for human subject research that make use of Big Data methodologies (e.g., medicine, nursing sciences, geography, urban planning, computer science, linguistics, etc.). In addition, the findings of this study are based on a small sample of researchers from only two countries that share similar ethical norms and values. For these reasons, the findings from this analysis are not generalizable globally. Future research that takes into account additional disciplines and different countries might contribute in delivering a more comprehensive understanding of the opinions and attitudes of researchers. Finally, a limitation must be acknowledged regarding the definition of Big Data used for this study. Using the term Big Data as an umbrella term prevented us from undertaking a more nuanced analysis of the different types of data used by our participants and their specific characteristics (for instance the different ethical challenges posed by online social media data as compared to sensor data obtained with the consent of the participants). In our discussion we referred to the contextual dependency of the ethical issues of Big Data and the necessity of a continuous ethical reflection that assesses the specific nuances of the different types of Big Data in heterogeneous research projects. However we already recognized the risks of conceptualizing Big Data as a broad overarching concept (Favaretto et al., 2020b). As a consequence we believe that future research on Big Data ethics will benefit from a deconstruction of the term into its different constituents in order to provide a more nuanced analysis of the topic.

6.7 Conclusion

This study investigated the code of ethics and the research strategies that researchers apply when performing Big Data research in the behavioral sciences and it also illustrates some of the challenges scholars encounter in practically applying ethical principles and practices. Our results point out how researchers find the traditional principles of the Belmont Report to be a suitable guide to perform ethical data research. At the same time, they also recognized how Big Data methods and practices are increasingly challenging such principles. Consent and protection of privacy were considered still paramount practices in research. However they were also considered the most challenged practices since digitalization of research has blurred the boundary between “public and private” and made obtaining consent from participants impossible in certain cases.

Based the results and discussion of our study, we suggest three key items that future research and policymaking should focus on:

- Development of research ethics frameworks that stay true to the principles of the Belmont Report but also accommodate the context dependent nature of the ethical issues of Big Data research;
- Implementation of education in ethical reasoning and training in ethics for investigators from diversified curricula: from social science and psychology to more technical fields such as data science and informatics;
- Design of models of consultancy and shared responsibility between the different stakeholders involved in the research endeavor (e.g. investigators, data owners and review boards) in order to enhance protection of research participants.

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Chapter 7 – Working through ethics review of Big Data research projects: an investigation into the experiences of Swiss and American academic researchers

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7.1 Abstract

The employment of Big Data as an increasingly used research method has introduced novel challenges to ethical research practices and to ethics committees (ECs) globally. The aim of this study is to explore the experiences of scholars with ECs in the ethical evaluation of Big Data projects. Thirty-five interviews were performed with Swiss and American researchers involved in Big Data research in psychology and sociology. The interviews were analyzed using thematic coding. Our respondents reported lack of support from ECs, absence of appropriate expertise among members of the boards, and lack of harmonized evaluation criteria between committees. To implement ECs practices we argue for updating the expertise of board members and the institution of a consultancy model between researchers and ECs.

7.2 Introduction

In recent years, the production of digital data has exponentially increased thanks to the employment of advanced computational analytic techniques and digital technologies in basically all sectors of human based activities (Lynch, 2008; boyd and Crawford, 2012). The ubiquity of data technologies and the increased ease with which greater amounts of data can be generated, gathered, stored and analyzed have had a huge impact on academic research, with Big Data[4] methodologies finding applications in a wide range of different fields such as social sciences (Salganik, 2019), psychology (Harlow and Oswald, 2016), geography (Kitchin, 2013), humanities (Ewing et al., 2016), and healthcare (Andreu-Perez et al., 2015).

In this article we define academic research as research conducted by university researchers. In Switzerland, academic research projects that involve humans typically require review and approval of Ethics Committees (ECs) and Institutional Review Boards (IRBs). In Switzerland (CH) research projects that fall under the scope of the Human Research Act (HRA) are evaluated by seven federally mandated cantonal ECs organized in one joint working group called swissethics. The main objective of the HRA is to protect the participant's health, dignity and integrity in research. Excluded from the scope of the HRA are projects with anonymized biological material and anonymously collected or anonymous health-related personal data (kofam, 2016: 9). Still it is not always clear what projects are within the scope of the HRA and

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[4] The term Big Data has had fluctuating and sometimes ambiguous meanings across the years (Kitchin and McArdle, 2016). For the scope of this study we define Big Data as a umbrella term that refers to a plethora of advanced digital technologies and computational methods – for instance data mining, machine learning and deep learning and neural networks – designed to analyze large datasets with the aim of revealing patterns, trends and associations, related to human behavior (Favaretto, De Clercq and Elger, 2019).

which ones do not (Xafis, 2015). In order to fill this gap, numerous universities in Switzerland have established IRBs to evaluate research projects in fields that are not covered by the HRA such as psychology and sociology. The implementation of such institutional review boards (IRBs), to complement cantonal ECs, is relatively recent and not homogeneous throughout universities since federal law only requires cantonal RECs and there is no legal obligation in Switzerland to add university IRBs (Mitroff and Sharpe, 2017).

In the United States, IRBs are independent panels that review research proposals to assess possible harms to humans. The IRBs are established by the Common Rule that regulates human subject research across the country and is heavily influenced by the Belmont Report of 1978 (Department of Health Education, 2014). According to the legislation human subject "means a living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information" (Ventola, 2014: 45 CFR part 46). Like in Switzerland the advent of Big Data, has problematized the concept of human subject research in the US (Ioannidis, 2013). Whether data research is human subject research or not depends on whether data is anonymous or identifiable. For Big Data, the risk to identify individuals from the data is often difficult to determine. In 2018 the Common Rule has been enacted to face the regulatory challenges introduced by Big Data research; however some scholars argue that these revisions, such as the inclusion of an "exempt" status from IRB approval for some data science research that involves anonymized personal data, might result in more harm than good for research participants (Metcalf and Crawford, 2016).

In order to avoid confusion and since the introduction of IRBs in Switzerland is quite novel and the differences between IRBs and ECs is a predominantly Swiss topic, we will use the following terminology throughout the paper: Ethics committees (EC) will be used when generally referring to ethics approval boards independently of the country while we will use the terms "Swiss EC" and "American IRB" when discussing a specific jurisdiction.

Due to the difficulties in conceptualization and assessment of what exactly constitutes human subject projects, researchers involved in digitalized Big Data research often face regulatory uncertainty. The aim of this study is to explore the experiences and attitudes of scholars involved in Big Data research in psychology and sociology with ethics committees in both Switzerland and the US. This was made in order to identify and understand the main challenges they perceive with the ethical review process in their respective fields.

7.2.1 Big Data methods and ethical issues

Some commonly used techniques and methodologies in research projects in sociology and psychology are: data gathering on the web through web scraping and crowdsourcing (Bates and Lanza, 2013); use of sensors and tracking devices to monitor subjects movements and activities and to observe social interactions in an unobtrusive fashion and/or at a larger scale; data processing techniques (e.g. natural language processing, network analysis, machine learning algorithms, automated sentiment analysis, artificial intelligence, agent-based modeling etc.) (Lazer et al., 2009; Harlow and Oswald, 2016). The datasets involved in Big Data research in these fields might differ depending on the project and include: sensor data, medically relevant data, social media data, publically available data, administrative data among others. Besides data on the internet, Big Data might be generated also in closed networks (e.g. literary texts and open government data), collected through crowdsourcing, and generated and stored in corporate and government databases (Ruppert et al., 2015).

Due to the increased use of these technologies, ethical issues that researchers and ECs are usually confronted with are becoming more complex and are challenging previous mechanisms and structures. For instance, enhanced concerns regarding data protection and privacy emerge when linkage of different digital datasets might reveal sensitive information about research participants (boyd and Crawford, 2012), or when the quality of the dataset clashes with ensuring anonymity of research participants (Daries et al., 2014). Concerns about consent are raised when data from digital spaces (e.g. social media) are used for research purposes without the subjects' explicit consent or awareness (Henderson et al., 2013; Xafis, 2015). The implementation of strategies to obtain consent is challenged by the unobtrusive nature of Big Data methods (Ioannidis, 2013). Other ethical issues related to Big Data research are: the protection of vulnerable populations (e.g. children, elders, pregnant women, prisoners, ethnic minorities etc.) and the risk of discrimination due to Big Data practices (Mittelstadt and Floridi, 2016); and the appropriateness of considering Big Data research as human subject research when the subject is most of the times detached from or invisible to the investigator (Metcalf and Crawford, 2016).

Recent studies have shown that researchers struggle in properly foreseeing some of these ethical issues. Two examples that generated public disapproval are the Facebook Contagion Study (Kramer et al., 2014) and the "Tagging Banksy Project" (which sought to reveal the identity of well-known anonymous British artist Banksy through geographical profiling (Hauge et al., 2016)). Both studies were considered exempt from ethics approval by either a university IRB –

for the Facebook Study – or an independent ethics board – for the Banksy Project. The concerned ethics committees considered the studies not directly engaged in human subject research based on the following grounds: in the former case, the involved researchers had no direct access to any individual identifiable data but only worked on aggregated non-identifiable data; in the latter, the researchers only used publically available data. Despite this, both studies were still widely criticized by the public and the scholarly research community for serious ethical violations including lack of consent, violation of privacy and possible harm inflicted on research participants (Shaw, 2016; Metcalf and Crawford, 2016).

At the basis of ethically problematic project design often lies researchers' lack of knowledge about both the ethical and technical aspects of their research projects that are increasingly multidisciplinary in nature (Vitak et al., 2016). One could easily envisage a scenario where a data scientist analyzing a dataset provided by a social media company is not fully aware of the ethical challenges regarding data analysis without consent from the participants. On the opposite side, one might imagine a psychologist trying to anonymize their dataset without the appropriate technical knowledge about the limitations of data anonymity and the risk of re-identification of the participants.

7.2.2 The relationship between researchers and ethics committees

As current research practices in psychology and sociology mostly involve human research participants, in the US scholars need to submit their projects for oversight to American IRBs. The situation in Switzerland is more complicated because the HRA applies only "to research concerning human diseases and concerning the structure and function of the human body" (Art. 2 HFG). Thus, by definition, many types of sociological and psychological research projects, although they involve persons, fall outside of the HRA, for example marketing research. In most countries, including the US and Switzerland, the increased digitalization of much of this research, and the absence of specific guidelines or comprehensive ethical frameworks for Big Data projects (Vayena et al., 2015; Kaplan, 2016) creates new important challenges for both researchers and regulatory bodies towards the adequate ethical design of research projects with Big Data methodologies (Shilton and Sayles, 2016), their proper evaluation (Vitak et al., 2017; Bruckman, 2014), and the institution of standardized criteria to assess them (Ienca et al., 2018).

7.2.3 Research questions

To better identify and address these challenges, we examine the attitudes of researchers from the fields of psychology and sociology towards Swiss ECs and American IRBs. More specifically, we aim to focus on the following research questions: a) what are for researchers the main challenges with Swiss ECs and American IRBs when evaluating projects using Big Data methods, b) what are according to researchers the main factors influencing their relationship with ethics committees, and c) what kind of recommendation do researchers give to improve the evaluation process. For this purpose, we have conducted interviews with researchers from eminent universities both in Switzerland and the US. We focused on psychology and sociology because 1) they are among the most underregulated research fields in the academic context (Fiske and Hauser, 2014; Vayena et al., 2015), especially in Switzerland (where the current study was conducted) and 2) Big Data research methods are questioning both the concept of human research subject (Metcalf and Crawford, 2016) and the current regulatory framework of academic research projects such as the Federal Act of Data Protection and the Human Research Act (Weber, 2010).

7.3 Methods

We carried out 39 interviews with academic researchers from prominent American and Swiss universities (professors, senior researchers, or postdocs) working with Big Data in the fields of psychology and sociology. The selection of the participants, based on their involvement in Big Data research, was carried out systematically and through snowballing. After compiling a list of keywords linked to Big Data (e.g. social media, data linkage, machine learning, neural networks, data mining, algorithms etc.), the first author systematically browsed the professional pages of all professors affiliated to the departments of psychology and sociology of all twelve Swiss universities and the top ten US universities according to the Times Higher Education University Ranking 2018 (accessed on December 13 2018) and selected those that had the keywords appearing in their personal page. Other participants were identified through snowballing. The selection process identified a number of data scientists working on research projects in the fields of sociology, psychology and similar fields (political science, behavioral science, neuropsychology). They were therefore included in the sample as their profile matched the selection criteria. For this manuscript, we included a total of 35 interviews with 16 Swiss and 19 American researchers. Four participants were excluded because at the time of the interview they were not involved in research projects that adopt Big Data methodologies. The research was part of a wider project that aims to investigate the ethical and regulatory aspects of Big Data research (Favaretto et al., 2019; Favaretto et al., 2020).

Ethics approval was sought from the competent Cantonal Ethics Committee and the study was deemed exempt by the Ethics Committee northwest/central Switzerland (EKNZ). Oral informed consent was sought prior the start of each interview. To ensure clear consent, the purpose of the overall study, the role of the interviewer in the project and the confidential nature of the interview were briefly restated prior to the start of the interview.

A semi structured-interview was used, designed upon the knowledge established during the theoretical phase of the project. Questions included information about: a) institutional regulatory practices for Big Data research; b) experiences and attitudes with American IRBs and Swiss ECs; c) understanding of the term Big Data and attitudes towards Big Data studies; d) the researcher's opinion on data driven research. See Table 1 for relevant interview questions for this article.

Interviews were tape-recorded, transcribed verbatim and transferred into the qualitative software analysis MAXQDA (Version 2018) (Guest et al., 2011). Data analysis was carried out using applied thematic analysis (Braun and Clarke, 2006). Detailed information on the study design, sampling and data collection and data analysis can be found elsewhere (Favaretto et al., 2020).

Most of the data presented in this paper derived from questions related to regulatory practices and ethics committees (see Table 7-1). Regarding the other topics, some have been analyzed in past manuscripts (Favaretto et al., 2020) and others will be analyzed in future ones.

Table 7-1: *Sample questions*

Sample questions
Did you have to ask approval to an Ethics committee to perform your research?
Did you have to ask for approval at an institutional level (IRB)? Did you have to ask it also at a Cantonal (EC) or federal level?
Could you describe the process for getting the approval?
Did you find your experience with this digital project in any way different from other non-digital research projects with regards to the ethics approval?
Did any ethical dilemmas emerge during the ethics approval process?
Do you have any suggestions on how to improve the ethics approval process?

All text segments of the 35 interviews that were coded within topics a) and b) were subsequently read again, analyzed and sorted into sub-codes. This phase was carried out by the first author and checked for consistency and accuracy by the second author.

7.4 Results

The 35 interviewees were psychologists, sociologists and data scientists involved in human subject research projects. Among the participants, 16 were Swiss and 19 were American scholars. The majority of the respondents (n= 31) were professors while four were senior researchers or postdocs at the time of the interview (See table 7-2).

Table 7-2: *Demographics*

	Sociology (S)	Psychology (P)	Data Science (D)	Total
CH Researchers	8	3	5	16
US Researchers	12	5	2	19
Professors	19	7	5	31
Postdocs/Senior researchers	1	1	2	4

The interviewed researchers were involved in a large number of heterogeneous research projects involving Big Data methods and technologies. Our participants used a variety of different types of research data.: Sensing devices and sensor data (e.g., smartphone data, GPS, fitness trackers, Wi-Fi interactions); physiological data (e.g., electrocardiograms, eye tracking); medical data (e.g., neuroimaging, blood samples, x-rays, genetic data); administrative data (e.g., university and state records, federal records, juridical, tax and census data); publically available data (e.g., newspapers, books, websites, public documents, data on public figures); social media data (e.g., Twitter, Facebook, GAAB, Telegram, Reddit); interview and survey data; crowdsourcing data (e.g., M-Turk, Crowd Flower, Safecast); data from companies (e.g., anonymized/aggregate purchase data, traffic phone data). The analysis of the researchers' attitudes towards ethics committees identified three major themes (and several subthemes): (1) Researchers' personal experiences with American IRBs and Swiss ECs and their opinions about the ethics approval process; (2) perceived challenges for ethics boards with respect to Big Data research; (3) suggested solutions to improve the ethics approval processes. The themes and respective subthemes are presented in Table 7-3.

Table 7-3: *List of themes and subthemes*

Theme	**Subtheme**
1. Researchers' experiences with ethics approval of Big Data research	
1.1. Positive experiences	Productive relationship with the ethics committees Role and importance of ethics committees
1.2. Negative experiences	Bureaucracy as hindrance for research Lack of support from ethics committees Legal protection versus ethical reflection Strategies to avoid strict regulations
2. Challenges for ethics committees	Composition of boards & lack of harmonization Big Data is exploratory Difficulty to assess harm in advance Consent issues
3. Suggestions	Separate evaluations of different types of research projects Introduction of different types of expertise in ethics boards Improvement in support and communication Harmonization of ethics approval Implementation of guidelines

To illustrate the reported results, representative anonymized quotes were taken from the interviews.

7.4.1 Researchers' experiences and opinions towards regulatory bodies

Positive experiences and opinions

Many participants, especially those in the US, reported having a good experience with the ethics approval request. A few of them attributed this positive experience to the efficiency and straightforwardness of the process and to personal expertise. For instance, P11 (Psychologist, US) noted, "It was fairly straightforward. I mean, I've acted as a chair of an IRB for a number of years myself, so it was very easy to be able to understand what was needed".

For many other researchers, the key positive component derived from a close and productive collaboration with the ethics committee that involved dialogue, negotiation, and consultation. P4 (Psychologist, US) shared:

> We interact with the IRB all the time so we have quite an ongoing relationship with...I don't think we get any favor treatment necessarily but we know, we know what is expected and we know people that can help us when we're not sure about some things.

One of the participants highlighted that such a close collaboration might be fruit of the new developments and challenges that Big Data projects pose both for researchers and EC members:

> So it was like a consulting together with the ethics board. So they basically supported us in developing this proposal. Which was quite a long process, and so I guess I didn't have a specific set of guidelines with the tick...check boxes that I walked through. I think we had the first study of this kind, that was conducted by my university. In that sense it was also kind of new idea to the ethics board. (P28, Sociologist, US)

The positive experience of many respondents also came from the fact that they had the impression that the ethics committees were fully committed to support the progress of research. For instance, P22 (Sociologist, US) noted, “So they want research to be able to happen. And they point out ways to make it more productive and safer for the researcher and the participants”.

Some researchers also emphasized the important role of ethics committees as gatekeepers of good research. On this regard, P2 (Sociologists, US) claimed:

> The role of the IRB, like IRB type bodies, (is) keeping researchers accountable in terms of data practices. I think that the IRB does a fine job, kind of making sure that researchers are accountable, that they take the right steps to anonymize the data, to make it confidential, to store it in safe places and all of these things.

On a similar note, some researchers, particularly from the US, shared how ECs incited ethical reflection and assisted them in foreseeing ethical issues in their research projects. For instance, P20 (Sociologist, US) claimed:

> Our IRB is very good in keeping us honest, it's very good at ensuring that we’re being thoughtful about these issues and they’re quite responsive. So yeah, we work early and often with our IRB to make sure that we're handling our research in an ethical fashion.

One Swiss researcher, while discussing the necessity of installing an institutional ethics committee (IRB) at their home university, stressed the importance of the ethics approval process as an educational tool both for students who want to approach research and senior researchers who supervise students' projects:

> It is also from an educational point of view. (The) student has really to think about what they are doing. And you have to have all the documents, the hypothesis, and so on together. And you just can't say: "Oh let's see you know when we are starting". No. You have to have it together. So I really appreciate it on that level and it also I feel puts the responsibility on the senior researcher to say: "Am I really signing that or not?" I hope they get it (the IRB) going because I think it's important. (P24, Sociologist)

In a similar vein, a few participants considered the ethics approval process to be an essential part of good research even if it the process was not mandatory for their projects. For instance P37 (Sociologist, CH) claimed:

> These days, (it's) still not mandatory. It's more something you would be well advised to probably go through as a process, if your project is approved. And I think it's becoming increasingly important but it's not something that is, at least not for us, a legal requirement.

In some cases, respondents sought for a kind of reassurance or confirmation from the ECs that that their research was ethically sound.

> I don't know if it's required. I mean, for every project, I go through human subject review, even if I think that's exempt. Because I want them to tell me it's exempt if it's exempt. That's fine. (…) It's a practice. (P6, Sociologist, US)

Even researchers that reported some of the negative aspects of ECs, still underlined the significant relevance of the ethics approval process. For instance, P17 (Psychologist, US) shared: "The IRBs I 've worked with have been pretty good, I mean, some of them are like a little sort of aggressive but I think is better to be overly nitpicky than to be over relaxed".

On the same note P1 (Sociologist, US) highlighted how the sometimes overbearingly strict protocols of American IRBs, might be justified due to the unpredictable ethical implications of Big Data research. They shared:

> As a researcher sometimes it frustrates you that the requirements of like, you know, data protection (…) and the procedures, and the bureaucracy that you have to go to get approval are kind of tedious. But I understand why it's necessary, you want to err on the side of caution and you want to make sure that you're...like being over protective is far better that being underprotective. It's justified in the sense that we

> are collecting data that we don't fully understand the implications of, with respect to people's private life.

This might explain why one researcher expressed the explicit desire to expand the ethics committees' role especially given that multidisciplinary collaborations with Big Data projects are advancing.

> You know, a lot of people especially on the engineering side, the computer science side, were doing this type of work completely unaware of any potential issues or any potential....you know, ethical issues specifically that are going on with that (Big Data) research. (P12, Sociologists, US)

Negative experiences and opinions

Various respondents voiced critical opinions about ECs and some of them reported facing explicit negative experiences. These respondents generally found the ethics approval process frustrating and confusing because they were uncertain about the necessary steps to undertake to achieve approval in a timely fashion.

Bureaucracy as a hindrance for research

A number of researchers consistently complained that ethics approval is an extremely prolonged process. For instance, P6 (Sociologist, US) reported: "Yeah. I mean, (it was) time consuming…we're still trying to secure final approval for some of the pieces of the project. After seven months!" Swiss researchers also reported high costs associated with the approval request. For example, P32 (Data Scientist, CH), who wanted to submit an additional request to the competent Cantonal Ethics Committee for an already running project said: "And ethics requests now cost two-thousand francs a piece. And it's a lot of money if you only have little addition. (...) And that is above frustrating in that case".

The perceived bureaucratic burden was often seen as a hindrance to pursue further research or develop new projects. P22 (Psychologist, CH) noted: "There we decided to not pursue scientifically interesting ideas due to constraints that are following the ethical approval procedures".

On a similar note a US researcher shared:

> At a certain point of my research I wanted to stop everything and just, I don't know, develop a framework, a form, an online form (…) because I was filling forms with my own hands and I'm talking about like 30 pages of documents. (…) It's crazy

> because you need to fill, I don't know, five or six forms with the same data, three, four times and then make copies. (P21, Sociologist)

Lack of support from ethics committees

Lack of support from the ethics committees on how to prepare the approval documents was one of the most frequently cited critiques both among Swiss and US researchers, For instance, P35 (Sociologist, CH) said:

> I personally believe that institutions should provide more support. Make the process more efficient because there's so many different people working on data these days, probably at least 20 percent of professors of an institution. So everyone basically has to go through this process anew and I think this is not very efficient. There is not....a unit that basically guides that process.

Similarly, a US researcher (P16, Sociologist) expressed the necessity of providing support throughout the project's full life cycle in order to assist researchers with the ethical challenges that Big Data research poses (e.g. computer security and data management) also after approval has been obtained. They shared:

> There does seem to be kind of a big gap even in the existing system. (…) There's very little follow up and very little support for sort of making sure that the things that are laid out at the IRB in the proposal and the project protocol actually happen. Not that I don't believe that most researchers have good intentions to follow the rules and all of that but there are so many of kind of different projects and different pressures that that...things can slip by and there's...there's nobody.

For one Swiss researcher (P34, Data Scientist), the lack of support was particularly aggravating due to their poor acquaintance with the ethics approval process. They shared:

> I had to write this proposal which was difficult for me because I did not have any experience with all these terms. So I had to ask what does this mean, what does that mean. So you know, it was like a different language to me, kind of. And it took some time and it cost money. So for me it was just painful.

Legal protection versus ethical reflection

Finally, numerous participants, especially from the US, but also from Switzerland, were concerned that the rulings of ethics committees are more about offering legal protection to the research institute than about protecting human subjects and that in the end ECs are nothing more than legal committees.

An American scholar (P14, Psychologist) noted: “The general view is that IRBs exists more to protect the institution than the research participant. In other words, they focus more on legal causes and more on that kind of risk than really protect…human research protection”.

Another Swiss researcher (P30, Sociologist) while sharing his experience with the American IRB system shared:

> I think in the US that it is not necessarily that these are people that deeply care about research ethics but it's essentially CMA, it's like "cover my ass". It's what universities do to legally protect themselves because otherwise they will get federal fines and be cut out of certain funding schemes. And so the original motivation is legal protection and not like any ethical consideration which leads to absolutely ridiculous demands and processes.

Possible harmful consequences

Due to a lack of skills of board members and insufficient support and oversight of ECs, some researchers were concerned by the ease with which some researchers could create strategies to get harmful projects to be accepted. On this, an American scholar, P18 (Data Scientist), shared:

> So in the end if I wanted to spin it to minimize the perceived harms rather than the actual harms, I could have done so. (…) But I think that a lot of the ethical details ultimately did come down to me because I don't think the IRB was equipped to judge.

7.4.2 Challenges that Big Data and digital research are introducing for ethics boards

Some of our respondents highlighted how, at the moment, ethics committees are not appropriately equipped to deal with Big Data and digital research. On this, P13 (Psychologist, US) commented:

> The IRBs are not up to speed on the nature of the event: how the platforms for storage of Big Data … or how to share Big Data … or, how to have a server where people could come in and do analytics on data because you might have... I think it's changing everything in terms of who has access, who should have permission.

Along the same lines, a couple of researchers had the impression that ECs’ procedures of regulating contemporary research are becoming obsolete (old-fashioned) in light of digitalization. For instance P2 (Sociologist, US) shared:

> I mean I think it's very complicated, I think that the IRB procedure was designed for very specific goals. I mean there are many different reasons why the IRBs exist, to some extent to prevent some of the scandals that took place, the Tuskegee experiments and kind of cases of medical malpractice. Just the framework is just not well designed for the current landscape of data ownership, and data studies.

Composition of the boards and lack of harmonization

Another complication that was reported quite frequently by the researchers was related to the composition of the ethics committees.

Lack of harmonization and standardization between ethics committees and lack of continuity of their board composition were seen by some researchers as hindrances for an objective and structured evaluation of research projects. P22 (Psychologist, CH) shared:

> Sometimes due to changing committee members… perhaps subjective experience, I don't know… sometimes the treatment of certain questions changes slightly. And that is, annoying is the wrong word but…I think it's sometimes that makes the prediction of what you have to write in a proposal, what you have to prepare for, a bit difficult.

P5 (Sociologist, US) noted:

> Part of the challenge that sometimes you could get a different answer from one place to another (from University to University). And there are not many tools that help us standardize that, right?

The lack of harmonization was further exacerbated when Swiss researchers were conducting projects involving different EU countries; for instance, P32 (Data Scientist, Switzerland) noted:

> We had to go through three ethics committees in different countries which is... (laughs) not easy even though, all of them should have a harmonized way of doing it. But it was very different in practice. So the questions that came were very, very different in each of the countries.

In addition, some researchers argued that the ethics committees members' often fail to understand the specific needs and approaches of single research projects. For instance, P30 (Sociologist, Switzerland) commented:

> So it's just...that the lack of understanding of the field was difficult. And I think it had to do with the kind of approach that no matter what the research question is or kind of the

> subject, as long as they're humans and something, they have certain guidelines, there are certain questions they have to ask.

On the same note, P8 (Data Science, US) shared:

> One of the comments that we got back one time was: why are you collecting so many measures, you should be able to tell just from the heartrate. And that was actually not the purvey of the IRB. I mean, then they certainly don't understand, they didn't understand that no, just one measure isn't enough.

Some participants connected this lack of understanding and subjectivity to the composition of the ethics committees boards, which, due to their original purview to regulate medical research, are mainly composed of medical doctors. For a Swiss data science researcher (P29) this was particularly problematic in light of the digitalization of research. They noted:

> But at this point, I guess we are a bit biased or those boards are biased because they're used to conflicts in say medicine and human projects (…). Because if biologists are reviewing our projects there will be again this big gap between potentially what they perceive and what we do.

Similarly, P38 (Sociologist, CH), while discussing the delays related to the ethics approval of their project, reported:

> At that time the ethical committee was basically composed of doctors and people from the medical domain. And so the first response we got was no. Because basically they didn't really understand what was at stake. So they preferred to reject. So we had to actually document a lot what we had to do before it was approved.

Specific Big Data research challenges

Some researchers also highlighted some of the specific challenges that Big Data research is introducing for ECs.

One researcher P32 (Data Scientist, US) explained how Big Data exploratory studies do not have a clear research question. In addition, it is sometimes problematic for researchers to ask ethics committees to make amendments, for example to include additional data fields or acquire a supplementary variable for the dataset, as they cannot predict the need of such variables in advance. While describing their project they commented:

> I think that, some of the difficult parts are like if we do data science on the data (…) but it's not a clear medical question. (..) It's something that it's then used in decision support tools (..) but it's not to....it's not any specific pathology or disease. So that is,

> for an ethics committee, what's the benefit. So there's no direct clinical question. (..) I mean sometimes it's...as I said like modifications are complex right now. So to do an amendment is often needed even if you need an additional data field. Because sometimes you realize, when you are actually doing the analysis that that might be a link with the different variable that you hadn't acquired.

Two other researchers emphasized how Big Data is challenging the concept of consent for research studies. For instance, P4 (Psychologist, US) shared:

> And it is interesting by the way around Big Data because in many cases, those data were generated by people who didn't sign any consent form. And they have their data used for research. Even secondary analysis of our own data the question is: what can you do without consent. And I think IRBs are still wrestling with that problem and I think it's become even more eh important as we are required to put our data in an archive somewhere anytime we publish a paper.

Connected to the issue of consent, an American researcher (P22, Sociologist) raised the concern that with data studies it is quite difficult to assess the risks for subjects in advance:

> How do we handle things like using people smartphone's data...that I mean that, is a consent that they give once, can they really give informed consent and these type of research where they, they don't really know what's happening in the next four months or whatever. So I think this whole...research area that's happening outside of the controlled environment, there (…) the ethics questions are a bit more complicated, and there are open questions.

The same researcher was also the only one who raised the issue of what constitutes human subjects in Big Data research. They noted:

> Of course, as you know well there are challenges around what exactly is human subject research with Big Data. What exactly do you need permission to do. You know, who you're allowed to look at and who you're not. Like who's expecting to be looked at and who is not.

The same researcher raised another interesting challenge related to the regulation of multi university collaboration where issues of data sharing and security might arise:

> I think the one thing it gets tricky...so in this case is a multi-university collaboration. And we really haven't updated IRBs rules around data storage and sharing so it's still all unclear. (..) So some of these things are still worked out but luckily on this

> particular team we have collaborators who are savvier than the IRB data security. So I feel confident that our data are secured. But we sort of had to make it that ourselves.

7.4.3 Projections towards the future and recommendations for ethics committees

Our participants expressed some opinions towards the influence that Big Data is having on regulatory bodies. For instance, some of them underlined how Big Data will act as a crucial remodeling factor for how ethics approval is handled in light of an overarching trend towards digitalization of research, especially in the field of social sciences. P23 (Sociologist, CH) argued:

> We will see changes I think, with regard to ethics boards because we do have to make decisions that take into account what we're going to do with the data later on, how do people give us consent to use data right away. So there's issue that are being introduced, that are also pushing small places like this (their home university that has a focus on humanities) where people think we don't have any ethical issues.

Suggested recommendations

Many researchers also gave some suggestions on how ECs could better understand and meet the needs that researchers have in light of the difficulties raised by Big Data research.

Evaluation of different types of research projects

Some scholars, both from the US and Switzerland, underlined that there is a timey need to critically evaluate what kind of projects need ethics committees' approval to avoid wasting resources. On this, P9 (Sociologist, US) shared:

> I'm just saying that I think it's...that it's a good moment to consider what sorts of projects require review and what do not. So in general I would have a much lower level of considerations required to review a lot of the stuff that's happening with survey data or Big Data even.

Similarly, a Swiss researcher (P24, Psychologist) suggested to develop a scheme to clarify if, how and where different projects need to be approved. They stated:

> We were thinking as well what is...what is the research that needs a full ethics application or not, that needs to go to the canton. Which one needs a kind of more light procedure and which one needs that you adhere to the guidelines of Helsinki. So we thought about a schema to discuss all the questions: do you randomly select

> participants, do you pre-select them, do you have gatekeepers, is the person able to give consent, informed consent and so on…

Introduction of different types of expertise in ethics boards

Some researchers suggested to introduce members with diversified skills and knowledge in ethics committees in order to properly evaluate the details of different research projects. This seemed particularly important in light of the digitalization of research. For instance, P35 (Sociologist, CH) claimed:

> I mean in a company that deals with data, they have units that employ professionals to go through all these different things and they have the computer science experiences, security experience, the legal experience and all this. And so I'm wondering why at universities this is not much more streamlined.

Such diversification of knowledge was suggested both in terms of expertise but also in terms of population demographics. On this, P17 (Psychologist, US) shared:

> I think that the population that has a stake in the IRB is sort of represented in the IRB, like the board to be diverse not just sort of in terms of sort of intellectual background but also sort of like demographics like race, gender, sexual orientation, gender identity, disability, the obvious, these sort of variables.

Improvement in support and communication

A few researchers gave suggestions related to the betterment of communication between the ethics committees and the researchers.

Two researchers for instance highlighted the importance of developing a relationship between researchers and ECs. On this, P28 (Sociology, CH) emphasized how, when proposing a research design that goes beyond what ethics committees are familiar with, it would be helpful to have the chance to interact directly with the EC's members, in order to develop trust between the committee and the researchers. They noted:

> Well, in our case it certainly helped (the Q&A session between the ethics board and the research team). I mean we had a second submission to the ethics board that went a lot more smoothly because by they knew of our type of doing research, of collecting data. I guess that they understood that we are responsible people.

Two other researchers, felt that in order to give more support to researchers, ethics committees should establish an official intermediary person that researchers could contact in case of necessity. On this P32 (Data Scientist, CH) noted: "A thing is it's best to have a person that you can call. Like having a direct contact person, where somebody can ask questions before submitting."

Harmonization of ethics approval and sectorization

Harmonization of the ethics committees' approval between different committees and the separation between the legal and ethical analysis of projects were other suggestions given by our respondents. For instance, an American scholar (P5, Sociologist) reported that the best way to deal with Big Data and digital research would be to work towards standardization of practices between different American IRBs. They shared:

> Often I work with them (the IRBs) for helping. So building tools that will help them to standardize more, how the different IRB groups or offices work. And that's why it was our hope with projects like *this* (name of the project anonymized) that would help to (…) standardize a little bit more the response from across IRBs.

A Swiss researcher (P31, Data Scientist) on the other hand suggested to more clearly divide the roles between legal departments and ethics committees and have ECs only focus on the ethical issues of different research projects.

> Well, it's very easy. To make it more ethical. That's you know, don't judge the law in an ethical commission. Which you know, in no means is as regulatory commission. (…) So I would split this process. I think that's reasonable to do. (…) But yes, that would be actually my proposal. Is, if you really want to have an ethics committee, and you call it an ethics committee, please talk with me about ethics, not about regulatory... Because we have a legal department.

Implementation of guidelines and ethical principles for Digital Research

Two researchers reported that many of the challenges that ethics committees are going through with digital research are related to the lack of implementation of appropriate guidelines for digital research in different fields. For instance, P18 (Data Scientist, US) underlined that it would be of the outmost importance to draft appropriate guidelines that safeguard research subjects and that should later be adopted, generalized and enforced by ethics committees:

> I think more work on identifying potential harm and writing ethical guidelines to mitigate those harms (…) there's no statement of social media research ethics or at least one that I've seen that is been widely adopted or recognized. And I think a lot of that would need to be forced from the top down, I don't think researchers

> especially within computer science where there is no human subjects training by default, would accept that in a grassroots way.

The same researcher, together with another participant, suggested that, although digital research in sociology and psychology is case-specific with regards to potential harm and risk for the participants, the Belmont Report would offer a good ethical framework for institutions to adopt as a starting point. They shared:

> I think the Belmont Report principles. The starting point so: beneficence, respect for the individuals, justice. And they would take some work for how to apply those exactly or what it would mean translating to this context. But that would be the starting point.

7.5 Discussion

The present study offers an important contribution to the existing literature as it is the first qualitative study that investigates the opinions and experiences of sociology and psychology researchers navigating ethics review of Big Data research projects in both Switzerland and the US. Interestingly, the analysis of our data did not reveal significant differences between the opinions of Swiss and American researchers. This finding highlights not only how researchers in both countries are struggling with similar issues when it comes to ethical evaluation of Big Data projects but also how the suggested solutions proposed by them are not in contrast. This is particularly significant as these found similarities could be a starting point towards the implementation and management of practical solutions that could be harmonized globally.

The results of this qualitative analysis of 35 interviews with researchers from Switzerland and the US show that the perceived role of ethics committees within academic research is rather ambiguous because they are seen both as ethical stewards of research participants and as legal protectors of institutions and researchers.

Numerous researchers highlighted the importance of ethics committees in foreseeing ethical questions involved in research design and in keeping researchers accountable to protect research subjects from possible harms. Some respondents, however, expressed the concern that ethics committees only function as a kind of safeguard to protect institutions from potential legal liability.

Some researchers reported that they submitted their projects for ethics approval even if their study qualified as exempt. They considered the submission process as part of good research, and sought for ethical reassurance both in the jurisdiction of American IRBs and Swiss ECs.

This raises the question of what should be the limits to the role of ethics committees as ethical gatekeepers. Current research guidelines in the field of social sciences and psychology that cover internet mediated and other Big Data research, place the responsibility for the ethical concerns of research projects mainly with researchers (Anabo et al., 2018). However, as highlighted by some of our researchers, Big Data research introduces novel and unpredictable ethical challenges (e.g., data management and security) that require expertise that social and psychological researchers often lack. In addition, the multidisciplinary nature of Big Data research brings together researchers with heterogeneous backgrounds and expertise. As highlighted by the literature (Buchanan et al., 2011), graduates from traditional computer science might not understand their work as human subject research and lack training in ethics to understand potential issues of harm.

The evaluation of the overall research project by ethics committees might therefore be critical to overcome this lack of expertise and stand as the bridge between various disciplines. Still, asking for ethics approval for numerous projects might become an overbearing task for ethics committees. This bureaucratic burden might create a backlog of requests that could aggravate the time consuming nature of the ethics approval process, and also increase the risk of letting problematic research pass due to oversight and inattention. Gunsalaus et al. (2006) referred to this situation as the mission creep of American IRB system where American IRBs are "overwhelmed by a focus on procedures and documentation at the expense of thoughtful consideration of the difficult ethical questions surrounding the welfare of human subjects", which leads to simultaneous overregulation of projects and underprotection of participants.

For the Swiss context this is crucial in light of the current implementation of ethics evaluation at an institutional level, that is the institution of Swiss IRBs as opposed to Cantonal Ethics Committees. In order to avoid repeating the well reported issue of the American IRB system mission creep, a sound reflection on the role of different levels of ethics committees in Switzerland should be undertaken.

Furthermore, passing on the responsibility to ECs might reduce ethical reflection from the researchers' side and therefore pose a risk for the ethical conduct of the involved scholars during the progression of the project once approval is obtained.

In addition, previous research has shown that without proper expertise from ethics committees, ethical violations might go unnoticed or uncorrected during ethics approval processes (Peden and Flashinski, 2004). In this regard many of our participants believed that ethics committees lack the appropriate expertise to understand their needs and handle the novelties and challenges that the digitalization of research poses. They in fact emphasized some of the main features and issues of Big Data research that are currently challenging the proper evaluation of research projects by ethics committees such as concerns of consent and privacy and the exploratory nature of data research – that make it difficult for ECs to assess risks for research subjects in advance, including possible re-identification.

Our findings also point out how lack of harmonization and of consistent evaluation standards among different ECs was felt by both American and Swiss researchers.

Several participants in fact argued that evaluations and rulings might differ depending on factors linked to the composition of the committee's board such as time – committees change their members after a few years – and location – different university, canton (in the case of Switzerland) and even country. This is in line with a findings of a Swiss-wide survey of clinical researchers who submitted a project for ethics approval in 2017 that expressed the necessity of increased standardization across Swiss ECs as they felt that ECs did not evaluate their projects with common standards (Elm and Briel, 2018).

The perceived incapacity of ECs in keeping up with the necessities of sociological and behavioral research raised by digitalization and the perceived lack of harmonization among ethics committees were attributed to the fact that ECs were originally designed to evaluate clinical trials (Heimer and Petty, 2010). Other researchers, in line with the study by (Shilton and Sayles, 2016), associated this deficiency and lack of harmonization to the inappropriate composition of the board members who often lack the appropriate expertise to evaluate and regulate increasingly digitalized research. Some researchers had the impression that they were more aware and concerned about the ethical issues of their projects than the committee.

This perceived gap between the needs of researchers and the expertise of ethics committees led to the perception that researchers could find strategies to avoid the burdensome principles and bureaucratic hindrances posed by ECs. A study by Schrag (2011) similarly argued that the overbearing requirements of IRBs encourage researchers to find loopholes in the system.

However, several of our researchers reported that committees seemed to have genuine intent to having research proceed. This is in line with the study from Vitak and colleagues (2017), which shows that American IRB staff members aim to provide adequate support to researchers but struggle with the evaluation of diverse research proposals due to the poor guidance of regulations, specifically of the Common Rule.

Critiques about the lack of consistent evaluation standards across American IRBs (Green et al., 2006) and the shortcomings of IRB procedures in sociological research in the US (Schrag, 2011) have been raised also before the advent of Big Data research. However, this inadequacy is becoming more problematic in the era of Big Data since the increased possibilities to store and share big datasets are boosting academic policies for data reuse and multi-university and multi-country collaboration (Daries et al., 2014; Fenner et al., 2019). Without proper guidelines and proper harmonization, global research will progressively be hindered. However, according to Dove and Garattini (Dove and Garattini, 2018) the coordination of international data-intensive research projects raises important practical challenges for the regulatory framework of research ethics review. Some of the challenges raised by their study were linked to jurisdictional diversity in a number of areas and vast cultural divergences between ethics committees in different countries, such as linguistic differences, style of communication, and the way distinct countries deliberate on ethical issues. In the Swiss context, overarching harmonization between ethics committees might be more complicated as Switzerland has three official languages and is based on a federal system. Therefore, cultural differences might need to be taken into account when developing cross cantonal guidelines and regulations.

Lack of harmonization and consistent evaluation criteria thus ask for the implementation of appropriate guidelines to regulate Big Data research. However, while developing a framework to regulate Big Data research, Xafis et al. (2019) argue that, due to the context- dependent nature of the issues related to the use of big amounts of data, an ethical decision making framework should not provide a single set of standard issues or concepts relevant to all Big Data activities. Rather, it should provide support to decision makers by identifying key values when evaluating a range of different Big Data uses. Although mostly directed to health related Big Data, their deliberative balanced approach to decision-making could assist policymakers in identifying ethical issues relevant in the different Big Data uses in psychology and sociology and provide ethics committees with the appropriate tools to evaluate Big Data research in these fields.

According to official statements from regulatory bodies (see for instance The Human Research Act and the Ethics Committees for Research (2016) and Chapter 7 of the “Policy and Procedures” of the Human Research Protection Office of the University of Pittsburg (2015)), ethics committees must be composed of members that have the appropriate skills, expertise and experiences to provide complete and thorough review of research activities. Our findings show how these requirements are currently not appropriately met, not only in the United States – an instance investigated by the American based literature – but also in Switzerland.

It is therefore of the outmost importance to reevaluate what appropriate skills and expertise mean in the era of Big Data research to provide timely and appropriate evaluation of research projects. As suggested by some of or respondents, we argue that ethics committees should update the composition of ethics committees and introduce members with diversified skills and knowledge. Areas of expertise covered within the committees should then transcend those traditionally required for the evaluation of research projects such as "medicine, psychology, nursing, pharmacy/pharmaceutical medicine, biology, biostatistics, ethics and law" (kofam, 2016) and include technical knowledge of computer science, data security, data management and data ethics.

In addition, since at the present moment composition of ethics committees is at the discretion of the responsible institution (different Universities in case of the American IRBs and swissethics in case of Swiss ECs), the standardization of the required expertise of different board members might be one of the firsts steps towards the formulation of consistent evaluation standards and the acquisition of harmonization among different ethics committees that is asked for by Big Data researchers in psychology and sociology.

Finally, researchers both from Switzerland and the US, also often complained about a lack of dialogue between them and the ethics committee members. It was difficult for them to ask for clarification about the forms for the approval procedure. Good experiences with ethics committees were associated with extensive support and contact with the committee members – such as a Q&A session that assisted them in developing the proper ethical design for their research process. Unfortunately, this was not a common practice among ethics committees, especially in Switzerland where researchers go through the competent Cantonal Ethics Committee. To mend this issue, a few researchers suggested establishing an official intermediary such a "contact person" to be reached in case of necessity.

A recent empirical study by Laurie et al. (2018) describes the need for 'stewardship' as a crucial component for regulatory frameworks, including in the implementation of the role of ethics committees. According to this study, some ethics committees members perceive themselves as providing "pastoral" support and stewardship to researchers to promote ethical research, through nudges, comments, and responses to queries (Laurie et al., 2018: 340). However, currently this is argued to be a largely invisible role that needs to be made clear in order to appropriately and harmoniously manage ethics evaluation processes.

The re-evaluation of the role of ethics committees might thus require a higher level of collaboration and consultancy between researchers and ethics committees. This recommendation is in line with the findings of Shilton and Sayles, who argue that "ethics review boards might be best be positioned as consultants to research designs rather than post-hoc enforcement mechanisms" (Shilton and Sayles, 2016: 1917). Such a model could also make the ethics approval process more flexible and approachable for researchers as they could more easily ask for additions and amendments of their projects without being blocked by time-consuming bureaucratic hindrances, as it has been highlighted by some of our participants As argued by Raymond in Nature (2019) "we should not be asking those tasked with protecting human participants to single-handedly identify and contend with the implications of the digital revolution" (Raymond, 2019). Together with the re-evaluation of the ethical principles of the Belmont Report in order to better frame potential risks and ethical issues in Big Data research in psychology and sociology (Vitak et al., 2016; Anabo et al., 2018), a consultancy model could also promote a shared responsibility partnership between researchers and ethics committees. By joining their diversified expertise it would be easier to flag the potential ethical concerns of research projects and provide better protection for research subjects.

7.6 Best practices

Due to the ethical and regulatory challenges in Big Data research, scholars are currently calling for a reexamination of ethics committees and ethics approval processes (Prosperi and Bian, 2019; Raymond, 2019). This study aims to contribute to the proper implementation of ethics committees by understanding and addressing the challenges that EC members and researchers face due to digitalization of research. Our study illustrates how the current composition of ethics committees seems not to include the appropriate expertise required to evaluate increasingly digital studies which might cause ethical violations to go undetected. In addition, it also highlights how lack of harmonization and consistent evaluation criteria among different committees was felt problematic by our respondents.

We argue that members with additional and diversified technical expertise of computer science, such as data security, data management and data ethics, should be involved in the composition of ethics committees in order to better face the novel and unpredictable ethical challenges that Big Data methods are introducing in research. In addition, the standardization of the required expertise across committees might increase the chances of having homogeneous evaluations of similar research projects across universities and countries, thus promoting harmonization of ethics committees and the design of consistent evaluation criteria. However, as it might be difficult to have enough data experts for each institution, another solution could be the institution of national or regional/state commissions for data research specialized in the evaluation of Big Data projects. Such more regional commissions could also promote the harmonization of decisions over different projects at least at a regional or state level.

Finally, as many of our participants complained about experiencing insufficient assistance by ethics committees about the appropriate ethical design of their research proposals, we argue that institutions should provide resources to offer pre-EC submission consultancy to researchers and make standards more transparent. An approach that focuses on consultancy, although demanding to put in place, has been explored for industrial research labs (Bowser and Tsai, 2015) and similar approaches could also be implemented for academic institutions. Such a model could assist researchers in having more flexibility from committees when their projects are in need of unpredicted additions or amendments and also promote a level of shared responsibility that will enhance appropriate protection for human participants in Big Data research. On the other hand, completely abandoning the gatekeeper role of ethic committees' might become problematic from an ethical standpoint. An ethically acceptable solution could then be a combination of the two: a consultancy approach that helps to clarify and flag the specific issues of a project that is then followed by formal EC approval. For the Swiss context the current implementation of institutional IRBs in Switzerland might be the right occasion to develop such collaborative strategies between researchers and regulatory bodies.

7.7 Research agenda

Since the data for this manuscript comes from a research project that aimed at investigating the ethical and regulatory challenges in the field of psychology and sociology, our respondents were mainly from these two disciplines. The data scientists that we interviewed were strictly connected to research projects in these two fields. As a result, we might have overlooked the perspectives of other relevant fields for human subject research that make use of Big Data methodologies (e.g., medicine, nursing sciences, geography, urban planning, computer science, linguistics, etc.). Psychology and sociology were chosen because they are among the areas of research that are currently challenging the concept of human subject research and the endeavors of ethics committees the most. In addition, since the findings are based on a small sample size, they are not necessarily generalizable to other disciplines. Future research should expand to other disciplines in order to acquire a more comprehensive understanding of the opinions and attitudes of researchers from multiple disciplines. Moreover, although our questions explicitly focused only on Big Data research and the participants were asked to share exclusively experiences and attitudes related to Big Data methods and research projects, we cannot exclude that some of the shared opinions and criticism about ethics committees were related to ethics approval procedures in general. Finally, our findings only included the perspectives of researchers working with Big Data and not those of ethics committees members. Although in our cohort there might have been participants also involved as committee members, future research should endeavor for comprehensive analysis of the perspectives of EC members worldwide.

7.8 Educational implications

In case it is not possible to implement the recommendations mentioned above, it might be effective to engage members of ethics committees and also researchers in specific training regarding the ethics of Big Data research. This will provide them with strategies and tools to better approach the complexities of digitalized research. This approach has been recently proposed by Sellers et al. (2019) with regards to social media research and we argue that a similar approach could be extended also to Big Data research. In addition, we also take into account Vitak et al. s' suggestion (2017) that due to the multifaceted nature of the ethical issues involved in digitalized research, ethics committees might have to evaluate studies on a case by case basis. In this regard expertise on the appropriate steps to take to evaluate diverse types of digital research will be achieved by building practical experience during the years in the evaluation and assessment of numerous different cases, different types of risks and consequences for research participants. While building this expertise, ethics committees could also establish an official registry where cases are summarized and published together with the different criteria the boards have used for decision-making. Such a registry could further discussion and exchange among different committees and ultimately lead to better harmonization.

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Chapter 8 – United in Big Data? Exploring scholars' opinions on academic-corporate partnership in digital behavioral research

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8.1 Abstract

The growing amount of data produced through digital technologies holds great promise for advancing behavioral research. Scholars worldwide now have the chance to access an incredible amount of personal information, thanks to the digital trace users continuously leave behind them. Private corporations play a crucial role in this scenario as the leading collectors of data on users, thus creating new incentives for partnerships between academic institutions and private companies. Due to the concerns that academic-company partnerships might raise and the ethical issues connected with Big Data research, our study explores the challenges and opportunities associated with the academic use of corporate data. We conducted 39 semi-structured interviews with academic scholars (professors, senior researchers, and postdocs) involved in Big Data research in Switzerland and the United States. We also investigated their opinions on using corporate data for scholarly research. Researchers generally showed an interest in using corporate data; however, they coincidentally shared ethical reservations towards this practice, such as threats to research integrity and concerns about a lack of transparency of companies' practices. Furthermore, participants mentioned issues of scholarly access to corporate data that might both disadvantage the academic research community and create issues of scientific validity. Academic-company partnerships could be a positive development for the advancement of scholarly behavioral research. However, strategies should be implemented to appropriately guide collaborations and appropriate use of corporate data, like implementing updated protocols and tools to govern conflicts of interest and the institution of transparent regulatory bodies to ensure adequate oversight of academic-corporate research collaborations.

8.2 Introduction

Over the last decade, due to the growing sophistication of digital technologies and the extensive use of the internet, the amount of data produced by humanity has grown exponentially. Although there is still debate concerning the quality of the data obtained from the world wide web and other digital sources (Boyd and Crawford, 2012), the digital age, the advent of Big Data, and the Internet of Things (IoT) have all created new opportunities for social and psychological research (Chen and Wojcik, 2016; Lazer et al., 2009).

While discussing the impact of digitalization in the behavioral sciences, Matthew Salganik writes, "when you think about social research in the digital age, you should not just think *online*, you should think *everywhere"* (Salganik, 2019). Scientists now have the possibility to access a vast pool of personal information about individuals. The digital footprint left by users through the use of multiple platforms and devices - such as social media (Facebook/Twitter/Reddit), streaming platforms (Spotify/Netflix), Google search queries, online purchases, mobile location, smartwatch recordings, and more - creates extensive records of their habits and preferences. These records can be conveniently used to investigate human activity and interaction, predict personality traits or serve as an external validation of classical interview studies in psychology (Matz and Netzer, 2017; Mønsted et al., 2018). Even more, the exploitation of aggregated data from social media, GPS, radio frequencies, and consumer data can be utilized to design smart city projects that aim to improve various sectors of urban living, such as education, transportation, pollution control, and energy consumption (Hashem et al., 2016).

In the ecology of Big Data research, private companies play an increasingly important role as the primary entities constantly collecting vast amounts of data. Through the provision of heterogeneous services, most of the time in digital form, corporations can collect a wide variety of data about their users. For instance, membership cards record customer purchases; streaming services register preferences regarding music and movies; smartphones track our location; electronic travel cards record our movements, to give a few examples. As the primary holders and owners of that data, commercial companies are frequently the ones performing research and making advances in Big Data research. Corporations have been using data from users and advanced technological resources to conduct research on their customers to improve their services (Kohavi et al., 2020). For example, OkCupid, a popular dating website, declared testing and working on their users' data to increase their predictive matching algorithms (Wood, 2014).

Academic-industry collaborations are a well-established reality dating back to the 1930s and have undergone a significant evolution over the past decades (National Research Council (US) Chemical Sciences Roundtable, 1999). For instance, around the 90s, universities started to be seen increasingly as key economic development actors capable of offering research projects that contribute to industrial innovation in various fields (Mansfield and Lee, 1996). Partnership with academic institutions represents an attractive opportunity for private companies as it grants them access to scientific and engineering talent in specific domains and cutting-edge research (Lutchen, 2018). At the same time, academic institutions and funding agencies recognize private firms as enablers of the collaborative development of capabilities on essential research questions and providers of resources in an environment where funding is limited (Jain et al., 2014).

This apparently mutually beneficial partnership, however, comes with its challenges. Recognized obstacles to developing long-term, collaborative relationships relate to the discussion of non-disclosure agreements and matters of intellectual property (IP) (Lutchen, 2018). In addition, it has been argued that the involvement of the industry's for-profit aims might impact some of academia's research objectives, such as basic research in multiple fields (Dooley and Kirk, 2007; Bekelman et al., 2003). Despite these challenges, the advent of Big Data and the potential it holds towards "solving the world's most intractable problems (…) from stopping terrorists to ending poverty to saving the planet" (Crawford, 2013: 1), plus the wealth of Big Data companies, created new sources and incentives for partnership between the academic and corporate milieus. These incentives were perceived not only in research fields most traditionally linked to corporate collaborations, such as science, engineering, and medicine but also in the humanities and social sciences (Jain et al., 2014; Davis and Binder, 2016).

Despite these promises, increasingly complex ethical and regulatory dilemmas emerge from the use of Big Data methodologies and corporate data in research. Concerns about consent have been raised when data from companies or digital spaces such as social media is used for research purposes without the user's explicit consent or acknowledgment (Rothstein, 2015; Xafis, 2015). Risk of discrimination and disparate treatment, together with possible harm to vulnerable populations (e.g., children, pregnant people, elders) and ethnic minorities, have been highlighted in the literature regarding corporate practices and research (Favaretto et al., 2019). Moreover, the definition of the human subject in research is becoming blurred as a consequence of Big Data methodologies since the subject of the research is most of the time invisible to the investigator, and the consequent implementation of appropriate regulations to protect research subjects is becoming more challenging (Fiske and Hauser, 2014; Metcalf and Crawford, 2016).

Traditional ethical frameworks adopted by behavioral research are based on two main documents, the Belmont Report (2014) and the Declaration of Helsinki (2001). Although primarily developed for medical research, these documents have been used to create ethical guidelines for research practices in other fields, such as psychology and social sciences (Anabo et al., 2018; Paxton, 2020; Salganik, 2019), with scholars constantly striving to adapt clinical research rules to the context of social and behavioral research (National Research Council, 2014). At the core of these frameworks are three fundamental *principles*: respect for persons, which is the acknowledgment of participants' autonomous participation and the need to collect informed consent from study participants; *beneficence*, which is the minimization of harm, either material (physical harm) or immaterial (privacy invasion); *justice*, as in fairness in distribution and dissemination of research outcomes and attention to the selection of research participant.

However, in the context of Big Data research, the interpretation of such principles is inherently challenged. *Respect for persons* is challenged, as mentioned earlier when the research subject is unaware of data collection or does not have control over the analysis of their data (Boyd and Crawford, 2012). It has become increasingly difficult to appropriately uphold the principle of *beneficence* in Big Data research due to the unpredictability of some of the outcomes of Big Data analysis. This concern, along with the abundance of anonymization issues and privacy infringement in Big Data, might cause unpredicted harm to human subjects (Vitak et al., 2016; Zook et al., 2017). Finally, the discrimination and disparate treatment associated with Big Data methods challenge the principle of *justice* (Favaretto et al., 2019). For this reason, recent research has examined how the values and principles embedded in these documents can guide Big Data research beyond the biomedical field and evaluate where (and why) these principles tend to flounder (Anabo et al., 2018; Paxton, 2020; Salganik, 2019; Zimmer, 2018; Steinmann et al., 2016).

Research regulations have struggled to keep up with the ethical challenges that Big Data methods are introducing in research globally. Recent studies have highlighted how there is still uncertainty about appropriately evaluating some of the issues embedded in Big Data research projects. For instance, studies in the United States highlight that Institutional Review Boards (IRB) are currently unequipped to appropriately handle the evaluation of digital research (Vitak et al., 2016; Shilton and Sayles, 2016; Bruckman, 2014) and that there is still little understanding of the unique risks posed by Big Data (Paxton, 2020). For instance, the 2018 revision to the Common Rule, the US policy that regulates research with human subjects in the US, excludes data science research that deals with individuals' data (such as publicly available or anonymized personal data and social media data) from review. This exclusion, it is argued, might result in more harm than good for research participants (Metcalf and Crawford, 2016). In addition, scholars have also highlighted how the absence of specific guidelines and comprehensive ethical frameworks aggravates uncertainty for ethics committees on what criteria to follow to review and evaluate research projects with Big Data methodologies (Ferretti et al., 2020; Ienca et al., 2018).

In this complicated regulatory context, research done by private organizations does not fall under the definition of human subject research, even if it explores human behavior and cognition through their users' data. This is because such research focuses on corporate objectives such as increasing and improving user experience rather than finding generalizable knowledge (Department of Health and Human Services, 2018). Corporations can still go through external private independent IRBs to receive an ethical review of their research. However, it is up to the company to choose to use these services rather than a legislative requisite. This differentiation between academic vs. corporate data use and regulation is becoming increasingly concerning for ethicists and data experts, especially as collaborations between private firms and academic research teams are flourishing (Paxton, 2020).

These multifaceted ethical and regulatory issues might create a backlash against Big Data research, societal fear about the use of personal data by scholars for research purposes, and reservations toward academic-industry partnerships. For instance, the case of the Facebook Contagion Study (Kramer et al., 2014), which involved the partnership between Facebook and a team of academic researchers from a renowned American University, created controversy and was widely criticized by scholars for ethical violations, including lack of consent and possible harm inflicted to research participants (Shaw, 2015). Nonetheless, as the Big Data era incentivizes partnership and data sharing between companies and academia, it becomes crucial to thoughtfully consider the issues, challenges, and opportunities associated with them to foster beneficial Big Data research.

Our study aims at identifying and exploring some of the challenges and incentives related to partnership and data sharing between private companies and academia in Big Data research. There are numerous different types of academic-industry interaction. This manuscript considers two broad categories of academic-corporate interactions: passive use of corporate data and active collaboration for data collection and analysis. The first is when a team of academic researchers can access company databases or obtain data that the company itself previously collected to perform their research projects. For example, a scholar is given access to mobile-phone network data to conduct dynamic urban research (Calabrese et al., 2014). The second is when an academic team and a company actively collaborate to collect data on a specific sample of users. This can happen when a software developer produces a tool – a device or an app – that the researcher then uses to collect data for an experiment (Mitroff and Sharpe, 2017).

To investigate these challenges, we have analyzed the opinion and attitudes of academic researchers involved in Big Data research towards collaboration with private companies and the use of corporate data for scholarly research purposes. To this end, we interviewed researchers in the fields of sociology and psychology from universities both in Switzerland and the United States in order to understand: their interest in possible partnerships with corporations and the use of data from companies for their research projects; the challenges they envisage or face when involved in company partnerships; their opinions towards private companies and the research they conduct. The present study directly investigates, through interviews, the views, and experiences of academic researchers regarding the use of Big "corporate" Data and academic-industry partnership. The study also provides suggestions for academic researchers, partners in commercial companies, and regulatory bodies (e.g., ethics committees) on creating a sustainable space for academic-industry interaction.

8.3 Methods

8.3.1 The NRP75 Project – Scope and Aims

This study is part of a larger project that explored the regulatory and ethical issues of Big Data research in psychology and sociology. The project is entitled "Regulating Big Data research: A new frontier" and ran between the 1st of February 2017 to the 30th of April 2021 as part of the National Research Programme 75 "Big Data" (NRP 75) funded by the SNSF (Swiss National Science Foundation) (Swiss National Science Foundation).

Overall, the study aimed at examining existing regulations and the ethical issues related to Big Data research, addressing the need for harmonization of Big Data research ethical and regulatory practices, and providing concrete recommendations to researchers and ethics committees on how to deal with the emerging challenges posed by Big Data research, specifically in the framework of academic research in psychology and sociology. On the one hand, these two disciplines were chosen because they are at the forefront of using Big Data methodologies in projects involving human research subjects directly and indirectly (Metcalf and Crawford, 2016). On the other, because regulation of academic research in psychology and sociology is being particularly challenged by Big Data research due to the risk of unpredictable harm that it poses for research subjects (Vitak et al., 2016) and because of the challenges that these methods introduce for the concept of human subject research (Metcalf and Crawford, 2016). Particularly in Switzerland, Big Data research is challenging the current regulatory framework for academic research projects (the Human Research Act) (2015). In the US, Institutional Review Boards (IRBs) have faced increased uncertainty regarding how to evaluate digital research projects in these two fields (Metcalf and Crawford, 2016). The study, funded by the Swiss National Science Foundation, was designed to investigate Big Data practices in Switzerland, the home country of the study, where federal institutions are starting to focus on the development of Big Data for research practices. The United States were chosen as a comparative sample because they were identified as a country where Big Data has been a focus of academic research for several years, as evidenced by the numerous federal grants placed for Big Data research (National Institute of Health, 2019; National Science Foundation, 2012; National Science Foundation, 2014). In addition, since the overall project aimed to analyze ethical and regulatory practices, the research team selected a country that shared similar ethical research frameworks with Switzerland – the Declaration of Helsinki and the Belmont Report (Department of Health Education, 2014; World Medical Association, 2001).

8.3.2 Sampling

The study gathered data from 39 semi-structured interviews with 19 American and 20 Swiss researchers (professors, senior researchers, or postdocs. Participants were selected systematically and through snowballing, based on their involvement in Big Data research in psychology and sociology. Inclusion criteria for selection in our study were: 1) academic researchers, from postdoc to professor (Ph.D. students were excluded); 2) involvement in Big Data research; 3) involvement in research in psychology or sociology. Due to the study's broad aim, collaboration with a company was not considered an inclusion criterion. In addition, no demographic information about the corporate partnership between recruited participants and private firms was systematically collected.

For the purpose of our study, we have defined Big Data as an overarching and inclusive umbrella term that comprises a set of advanced data techniques (e.g., artificial intelligence, neural networks, deep learning, natural language processing) used to analyze large datasets of heterogeneous data to reveal trends and patterns related mainly to human behavior. To identify suitable participants, the research team compiled a list of 17 keywords linked to Big Data, such as Big Data, internet, social media, data linkage, neural networks, etc. (see table 1). Subsequently, the professional page of professors affiliated with the faculty of sociology and psychology was systematically browsed by the first author for 1) all twelve Swiss universities (ten universities and two federal institutes) and 2) the top ten US universities according to the Times Higher Education University Ranking 2018 (accessed on 13.12.2018). Participants that had these specific keywords appearing on their personal page were selected. Snowballed participants were identified by asking interviewees to suggest the names of up to five possible candidates that would meet the criteria to fit in our study. The snowballed participants were then contacted via email, stating that the correspondent interviewee suggested their names. Since the selection of the sample identified a consistent number of data scientists working on research projects involving data from human subjects, some scholars with a background in data science were included in the sample as their profiles matched the selection criteria set for our study.

Table 8-1: *Keywords for participants' selection*

Keywords for Systematic Web Search
1. Big Data
2. Internet
3. Social Media
4. (Data) Linkage
5. Neural Networks
6. Machine Learning
7. Computational/Computer Based
8. Prediction
9. Data Mining
10. Algorithms
11. Data Analytics
12. Deep Learning
13. Profiling
14 Scoring System
15. (Algorithmic) Modeling
16. Network Analysis
17. Informatics/ Bioinformatics

The research team identified and contacted 194 possible participants – 50 for Switzerland and 144 for the United States. Of those, 39 scholars - 20 from Switzerland and 19 for the US - accepted the interview. Table 8-2 provides a list of the universities included in our sample.

Table 8-2: *Number of participants per selected institution*

Switzerland	
Systematically browsed	**N. of participants from the institution**
University of Basel	5
University of Bern	1
University of Fribourg	2
University of Geneva	2
University of Lausanne	2
University of Lucerne	1
University of Neuchatel	0
University of St. Gallen	1
Università della Svizzera Italiana	0
University of Zürich	2
École Polytechnique Fédérale de Lausanne (EPFL)	1
Eidgenössische Technische Hochschule (ETH) Zürich	2
Through snowballing	
Institut de recherche informatique de gestion	1

United States	
Systematically browsed	**N. of participants from the institution**
Harvard University	3
Columbia University	1
Massachusetts Institute of Technology (MIT)	1
Stanford University	2
Duke University	4
Yale University	2
California Institute of Technology (Caltech)	0
University of Pennsylvania (UPenn)	0
Princeton University	0
Cornell University	0
Through snowballing	
University of Hawaii	1
University of Southern California	1
Georgetown University	1
Emory University	1
Vanderbilt University	1
Northeastern University	1

The 39 interviewees were researchers with a background in sociology (n=21), psychology (n=11), and data science (n=7). Among them, 34 were professors, and five were postdocs at the time of the interview (Table 8-3).

Table 8-3: *Participants*

	Sociology	**Psychology**	**Data Science**	**Total**
CH Researchers	9	6	5	20
US Researchers	12	5	2	19
Professors	20	9	5	34
Postdocs/Senior researchers	1	2	2	5

The research team asked for ethics approval from the Ethics Committee northwest/central Switzerland (EKNZ). Since, in Switzerland, interviews with experts (not patients) do not fall under the purview of the Human Research Act, the study was deemed exempt by the ethics commission. Before the beginning of the interview, the interviewer briefly restated the purpose of the overall study, their role in the project, and the confidential nature of the interview to ensure informed consent. In addition, the interviewer allowed time for the participants to ask questions.

8.3.3 Data Collection

The interviews were performed between January 2018 and August 2019 by two research team members. The interviewers were two doctoral students with a background in philosophy and empirical ethics and geography and computer science, respectively. Prior to the start of the interview phase, both interviewers took formal methodological courses as part of their Ph.D. education and received training in interviewing skills.

The interviews were conducted using a semi-structured interview guide designed on a systematic literature review on the topic (Favaretto et al., 2019). The research team designed the interview guide through discussion and consensus regarding relevant ethical and regulatory themes and challenges related to Big Data research. Questions investigated topics such as (1) regulatory practices for Big Data research; (2) opinions and attitudes regarding collaboration with private companies; (3) integration of outsourced data (Social Media data, data from smartphones or sensing devices); (4) opinions regarding data-driven research; (5) ethics of conduct with regards to Big Data studies; and (6) definition and understanding of the word Big Data and attitudes towards Big Data research. Most of the data presented in this manuscript derive from questions related to topics (2) and (3). Other papers have covered different topics (Favaretto et al., 2020b; Favaretto et al., 2020c; Favaretto et al., 2020a). The interviews lasted between 35 and 90 minutes. They were tape-recorded and transcribed verbatim. Subsequently, the interviews were transferred into the qualitative software analysis MAXQDA (Version 2018) to support the managing of the dataset and the analytic process (Guest et al., 2011).

8.3.4 Data Analysis

We applied reflective thematic analysis to analyze the interviews. Thematic analysis is a recognized research approach to data analysis in the context of qualitative empirical methods that aims to arrive at an understanding of a particular phenomenon by investigating the perspective of those involved in it (Vaismoradi et al., 2013). Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) that emerge from the data, usually using semi-structured interviews where participants are asked open-ended questions that allow them to share their opinions and perspectives on a topic or phenomenon. In thematic analysis, the importance of a theme is not dependent on quantifiable measures but rather on whether it captures something important concerning the overall research and represents some level of response pattern or meaning within the dataset (Braun and Clarke, 2006; Ritchie et al., 2013). We followed Braun and Clarke's data analysis processes that included several steps: familiarizing with the data; generating the initial codes; searching for themes; reviewing themes; defining and naming the themes; producing the report (Braun and Clarke, 2006). The analysis was carried out as follows.

After data familiarization through reading and transcription, the first and second authors initially coded the data from four interviews based on a close line-by-line analysis. They examined the codes to identify potential themes. The two team members subsequently refined their respective categories and provisional themes by discussing them and checking them against the dataset. This was done to reflect on the data and ensure that nothing had been overlooked. Sub-themes were added, and similar ones were combined whenever needed. Finally, clear definitions and names for each theme were generated. Several relevant themes that openly discussed academic and corporate partnership emerged from the interviews, including a) collaboration with companies and opinion on the use of company data; b) integration of data from sensing devices and social media; c) attitudes regarding the conduct of private companies; d) challenges in collaboration with companies; d) regulatory practices for research in private companies.

Due to the relevance of the content that we found within the data regarding academic-corporate collaboration, the research team agreed to report these findings and engage in the description of how academics perceive collaborating with firms and a discussion of these impressions. While discussing corporate partnerships, respondents shared both a) their personal experiences and collaborations with private firms and b) general opinions regarding the challenges and opportunities between academic-corporate partnerships and the use of corporate data. Since a systematic distinction between these two could not be drawn, the research team agreed that all the themes identified would refer to the general opinions of researchers over corporate collaboration. In addition, neither the questions in our semi-structured interview guide nor the participant's opinion clearly explored the differences/distinctions between active and passive partnerships with corporations. Consequently, the team again agreed to analyze and report the findings as generally referring to corporate partnership, both active and passive. Nevertheless, it is relevant to have both groups represented as this gives an idea of the fundamental challenges that some have encountered and, at the same time, of the (founded/unfounded) fears or hopes of those who do not have any or little experience.

After data analysis, we proceeded with reporting the results of the previous stages. To achieve this, all interviews were analyzed for units of text that related to the themes mentioned above. Such text segments were reread, analyzed, and sorted into sub-codes by the first author. The sub-themes that emerged from the analysis of the text segments included: a) openness of researchers towards the use of corporate data or collaboration with private firms; b) ethical reservations towards corporate research; c) regulatory standards and constraints related to corporate research and partnership with private firms; d) academic vs. corporate research practices.

8.4 Results

Our respondents were participating in research projects that involve the use and analysis of diversified types of data. The table below illustrates the type of data that our respondents were incorporating in their research projects (See table 8-4).

Table 8-4: *Data used by participants*

Type of data	Sociologists	Psychologists	Data Scientists
Data from companies (anonymized/aggregate purchase data, traffic phone data)	P35CH-S; P38CH-S; P1US-S.		P18US-D; P29CH-D.
Sensing devices and sensor data (smartphone data, GPS, fitness trackers, Wi-Fi interactions)	P28CH-S; P38CH-S; P20US-S; P22US-S.	P22CH-P; P4US-P.	P18US-D.
Social Media data (Twitter, Facebook, GAAB, Telegram, Reddit)	P28CH-S; P3US-S; P12US-S; P20US-S; P21US-S; P22US-S.	P24CH-P.	P29CH-D; P18US-D.
Physiological data (EG, eye tracking)	P22US-S.	P22CH-P.	P8US-D.
Medical data (neuroimaging, blood samples, x-rays, genetic data)	P9US-S; P12US-S; P16US-S.	P1CH-P; P4US-P; P11US-P; P13US-P; P14US-P.	P31CH-D; P32CH-D; P34CH-D.
Administrative data (university and state records, federal records, juridical, tax and census data)	P33CH-S; P39CH-S; P6US-S.	P4US-P.	
Publicly available data (newspaper, books, websites, public documents, data on public figures)	P23CH-S; P30CH-S; P35CH-S; P37CH-S; P1US-S; P2US-S; P3US-S; P6US-S; P19US-S; P20US-S.	P17US-P.	
Interview and survey data	P26CH-S; P28CH-S; P39CH-S; P2US-S.	P24CH-P; P25US-P; P4US-P; P14US-P; P17US-P.	P29CH-D.
Crowdsourcing data (M-Turk, Crowd Flower, Safecast)	P29CH-S; P20US-S.		P27CH-D.
Not specified	P5US-S.		

Key: P = participant+ID number+country (CH = Switzerland; US = United States)+background (P = Psychology; S = Sociology; D = Data Science). Eg. P1CH-P = Participant 1, Switzerland, Psychology.

The analysis of the researchers' opinions and attitudes towards using company data and collaboration with private firms led to three themes: 1) inclination towards using data from companies or collaborating with them; 2) challenges towards interactions with companies; 3) differences between academic and corporate research. The themes and the respective subthemes are listed in Table 8-5.

Table 8-5: *List of themes and subthemes*

Theme	Subtheme
1. Inclination towards collaborations with companies	
2. Challenges	2.1 Ethical challenges - Commercial interests and for-profit motives - Transparency in company practices - Privacy - Consent 2.2 Methodological challenges - Theory driven vs. data driven research - Data quality issues 2.3 Issues of access to corporate data - Value of corporate data access - Causes of lack of access
3. Status of academic research	3.1 Academic research is slower than/lagging behind corporate research 3.2 Regulatory inequalities

To illustrate the results, we have reported representative anonymized quotes from the interviews. The findings are reported employing a low level of interpretation, which is customary to thematic analysis approaches (Vaismoradi et al., 2013), to avoid over-interpretation of the data.

8.4.1 Researchers' inclination toward company collaboration

As a general trend, participants expressed openness towards collaboration with private companies and the use of data from private firms to perform academic research. When asked if it would be appealing for them to cooperate with companies or to use their customer or behavioral data, some participants highlighted the value of this type of data for their research field. The use of this data could both enhance their current research projects or even create new investigation opportunities (See table 8-6, 1. a).

In this context, a couple of interviewees emphasized Big Data's impact on scholarly research and the state of academic-industry collaboration. Cooperation between companies and researchers was seen as essential for academic research to have an impact on society since corporations are the entities that have the resources, both financial and technical, to invest in developing and delivering beneficial products and technologies for the public. In addition, it was envisaged that universities would be more inclined to obtain data from commercial providers to conduct Big Data research in the future. This circumstance would see an increment in the use of data acquired from external sources rather than research groups performing data collection themselves (See table 8-6, 1. b, c).

Table 8-6: *Relevant quotes over participants' interest in corporate partnership*

1. Researchers' inclination towards company collaboration	a) This data [commercial data] is a gold mine because you get purchase data, scanning data, you get travel data from these mobile phones, and so on. So, this is extremely revealing. (P38, Sociologist, CH)
	b) Well, I think...this is going to sound erratically to you, but I actually think that [collaboration between companies and academia] it's essential. And the reason I say that is because, at the end of the day, what we do with the discoveries that we make in the academy doesn't get to work with the patients in new products unless we collaborate with companies. (…) It's really clear that companies have a role to play in the ecology of delivering products to people. And, you know, universities they don't make things… (P14, Psychologist, US)
	c) So, another question I think for research will be interesting, and that's going to be changing within the next couple of years, is that we buy more data from commercial providers. In addition to databases of… I don't know newspapers, for example (…). We may also start buying data from companies who have, I don't know, forty-thousand Swiss consumer interests in it and... just like commercial enterprises buy data. (P23, sociologist, CH)

8.4.2 Challenges towards interaction with companies

While expressing their opinion toward academic-industry interaction, many participants pointed out some challenges that might hinder the relationship between academia and companies. We subdivided such concerns into three categories: 1) ethical reservations, 2) methodological concerns and 3) access issues.

Ethical reservations

Although they recognized the value of corporate data for research purposes, a consistent number of participants reported their uneasiness regarding collaborations with private firms or expressed reservations about the academic use of commercial data due to concerns regarding the ethical challenges such interactions might bring.

A frequent concern shared by our participants was related to the commercial interests of private companies. In this context, some researchers, even though companies typically spend 2-23% of revenue on research and development (Statista, 2018), underlined an ethical tension between the purpose and values that characterize scholarly investigation (advancement of knowledge) as opposed to the interests that move corporate research (making a profit) (See Table 8-7, 1. a).

Commercial interests and for-profit motives were often mentioned as factors that might decrease research integrity, as they might create ethical tensions and ambiguities within academic research endeavors, especially concerning the values that drive data collection and use (See Table 8-7, 1. b). In addition, assessing the purpose and intentions behind a research project and the applications of research outcomes were considered determining factors to be evaluated in relation to corporate-research partnerships. In this regard, companies' involvement and commercial motives might raise conflicts of interest between the investigator and the company. Hence, according to the participants, it is not necessarily the design (e.g., analysis of personal data or prediction of sensitive characteristics) of a project that makes it ethically problematic but the entity conducting it, its motives, and its purposes (See Table 8-7, 1. c). Furthermore, in the context of economic interests, some researchers were concerned about academic researchers being exploited by companies for their gain. For instance, when academic researchers are not appropriately compensated for their work on corporate data (See Table 8-7, 1. d).

A few of our participants were also concerned that many private firms are conducting research without sufficient transparency regarding their purposes and practices, such as data collection and the use of personal data. On this, a researcher highlighted how scholars in the social sciences are concerned mainly by the fact that "privately held companies are collecting vast amounts of social data in ways that are not transparent" (P19, Sociologist, US). For some of our participants, transparency thus emerged as a crucial research standard to be promoted in academic-industry partnerships. According to a participant, research with corporate data is essential to advance knowledge and improve society. However, education and transparency regarding corporate practices should be enhanced in order to benefit all members of society (See Table 8-7, 1. e).

Two researchers were concerned about startup companies being acquired by more prominent firms as this might create issues of policy change, trustworthiness, and transparency regarding how the collected data will be handled or used after the acquisition. For example, one of our participants, who had first-hand experience with data collection through a startup, pointed out that data collection from a device could be transferred from one company to another without having guarantees that the new company or institution would respect the previous agreement signed by the user (See Table 8-7, 1. f). Another participant similarly shared that big corporations are usually associated with lower ethical standards and a lack of transparency regarding their data practices. Scholars should thus be careful when partnering with small startups that big firms could, later on, buy (See Table 8-7, 1. g).

Finally, consent and privacy issues were sometimes perceived as a deterrent to the use of corporate data. On the one hand, participants shared their uncomfortableness about using data without the subject's explicit consent or awareness. On the other, they highlighted issues of re-identification and anonymity that could emerge from the analysis of certain types of corporate data, making it problematic to analyze corporate datasets safely (See Table 8-7, 1. h, i).

Methodological challenges

On top of these ethical reservations, our participants also highlighted some issues related to the value of corporate data for academic research. For example, several researchers pointed out that data collected by companies might not be suitable for academic research practices in psychology and sociology as they are mainly theory-driven fields. In contrast, big amounts of aggregated data collected by companies are mostly suited for post-hoc analysis (See Table 8-7, 2. a).

A few participants also had reservations regarding the quality of the data collected by companies. A crucial concern in this context was that data from companies is difficult to use and interpret, as it often lacks some essential information to be properly used in the academic environment. For instance, a participant underlined how issues for academic publishing might emerge when scholars use data from companies as they would have minimal control or knowledge over data collection practices (See Table 8-7, 2. b).

Additionally, according to a couple of researchers, data from companies is qualitatively not accurate enough to be used in academic research as it is usually full of inaccuracies and thus not trustworthy for methodologically sound research practices (See Table 8-7, 2. c).

Issues of access to corporate data

Another challenge many of our respondents emphasized was that companies do not seem interested in collaborating with academic researchers. According to our participants, companies do not allow access to their databases or share data with university-based scholars (See Table

8-7, 3. a). Furthermore, some of our participants declared that even if they got access to corporate data, it would not carry an added value to their research. They would, in fact, not be allowed to publish their results or to perform the type of research they are interested in freely. Participant 9 (Psychologist, CH), for instance, reported: "the companies where I get the data from, they say: << you can describe the method you developed, but not the results >>. So I always have big problems with publishing my studies". Another researcher noted that companies might not allow them to perform critical research about the limitations of corporate data or methods by imposing data agreements that would prevent them from pursuing their desired line of research (See Table 8-7, 3. b).

Lack of access to companies' original data repositories, or restrictions regarding the publication of results, were connected by two of our participants to issues of reproducibility. In their opinion, both research performed internally by the company and conducted by an external scholar cannot be verified by other researchers as they would not have access to the same resources (See Table 8-7, 3. c).

Some of our respondents provided reasons for this reluctance to share data with the academic milieu. One participant claimed that companies tend to mistakenly treat data like money, assuming that sharing their data will result in a loss for the firm. In the participant's view, data sharing would actually increase the value of the data and benefit both the company and its collaboration partners (See Table 8-7, 3. d). A few participants associated this reluctance with protecting customers' privacy and preserving corporate business models (See Table 8-7, 3. e). Finally, a couple of researchers linked this issue to a reputational concern. According to them, companies might prevent scholars from publishing their results or conducting critical research with their data because they fear such research might tarnish their reputation. Academic researchers having access to company resources could willingly or accidentally expose some of the company's practice that might be considered unethical or attract public and academic scrutiny. This happened in the case of the Emotional Contagion Experiment, where the partnership with an academic institution resulted in a huge societal backlash for Facebook (See Table 8-7, 3. f).

Finally, challenges of data access were also associated with a lack of skills. For instance, a couple of researchers pointed out that they lack the appropriate research skills to properly analyze and benefit from the large datasets companies offer. A Swiss sociologist, P24, shared: "I would not touch Twitter but I would collaborate if somebody then has the skills, because otherwise, I would have to acquire all these skills".

Table 8-7: Relevant quotes over perceived challenges for corporate partnership

1. Ethical Reservations	a) Because mostly we [academics] are doing research, and they [companies] are doing business, right? They want to earn more money. We're not interested...well, that is not our concern, right? We want to do research, right? (P29, Data Scientist, CH)
	b) I think that the goals of certain commercial research very often are to accumulate data that can be used for profit ends. Which, again is not inherently a bad thing. But I think that one of the things that can happen is that the infallibility of data for profit sharing and co-commercialization can create certain ambiguities - if not tensions - with regard to the values under which data are collected and utilized. So I think that there can be an issue there, you know? Data for sale and multiple commercial uses that have profit motives can be problematic. (P11, Psychologist, US)
	c) Now, the ethical issue behind it is, of course, companies conduct those experiments all the time. It's only that researchers are supposed to have their hands bound more than companies do. So it's not so much necessarily a specific experiment that is a problem. More the ethical concerns: who is conducting the experiment and for what purpose. (P2, Psychologist, US)
	D) So I think that... there need to be guidelines in place so that the company doesn't exploit the researcher. So I think sometimes researchers are so desperate to get access to information and data that we agree to work for free. And that's not fair, I mean, that's a different kind of ethical problem right? So companies should have to pay for our time (laughs). (P22, Sociologist, US)
	e) I think, as part of the education for society, it would be important to have more transparency about how this data from all those companies, how it is used in...people have to have some choice on…well if they're going be using this (…) So, the transparency part is important, I would not limit research being done on that kind of data because the more we know, the more we can help improve the system, right? I mean, always in within…a humanist way, how to improve it for a better society. (P5, Psychologist, US)
	f) During the two weeks when we collected the data via the phone, people actually wore a Fitbit type of device. At the time, it was a company called X (*name anonymized*). It's very interesting, by the way…the company went under, and one issue in this world of using technology to collect data is that this happens to many companies. It's remarkable how many companies will show how they're going to be fantastic, and they'll lure you in, and you use their product only to find a year later they'd gone under, or they were bought by someone, and they changed it. (P4, Psychologist, US)
	g) I mean, so you have to a certain extent to trust the commercial. But you really have to be careful about who it is, and the big companies are the worse by far. And the startup normally gets bought up, and then they turn into the same thing. So you know, I think it's really kind of a dangerous time right now, I mean, we do need to have regulation of some kind. (P8, Data Scientist, US)
	h) If the data is public and the participants knew that it was going to be public, then it's fine. But if it's something that, you know, first of all, you have to purchase and a company collected that data without the participants consciously knowing that the data's being collected, I don't want to participate in that. (P12, Sociologist, US)

	i) I do know that one of the big problems with these kinds of data is the potential for re-identification. The data themselves might not be formally linked to any individuals or households, but particularly if data sources are brought together, it can be straightforward to figure out who's who. (P16, Sociologist, US)
2. Methodological Challenges	a) Well, the problem with commercial data is that is not intended to do research with most of the times. (…) I think this is a big problem in a way, because when you have these big data or these data stuff, you're not completely free in theorizing and making your hypothesis and so on. (…) But this is not sound psychological scientific endeavor in a way that, yeah, you need first a theory, the hypothesis, and then you look at the data. (P9, Psychologist, CH)
	b) I mean...it obviously it depends on how the data are acquired. Whether it corresponds to a population. And how much we could control it because it's always the question of quality control. So, if you want to publish with it we need to be able to make sure how the data exactly are acquired, how the people are sampled, and unless that is known, it is relatively difficult to do anything with the data because sometimes is quite hard to interpret. (P32, Data Scientist, CH)
	c) The quality of data that advertisers and marketing is willing to rely on versus the quality of data that I would want for academic research is very, very different. So I would maybe be able to study what sorts of things they can do with the data, but I would not be able to know how accurate they are. I would not be able to, based on the data quality, which will be very loose. Because there'll be tons of inaccuracies. (P18, Psychologist, US)
3. Issues of access to corporate data	a) Google or with Facebook or with other companies, that they are internally using all this data, and they're making advances, and they're sort of withholding the data from the greater researcher community. Then yes, that case is problematic. (P12, Sociologist, US)
	b) I think that, in general, I'm interested in doing much more skeptical and critical research, and if I get data from a company under certain agreements, I would be concerned (…) that I wouldn't be able to use that to kind of critically analyze the data and talk about its limitations. And certainly, if I were within a company doing that research, I would have that concern. (P18, Data Scientist, CH)
	c) So, in that case, it's very typical that the provider of the data only allows you to work with the data in a secured place within the company. So then again of course, the problem emerges of how can we verify that these results hold. Because you wouldn't get access to reproduce it or whatever. (P30, Sociologist, CH)
	d) Now, what happens is that a lot of companies they realize that data is value, but they don't always understand what kind of value it is. And then they don't want to share it because they don't know... The good thing is that, compared to money, when you share the data, you actually increase the value on both sides. When you give money to somebody, you lose money, but if you share data with somebody, I think both parties are better off. But a lot of companies still deal with data like with money and they don't like to share it because they believe they would lose some...some power. (P38, sociologist, CH)
	e) Because they [the company the researcher was collaborating with] were not really too much excited about providing any data. Because they wanted to protect their customers and maybe because they also wanted to protect their business model, right? They're not interested in sharing how much sales in which regions… (P29, Data Scientist, CH)

	f) I see that the major difference in the sense that companies like Facebook, Google, Amazon, Uber, whatever, you pick the ones you like, are sitting on like massive amounts of data that would be amazing for social scientific projects. And they are hiring lots of PhDs to work in their data science teams, except that PhDs don't usually have the right to publish or, when they publish, they can only publish things that are not detrimental to the company's image and brand, right? Obviously like kind of sampling in a bit of weird way because they can't say anything negative about the company…these companies don't usually like sharing their data with academics, with a couple of exceptions like Facebook and the emotional contagion experiment but then...there was this big backlash, so you know, now they don't want to do it anymore really. (P2, Sociologist, US)

8.4.3 Are corporations and academia on the same page?

While voicing their opinions on private firms and Big Data, some participants also discussed the current state of Big Data scholarly research compared to the condition of companies and corporate investigations. For example, a couple of participants claimed that companies have been dealing with Big Data long before academic scholars; therefore, they might be more prepared to deal with both the challenges and the potential that Big Data has to offer (See Table 8-8, 1. a). In this context, while admitting that scholarly research in Big Data is lagging behind compared to corporations, a participant suggested that this would be the right time to reflect on how academic institutions should move forward with corporate Big Data: to what ethical standards academics should comply, what type of data should be investigated and invested in, what type of collaborations they should entertain with private corporations (See Table 8-8, 1. b).

A Swiss respondent highlighted the differences in research standards between companies and academic researchers by mentioning the concept of the "research clock". In their opinion, scholars have the possibility to conduct valuable research on datasets that are considered outdated by companies. The researcher illustrated this at the hand of the time lapse between data collection and the review process of academic journals. By the time one of their manuscripts went through the review process of an academic journal, the research team was allowed by the company to disclose information that was considered sensitive at an earlier time. This allowed the scholars to successfully publish their research (See Table 8-8, 1. c).

A few participants also complained that academic researchers do not have the same support system that companies possess. In their opinion, companies that deal with Big Data operate together with units with diversified expertise – computer science, data security, law – that assist their researchers with all facets of Big Data research, such as compliance with regulatory standards, methodological and infrastructural support, and others. For instance, while discussing some of the regulatory issues they faced with their research project, one scholar shared their frustration of not having adequate support and, therefore, always being at risk of doing something wrong (See Table 8-8, 1. d).

Numerous researchers discussed the difference in regulation between corporate research and academic research. In particular, researchers from the US and Switzerland saw it as problematic that companies do not have to obtain ethics approval as opposed to scholarly researchers. In some cases, the circumstance of being subject to more restrictive regulations was felt by some scholars as a frustrating double standard where regulations are lacking to govern big corporations. At the same time universities are subject to excessive scrutiny (See Table 8-8, 2. a, b). In this context, while discussing the regulatory constraints of academic Big Data research, one of our participants complained that their research was overregulated out of excessive cautionary attitudes and suggested that universities and companies abide by the same rules (See Table 8-8, 2. c) . On the other hand, according to one of our researchers, reputation might become one of the driving regulative forces toward research integrity in corporate research more than legislation and regulatory bodies. Should customers and users be discontent about how their data is handled, companies will have to face possible adverse reactions (See Table 8-8, 2. d).

Table 8-8: Relevant quotes over differences between corporate and academic research

1. Status of academic research vs corporate research	a) Three, four, say five years ago in our society, very few people were talking about Big Data. Most people didn't even know it existed. This has been going on for years, probably several decades. So companies, certain kind of companies, and services have been doing this before scientists were actually looking into the implications and how to do it right. (P35, Sociologist, CH)
	b) What do we do with the fact that there's data sets that are being used to make predictions about what we are going to buy at the supermarket and what I really need as a consumer? (…) And the question is, what do we want? Do we want, and I don't have an answer to that, but do we want only publicly funded, very thorough panel studies of retrospective ideas of what I bought yesterday? Or do we want that kind of data and how can we combine even the retrospective and the actual tracked data of consumers? I think that's...those are interesting questions that we have to answer. Now, I'm not saying that we should become, you know, yet another tool of marketing. But I think it's an interesting challenge to think about what data sources are available and which ones do we want to use, and which ones do we want to have access to. (P23, Sociologist, CH)

	c) The good thing is that the clock of a company is not the same as the academic clock (…) So the first version of the paper, they [the company] were really afraid of the sensitivity of the results. But six months or eight months after, it did not matter to them anymore, and we could proceed with the publication. So this is something I've seen several times, and that helps also to publish even if it is at some point perceived as sensitive. So it was aging quickly for the business, but it was still relevant for research. (P38 Sociologist, CH)
	d) We don't want to go into troubles because we don't have time, that's one thing, and the other thing, we don't have the legal support that basically big companies have. So…Facebook or Google or whatever, they will continue doing it because if this happens, they can afford it. We cannot afford it. Right? We don't have time, simply we want to avoid that, right? That's the point, right? That makes it a bit complicated. So the assumption is simply that we as research institutions would have a kind of lawyer next to us who would simply…like each time we face a problem, we get in touch with the person, which is not really the case. (P29, Data Scientist, CH)
2. Regulatory Inequalities	a) And this is probably because the regulations are much more restrictive for scientists in institutions than for companies because companies don't undergo a cantonal ethics approval and they have a business secrecy, and so there are a lot of things going on that couldn't be studied by scientists. (P35, Social Scientist, CH)
	b) I think that the biggest problems are not universities but private companies. Private companies are collecting inordinate amounts of data, some of them have almost data monopolies, and we don't have access to that data. And we saw what happened, we've only seen the tip of the iceberg of what is happening with Facebook. And nobody has the power to regulate Facebook, the markets are not going to regulate Facebook, consumers are not going to regulate Facebook. (…) Universities are nonprofit organizations and they have...they're subject of scrutiny in more ways than private companies are. (P1, Sociologist, US)
	c) I do want fairness, I do want rules and all, there should be some ways to have rules for everybody. And if you can't enforce rules for everybody, then quite frankly, there should be rules for nobody. I can take a very libertarian point of view. (P13, Psychologist, US)
	d) Big companies, even Facebook, they have real reputational risk at stake. I think that the issues that the big companies, the big holders like Facebook, like Twitter, like, Reddit, like all these things… you know, I think that what's ultimately going to bring them in line is just the concern that people aren't going to be happy with what they do, and that'll be a big issue. And you notice that that's actually not a legal thing. That's just going to be the major driver as opposed to any sort of legal solution. (P14, Psychologist, US)

8.5 Discussion

Big Data methods and digitalization are incentivizing interactions between private companies and academia. This study contributes an analysis of the incentives and barriers to creating sustainable and productive partnerships between corporations and researchers in the behavioral sciences from the perspective of academic researchers or as perceived by academic researchers. Our respondents did not provide a clear distinction between active and passive types of interactions with companies while sharing their opinions and attitudes. Therefore, the analysis in this section will generally refer to both and make distinctions within the analysis whenever suitable.

In addition, data analysis did not reveal significant differences in attitudes between Swiss and American researchers. Despite the different continental affiliation of half of the sample from the other, scholars from both countries seem to have faced similar ethical reservations and technical challenges when considering academic-industry interactions. We hypothesized some of the reasons that might have contributed to this circumstance. First, the academic environment is an intrinsically international and dynamic reality, with researchers moving from one country to another and between the European and the American research scene. It was not uncommon for our participants to share that they had previously worked in different countries or were originally from a different continent. Secondly, the main ethical frameworks used in behavioral sciences are based on the Belmont Report (for the American side) and the Declaration of Helsinki (for the European side), which share numerous ethical principles and procedures (e.g., respect for persons/subjects, informed consent, and others).

Finally, the companies our participants explicitly mentioned were mostly American-based (Twitter, Facebook, Telegram, WhatsApp), which might have aligned opinions on corporate interactions. In addition, our sample, consisting of a limited number of participants also identified through snowballing, statistically could not identify a difference. As such, it would be of paramount importance to perform additional research that specifically investigates the attitudes of researchers from different countries towards cooperating with for-profit corporations. This will allow a better understanding of the different ethical and economic positioning towards corporate data to see what factors (country, discipline, ethical tradition) might influence them.

8.5.1 The role of academic-corporate partnership and the value of using corporate data

Most participants considered both active collaboration with companies and passive use of corporate data as a promising, if not an essential, part of current academic behavioral research. Some of them emphasized the usefulness of the data that companies offer. Others highlighted the importance of industry resources towards developing truly impactful academic research on society, as companies have resources to invest in technologies needed for research, deliver the results of academic projects in the form of products (devices, algorithms, infrastructures), and collect and manage vast amounts of heterogeneous data. Specifically, in direct collaboration with companies, academic-corporate partnerships have been seen as an opportunity for academic institutions, companies, and society at large. A large corpus of studies has, in fact, proposed and critically analyzed models and strategies for sustainable and long-term collaboration between companies and academic research in medicine, chemistry, engineering, and biology. For instance, Bekelman, Li, and Gross (2003) conducted a systematic review analyzing the impact of financial conflicts of interest in biomedical research (2003). Dooley and Kirk (2007) proposed and analyzed the challenges and promises of a “triple helix” model of government-university-industry research collaboration (2007). Jain, Rosenblatt, and Duke (2014) analyzed the potential of Big Data and electronic health records to create new partnerships between university hospitals and pharmaceutical and device companies, by discussing the example of a five-year collaboration between the Indiana University School of Medicine and a global pharmaceutical company (2014).

As seen in our results the drive towards collaboration has similarly polarized behavioral sciences such as psychology and sociology, with the advent of Big Data research. Such a shift has also been identified in a study by Davis and Binder (2016) on the rise of Corporate Partnership Programs (CPP) in university career centers. The study showed how companies in the US, traditionally more oriented toward technical universities and STEM programs, are starting to take an interest in academic institutions that include more liberal arts programs (Davis and Binder, 2016). At the same time, in line with a study from Muscio and Pozzali (2013), academic researchers have highlighted some barriers to interaction with industry, such as finding appropriate business partners, the short-term orientation of industry research, different (on both sides) expectations and work priorities (Muscio and Pozzali, 2013).

8.5.2 Data quality and issues of reproducibility

Especially when it comes to the passive use of corporate data, where investigators are not actively involved in the procedures and methods for data collection, our study highlighted critical methodological challenges. Some of our participants raised the issue that data collected by companies is qualitatively not suitable for performing academically relevant scientific research. They highlighted that research practices in sociology and psychology are mostly theory- rather than data-driven and that the data provided by companies might lack essential information. The validity of knowledge based on big datasets and data-driven models is a discussion that has permeated the literature since the advent of the term Big Data. In line with our respondents, some studies claim that data offered by companies is biased and limited in its interpretability and that data-driven methods offer misleading results due to their tendency to mix up correlation and causation (Boyd and Crawford, 2012; Mittelstadt and Floridi, 2016). Despite these concerns, the scientific community in the fields of sociology and psychology is finally recognizing the value of data-driven methods and new means of data gathering, such as access to corporate datasets, for research and is also exploring appropriate ways to merge more traditional theory-driven approaches with novel Big Data methodologies (Woo et al., 2020; Salganik, 2019).

Some researchers also related the issue of validation and reproducibility of research with the problem of access to corporate data. They were concerned that the difficulty or even impossibility of accessing corporate data, currently experienced by academic researchers, might compromise scientific validity. Schroeder (2016) has similarly argued that companies' protectiveness about sharing data is problematic for the progress of scientific knowledge since it may be impossible to replicate studies or make their methods public (2016). This issue of corporate access to data and methods was also raised in the context of the Google Flu Trend (GFT), a study that aimed to provide real-time patterns of influenza activity. The study ultimately failed because of the dynamism of the algorithm used by Google, which was constantly changed and improved by the company. However, scholars argued that the lack of transparency of Google regarding their supporting materials and methods presented a barrier to replicability for researchers outside of the company that prevented the initial vision of GFT from being developed and perfected into a more accurate or even working model for flu prediction (Lazer et al., 2014).

8.5.3 Data sharing and conflict of interests

Our respondents saw the reticence in sharing corporate databases as an exclusion of the greater research community from valuable research data that might result in a disadvantage for scholarly investigation. Dooley and Kirk (2007) claim that one of the biggest drivers behind companies' reluctance to share data with researchers is a consequence of conflicting interests/desires between the two actors. The industry wants to maintain secrecy to secure intellectual property rights and keep a competitive advantage. At the same time, academics aim to publish their results to validate their research and to advance both scientific knowledge and their academic careers (2007). Some of our participants voiced this conflict of interest and complained that companies were not too keen on providing data or they were not allowed to publish results stemming from company research.

We argue, however, that these different interests might be used to properly plan advantageous data-sharing strategies between academic institutions and private companies. For instance, as pointed out by one of our researchers when discussing the concept of the "research clock", academia and companies work on two different timescales, with academic research generally "lagging behind" the companies' schedule and interests (Elmuti et al., 2005). This time gap could assist in sharing "old" data that is no longer considered sensitive by the company's standards but is still valuable for academic research. At the same time, an interesting tension emerged from our results where some researchers claimed not to trust companies as they offer fewer protections to their users. In contrast, others, in the context of data sharing, argued that companies refrain from giving access to their data to protect their users' privacy from further scrutiny. This concern is in line with a recent paper from Sikorska et al. (2020) that argues that reasons for reticence in data sharing include lack of trust, loss of privacy, especially risk of re-identification, and risks to regulatory compliance associated with how researchers use their data, in addition to the aforementioned inadequate economic incentives (Sikorska et al., 2020). This tension only highlights the need to build a framework of trust and transparency to incentivize proper collaboration.

8.5.4 Transparency in corporate research

Furthermore, the results point to an interesting tension: while many researchers voiced openness towards a possible active partnership with private corporations, they also expressed multifaceted ethical concerns and reservations linked to transparency of motives and research practices, consent, and anonymity. This should not come as a surprise, given that academic researchers are used to and trained to abide by a specific range of ethical standards that companies often do not need to consider. In line with our results, it is often argued that academic scholars are generally held to a higher ethical standard than industry researchers (Vitak et al., 2016), while companies generally tend to fail to acknowledge the moral nuances behind for-profit corporate decisions. In a recent study on the morality of predictive models, Kiviat (2019) highlighted how corporations tend to protect themselves behind the claim of objectivity in algorithmic prediction just because it suits their for-profit motives, thus failing to consider that the mathematical objectivity of algorithms is at the core of many practices of unfair and unequal treatment (Kiviat, 2019; O'Neil, 2016).

In the context of research ethics, transparency is often intended as a flexible principle that brings together different ethical components related both to the intent of research (what you are doing with the data and why) and practice (how you are getting the data – informed consent – and how you are processing it – data anonymity). This principle is currently considered a paramount component of research integrity by the academic online-data research community (Vitak et al., 2016). However, our respondents noted that transparency of motives and practices is generally not associated with corporate research. In his paper on the ethics of Big Data research, Rothstein (2015) shares this concern when he criticizes the practice of performing research behind the user’s back. This happened in the case of the Facebook Contagion Experiment or the OK Cupid website, where they publicly admitted to manipulating what was shown to their users to test and enhance their matching algorithms (Rothstein, 2015; Hern, 2014). Also, the risk of having corporate motives and incentives creeping into academic work and compromising research integrity was considered a significant hindrance to corporate collaboration. Unfortunately, several recent reports (Bekelman et al., 2003; Serôdio et al., 2018; Nestle, 2016) highlight how financial ties pose a threat to scientific integrity, such as distortedly reporting pro-industry conclusions. These transparency issues might refrain academic researchers from engaging in collaborative efforts with private corporations.

Our participants also raised consent and privacy issues when dealing with academic-corporate collaborations and social media research. Consent is among the most challenging ethical concepts in the context of Big Data research for a twofold reason: on the one hand, Big Data methods are designed to reveal unforeseen connections, patterns, and information from the data, which makes it difficult for researchers to clearly delineate, at the time of consent, what will be the nature of the information that will emerge from a study and/or an experiment (Mittelstadt and Floridi, 2016); on the other hand dealing with consent in corporate data, poses challenges to consent practices since the subjects/users might be unaware of the details regarding how their data is being and analyzed and, most times, lack the appropriate control over their data (Xafis, 2015; Henderson et al., 2013). Closely connected to consent are issues of privacy in corporate Big Data research as studies could disclose private and sensitive information about the users/subjects, again due to the unpredictable information that will emerge from analysis (Metcalf and Crawford, 2016; Matzner and Ochs, 2017).

Despite these inherent challenges, a recent study by Hemphill, Schöpke-Gonzalez, and Panda (2022), which explored users' feelings about social media data privacy and use, showed how users consider their social media data to be "moderately sensitive" and in need of protection. As such, they prefer that researchers clearly articulate the benefits and risks of a research project and explicitly seek consent before conducting a study (Hemphill et al., 2022).

As a detailed examination of these points is outside this manuscript's scope, we refer to related literature that discusses both these two topics more in-depth (Sangeetha and Sudha Sadasivam, 2019; Buchanan and Zimmer, 2018; Salganik, 2019; Zook et al., 2017; Shilton and Sayles, 2016). For a more in-depth analysis of consent and privacy, we refer to our previous paper from this research project (Favaretto et al., 2020b).

8.5.5 Increased oversight for corporate research

Many respondents complained about being subject to more restrictive regulations than private firms and were concerned about the absence of regulatory oversight for corporate research. The lack of ethical evaluation for corporate research practices is becoming extremely problematic as private firms increasingly collect and analyze sensitive data from their users. On top of the risk of unethical studies, corporate research faces a growing societal backlash as scholars and the media are accusing companies of conducting unethical and harmful research (Schneble et al., 2020; Rothstein, 2015). As such private–academic research partnerships might become a source of additional confusion within the already complex realm of regulatory practices in social computational and psychological Big Data research (Metcalf and Crawford, 2016) and create reputational issues for academic scholars. The latter might inadvertently be involved in ethically opaque research or be accused of seeking partnerships with companies as a strategy to avoid research regulations.

For instance, this happened with the Facebook emotional contagion study. Although in line with regulatory standards, the study still raised ethical concerns within the academic community and society (Kahn et al., 2014; Shaw, 2015; Caplan and Seife, 2014). In that experiment, Facebook's data collection practices were not fully consistent with research ethics principles such as informed consent (2014). Nevertheless, the Cornell University IRB did not flag the experiment as they "determined that the project did not fall under Cornell's Human Research Protection Program" because Facebook conducted it for internal purposes. The Proceedings of the National Academy of Sciences of the United States of America (PNAS) therefore deemed it appropriate to publish the study. However, they admitted Facebook data practices to be a matter of concern (2014).

However, a couple of respondents, hinted at the fact that the industry also has a reputation to protect. While academic research, as argued earlier, is usually considered more “ethical” (Vitak et al., 2016), the private sector is setting up mechanisms to actively take responsibility to “respect, protect, and remedy human rights” (Kahn et al., 2014). Facebook, for instance, has set up an internal review process as a response to the public outcry that followed the emotional contagion experiment.

As the evidence of possible harm from corporate research is growing, increased regulatory measures for corporate research should be taken. Practical approaches to forming company review committees are currently being proposed to bring company practices into frameworks of trust and accountability (Polonetsky et al., 2015; Metcalf and Crawford, 2016; Calo, 2013). For example, the institution of structures similar to IRBs within private corporations could benefit collaboration between companies and institutions as they could flag ethical/regulatory inconsistencies and issues promptly, facilitate the setting of common standards and goals, and provide a mutually shared regulatory and ethical framework (Bowser and Tsai, 2015). Another important tool that has been used increasingly in the past years is external private independent IRBs such as Advarra Inc., and the Western Institutional Review Board (WIRB) – now known as WIRB-Copernicus Group (WCG IRB). Since these corporations aim to provide a thorough ethical review of research projects, they could be a way of enhancing collaboration and trust between academia and research when joining in a research project.

8.5.6 Creating a sustainable space for academic-corporate interactions

The ethical and methodological tensions that emerge from this study raise the question of whether collaborations with corporations are really of value for the academic environment and what (if any) sustainable space can be created for both active and passive interactions between corporations and academia. According to Mittelstadt and Floridi (2016), a clear distinction should be drawn between “academic” and “commercial” research practices due to the different motivations that drive them: basic research to advance scientific knowledge in academia and product development and placement for profitmaking in the industry (2016). We do not believe that this distinction is practicable or even desirable. However, recognizing transparently and even exploiting this inherent difference could be considered a starting point to create sustainable, transparent, and ethical collaborations between companies and academia. This approach would allow us to have more realistic expectations regarding the different research approaches, aims, and goals between the two actors.

The advent of Big Data especially has led to an overturning of the balance between applied and basic research by increasingly entwining industry and academic interests (Leetaru, 2018). As such, a suitable space for interaction should be created. As one of our respondents noted, the time is ripe to ask critical questions about what data sources should be available for academic scholars, what type of collaborations scholars should be involved in, and what ethical framework should regulate academic-corporate partnerships. Based upon the discussion of our results, we provide a few suggestions on how to both improve active academic-industry collaboration and strategize dynamics for sustainable data sharing between corporations and academic institutions. Although far from being exhaustive, these suggestions represent a starting point to initiate a discussion on how to tackle this situation appropriately (Fig 8-1).

Figure 8-1: Suggestions to foster sustainable academic-corporate interaction

Transparency of motives and purposes	balance and tradeoff of conflicting interests for active collaboration
	development of strategies for data sharing
Development of protocols	govern conflict of interests
	safeguard the research subjects
Introduction of oversight by regulatory bodies	enhance protection of research participants
	enhance trust and transparency
	level inequality between private and public sector

Transparency of motives and purposes

First, to enable sustainable active partnership, it becomes paramount to ensure transparency of motives, purposes, and interests when starting a collaboration between an academic institution and a company. Finding an appropriate balance of objectives and value systems between the two sectors is challenging. However, leading technology companies increasingly consider their commitment to the public good important (Nielsen, 2013; Ruggie and Des Nations, 2011) and are more accepting of ethically sustainable collaborations. Mitroff and Sharpe (2017), for instance, provide an example of a successful partnership and give some suggestions to scholars on how to set up such a collaboration. These include choosing the right industry partners - usually the ones that have an established useful program for the research project that they are willing to share with academics - and aiming to achieve both theoretical and practical advances to satisfy industry expectations and interests as well (2017). In addition, strategies on how to sustainably share corporate data with academics should be explored further. For instance, the exploitation of the aforementioned "research clock" mechanism could be investigated to align some of the goals of companies and researchers (See Fig. 1: "Active collaboration").

Development of protocols

Secondly, appropriate protocols should be implemented to govern possible conflicts of interest, safeguard the human subject, and appropriately balance scholar's ethical and legal concerns and the industry's fear of overregulation. A study by Bekelman et al. (2003) highlights how finding the right balance between the two actors can sometimes be challenging to obtain. Academic researchers often consider proposed regulations ethically too loose, while the industry considers them too restrictive and an impediment to innovation (2003). The development of appropriate protocols thus becomes paramount both for active partnerships and passive use of corporate data. Without appropriate guidelines to regulate the former, the risk of having academic researchers undergoing undue influence from industry partners is high, especially when they depend upon companies for funding and essential infrastructures. When it comes to researchers accessing corporate databases, appropriate policies will provide academic researchers with the assurance that the data they are analyzing has been collected by following basic research ethics standards (See Fig. 1: overlap between "Active collaboration" and "Passive use of corporate data"). For instance, the DRAT (Data, Risk, Assessment, Tool) for university-industry collaborations developed by Sikorska et al. (2020) might prove to be an adequate step in this direction. This tool is set up to function as a medium to assess and control the risks associated with data sharing between universities and private companies, a task usually left to the individual corporate managers whose attitudes and motives for data sharing vary widely (Sikorska et al., 2020). It would also be of paramount importance to investigate more closely the practices already put in place by private corporations to determine the appropriate standards to conduct research and initiate collaboration with private researchers.

Introduction of oversight by regulatory bodies

Third, in parallel with the development of policies, the implementation of review practices for corporate research would promote sustainable interaction and ethical research. As concerns of harm for research participants are emerging in corporate research, comprehensive oversight by regulatory bodies, either internal to the corporation (Bowser and Tsai, 2015) or instituted by third parties (Polonetsky et al., 2015), should be put in place for the safeguarding of human subjects (Schneble et al., 2020). Both approaches, either having an external or an internal review committee, come with several complications that need to be addressed - for instance, issues of funding for the former and undue influence for the latter. However, the introduction of ethical review in corporate research would be valuable on many levels, especially for implementing data-sharing strategies between corporations and scholarly institutions and for viable academic use of corporate data. It would prove essential to predict and avoid the harm that could result for the users in specific data research practices; it would enhance transparency and trust between the different stakeholders involved in the research endeavor - academic partners, companies and their users/research subjects; it could assist in avoiding societal backlash, scandal and loss of reputation for both academic scholars and corporations; and it would level the current inequality of regulatory oversight between public and private entities (See Fig. 1: "Passive use of corporate data").

8.6 Limitations

The first limitation of this study relates to the broad "umbrella" definition of Big Data utilized in this manuscript and in the overall research project. As mentioned in the methods section, we defined Big Data as "an overarching umbrella term that designates a set of advanced digital techniques (e.g., data mining, neural networks, deep learning, artificial intelligence, natural language processing, profiling, scoring systems) that are increasingly used in research to analyze large datasets with the aim of revealing patterns, trends, and associations about individuals, groups, and society in general" (Favaretto et al., 2020c). Especially in this manuscript, this broad definition did not allow for a nuanced analysis of the different types of data used by our participants and their specific characteristics and features - such as the different ethical challenges posed by high-risk data (financial and medical) versus minimal risk-data (social science and anonymized data). Future research on the topic will benefit from a more specific distinction and will provide additional insight into the specific challenges that emerge from different data types. In addition, our results are not generalizable to the opinions of the entire academic community due to several methodological choices, including the size of the interviewed sample, the focus limited to psychology and sociology as research fields, and the restriction of the recruitment to solely two countries, Switzerland and the United States. Therefore, future research should aim at providing a complete picture of how scholars perceive the opportunities and challenges of corporate partnership by expanding the investigation to other disciplines – such as computer science, biomedical informatics, physics, mathematics, and medicine – and other countries with different cultural and ethical backgrounds.

Secondly, some limitations emerge as a consequence of the overall aim of the project this manuscript stems from. The data used in this manuscript comes from a larger project designed to investigate the regulatory and ethical issues of Big Data (see details in the methods section). Therefore, the study was not designed to perform an in-depth exploration of scholars' personal experiences with private firms nor to explicitly analyze the differences in attitudes between active and passive interactions with corporations. In addition, due again to the scope of the study, our sample did not exclusively include researchers involved in corporate collaboration, as the interviews we performed did not focus on this topic alone. Our sample included researchers who entered into collaboration with a private company and some who did not. We could not record as demographic data whether the participant was collaborating with a specific company due to the open-ended nature of our interviews, where participants were allowed to freely discuss topics pertaining to Big Data research, including personal experience with company collaboration and more general opinions regarding corporate practices. Consequently, our findings only mapped the opinions of academic researchers on academic-industry collaborations in general. Further research should focus on the experiences of researchers with private corporations more directly by closely analyzing their experiences and by clearly mapping the specific challenges and opportunities provided by both active and passive types of collaboration with private firms.

Finally, our sample only included academic researchers, thus omitting the input of researchers and people working in corporations and industries. For instance, our results did not allow us to make any remarks on the challenges faced by industry to engage with academia. Therefore, it would be essential that future research investigates the opinions and experiences of people in the industry sharing their data with universities to discuss the corporate side of the issues presented in this study and, at the same time, enhance appropriate practices of collaboration with academic institutions.

8.7 Conclusion

This research illustrates some challenges, tensions, and opportunities associated with partnership and data sharing between companies and academia. Our results highlight how academic researchers were generally open to the use of corporate data for academic projects as they recognized the value that corporate datasets and resources could have for the advancement of scholarly research. However, they often associated partnerships with companies with several challenges. They reported restrictions towards access to corporate data that could result in issues of scientific validity and disadvantage for the academic research community. Participants also shared several ethical reservations, such as a lack of transparency of motives and practices of companies, issues of consent and anonymity, and possible loss of establishing the integrity of research caused by companies' for-profit motives. Finally, our results highlight a perceived regulatory inequality between the private and the public sector, as many of our participants voiced their concerns regarding the lack of ethical oversight in corporate research.

As Big Data and digital technologies are creating new opportunities and incentives for academics to partner with private firms, strategies can be articulated and accepted to enhance and improve sustainable and ethical interaction, despite the ethical controversy and conflict of interests that academic-corporate partnerships might and have raised in some cases (Bekelman et al., 2003; Jain et al., 2014). According to Lutchen (2018), the last decade has brought a burst in the number of research deals between companies and universities, with both sides looking for more long-term, collaborative relationships (Lutchen, 2018). This research only illustrated the advantages of corporate partnership as perceived by and for academic researchers. However, there are increasing incentives for corporations to undergo partnerships with academic institutions such as access to cutting—edge research and talent, a focus on basic research that companies lately are neglecting in favor of product development (Lutchen, 2018), observation of scientific development, and knowledge-transfer from academia to private companies (Valentín, 2000). Additional research should investigate the point of view of corporations and private firms to understand their opinions regarding academic-corporate collaborations and what appropriate strategies could be arranged to foster sustainable and mutually beneficial interactions between the two actors.

8.7 References

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Chapter 9 – General discussion

The findings presented in this dissertation shed light on some of the most pressing ethical issues of Big Data in research and the impact that they have on the development of appropriate ethical research practices. In addition, this study provides insight into the practices, preferences and needs of Swiss and USA-based investigators involved in Big Data studies in relation to ethical guidelines, regulatory oversight and collaboration with private firms. Designed as a study to explore Big Data practices in Switzerland, the United States were chosen as a comparative sample because, as evidenced by the numerous grants placed for Big Data research projects by federal institutions (such as the NSF (2012; 2014) and the National Institute of Health (NIH) (2019)), advanced Big Data research is since several years a focal point on the US academic research agenda. As such, compared to CH, knowledge and familiarity with the challenges of Big Data might be more widespread among scholars and academic institutions.

Overall, no significant differences in attitudes, opinions, and suggested solutions were found between the two groups of participants. This highlights that in both countries researchers are struggling with similar ethical issues and that the solutions they propose to tackle them are not in contrast. This is a particularly relevant result as it could be the foundation for the development of practical solutions that could be harmonized globally especially for the Swiss research environment where the diffusion of Big Data research is still in the early phases. Through the harmonization of research practices, collaboration and exchange between different countries could be promoted. In addition, as legislations and guidelines for Big Data studies especially in CH are currently lagging behind (Vayena et al., 2015; Rothstein, 2016), the recommendations and suggestions provided by this study could assist the enhancement of sustainable regulatory and ethical frameworks that are in line with international standards.

9.1 Risk of harm – privacy and discrimination

The results of the theoretical part of this study (Chapter 3 and 4) highlight the importance of careful ethical consideration for the development of new technologies and the design of research that use digitalized and Big Data methods.

As highlighted in Chapter 4 and in line with the literature (Mittelstadt and Floridi, 2016b), breaches of privacy and confidentiality are closely correlated with Big Data practices. They can arise if the infrastructures for data storing and sharing are not appropriately developed, allowing access to sensitive data to unwarranted third parties (Cederberg and Valenza, 2012; Cvrkel, 2018; Jampani et al., 2011; da Costa et al., 2011), when data is linked and recombined as to reveal sensitive information about an individual (Ploug and Holm, 2017; Susewind, 2015) or when data is not appropriately anonymized (Spallek et al., 2015). These issues pose considerable challenges for research ethics since an essential part of minimizing harm in research is to protect the subject's privacy and confidentiality (Zimmer, 2018). As demonstrated in Chapter 6, academic investigators consider protection of privacy and anonymity an important component of ethical research, in face of the challenges posed by Big Data.

A crucial finding of this study is that discrimination and marginalization of vulnerable categories is one of the most tangible forms of harm that can derive from Big Data practices in numerous sectors, from the biomedical field (Chapter 4) to research and daily living (Chapter 3). As the results in Chapter 3 thoroughly describe, algorithmic mechanisms in Big Data, data linkage and the digital divide, could perpetrate discrimination towards protected classes and vulnerable categories (Kuempel, 2016), increase social marginalization and stigma (Lupton, 2015; Barocas and Selbst, 2016) exacerbate existing inequalities (Voigt, 2017) and also introduce new forms of discrimination such as health prediction discrimination (Hoffman, 2010) and economic discrimination (Peppet, 2014). Due to the proliferation of data technologies, social inequality and injustice are spreading in our society (O'Neil, 2016). This usually happens without much awareness and control since the algorithmic processes responsible for unfair practices are carried out by black box systems where the inner process of decision making remains unknown to data developers and that have little to no human supervision (Brannon, 2017; Citron and Pasquale, 2014; d'Alessandro et al., 2017).

9.1.1 The implications for research practices

Such issues are particularly relevant in the research ethics setting where paramount attention must be payed to avoid the infiltration of discriminatory practices and unfairness. As demonstrated in Chapter 3 there are many ways in which discrimination and unfairness could creep, even involuntary and accidentally, in Big Data research practices (Barocas and Selbst, 2016). For instance, underrepresentation of certain groups in the dataset could deliver a fragmented and incomplete representation of the population (Brannon, 2017); some interventions in research based on biased datasets could favor only one part of the population (e.g. the persistent problem of structural racism in precision medicine (Geneviève et al., 2020)); and linkage of data from diverse registries may result in the disclosure of sensitive data that could result in stigma and marginalization of research participants (Lupton, 2015).

Such threats of privacy, discrimination and injustice, imply that researchers and institutions, especially when they are dealing with personal and private data from individuals, should make extensive efforts towards the development of a) appropriate infrastructures and strategies to ensure the proper protection of research data (Lazer et al., 2009), b) strategies to anonymize the data (Daries et al., 2014) and c) practices to reduce discrimination that might derive from data bias or poor selection of the research sample (d'Alessandro et al., 2017).

Since Big Data is related to data science and informatics, most of the suggested solutions towards ethical issues of Big Data underlined in Chapter 3 and 4 are either strategies on a legislative or policy level (rules that determine what are the legal boundaries of the use of data – which this dissertation does not discuss in detail) or, more frequently, solutions related to software and infrastructure development, such as the establishment of secured networking communication for data sharing (da Costa et al., 2011) and the development of both privacy-preserving data mining models (Hajian et al., 2015), and discrimination-aware methods and processes (d'Alessandro et al., 2017).

However, as shown by this study, there are some important obstacles towards the development and implementation of these practical data science solutions within academia. Besides the fact that these technical solutions require a level of technical expertise that most scholars in behavioral science lack (Chapter 7) (e.g. appropriately balancing data quality and data usability (Daries et al., 2014)), at the same time it is important to point out that privacy, discrimination and justice are complex philosophical and conceptual notions, which are hard to translate into a formal statistical set of operations (Chouldechova, 2017). Furthermore, Big Data is profoundly reshaping the concepts of privacy and discrimination: for instance, automatic decision making and profiling technologies have altered our understanding of discrimination beyond legally accepted definitions, making it difficult to appropriately evaluate cases of algorithmic discrimination (Barocas and Selbst, 2016); concepts like “identity” and “group” are being transformed by data mining technologies as individuals are increasingly sorted into arbitrary groups created in accordance with algorithms’ arbitrary correlations (de Vries, 2010); the concept of privacy within research practices is challenged because Big Data is blurring the boundaries between private and public, especially in the context of online research and research that uses publically available data (Zimmer, 2010). For these reasons, the concepts of privacy and discrimination should not and cannot be reduced to “petrified” statistical measurements and the implications of new discriminatory practices, privacy threats, and their consequent solutions should be accompanied by a theoretical, conceptual and philosophical reflection.

9.1.2 Beneficial outcomes of Big Data

The results discussed in Chapters 3 and 4, underlined how Big Data technologies could also help solve some ethical issues that are currently affecting society. It is interesting to notice that most of the beneficial applications focus on the potential of Big Data to enact meaningful systemic changes by levelling inequalities and promoting justice, such as: empowering individuals through increased democratization of knowledge (Gross et al., 2019), promoting urban development (Mao et al., 2015; Vaz et al., 2017; Voigt, 2017), stimulating equality and social integration in healthcare research (Cvrkel, 2018; Voigt, 2017) by implementing tailored strategies that take into account an individual's ethnicity, living conditions and general lifestyle (Bakken and Reame, 2016).

The beneficiality of such applications is based on a double assumption: (1) that of a widespread and uniform distribution of digital technologies globally (Yu et al., 2018); (2) the idea that data mining promotes objectivity in classification and profiling which limit human error and bias, because decisions are made by a formal, objective and constant algorithmic process with a more reliable empirical foundation than human decision-making (Barocas and Selbst, 2016).

Unfortunately, as shown in Chapter 3, the digital divide is still a major cause of inequality as lack of access to digital technologies is growing in many sectors including health (Weiss et al., 2018), public participation/engagement (Bartikowski et al., 2018) and public infrastructure development (Pak et al., 2017; Taylor, 2017), despite the efforts to enhance digital participation worldwide (Yu et al., 2018). Moreover, it was also demonstrated that data mining can never be free from the human component. Insofar human subjectivity is at the very core of the design of data mining algorithms and human intervention is crucial to avoid improper correlations and to ensure fairness in data mining. Hence, the assumption that data analytics is less biased than human decision-making was undermined.

9.1.3 Lack of empirical research

The dichotomy between beneficial uses of Big Data technologies and possible harmful outcomes for individuals, that emerged multiple times from the results of this study, only underlines the urgency of extensive in-depth empirical research on the specific ethical issues related to Big Data research to appropriately understand and confront them.

In line with Mittelstadt and Floridi (2016b), this dissertation indicates that the discussion on the topic of Big Data in different sectors and disciplines remains mainly theoretical and that empirical studies on the harms stemming from Big Data research is largely lacking. Lack of evidence should however not be considered as evidence for lack of harm, as ethical issues stemming from Big Data are largely recognized by the research community (Mittelstadt and Floridi, 2016a).

The Nuffield Council of Bioethics (2015) attributes the shortfall of evidence from the abuse of biomedical Big Data to a lack of robust reporting mechanisms and empirical research, with most notified cases coming from anecdotal accounts and notable media stories. Similarly, reports of discrimination, injustice and breaches of privacy in Big Data outside of the biomedical field usually attain public attention through newspapers and media coverage. For instance, reports of the Cambridge Analytica scandal, where millions of user profiles were gathered improperly from Facebook by a British political consulting firm to build voter profiles for tailored political advertising, were first provided by a piece of investigative journalism by the New York Times (Confessore, 2018). Likewise, racial bias against black offenders, found in software used for intelligent predictions in police and law enforcement in the US, was revealed by an investigation of *ProPublica*, an independent non-profit newsroom (Angwin et al., 2016). Moreover, analysis of harm deriving from research projects is usually performed by theoretical papers that point out the possible harm that a study could cause to its participants, but lack data to empirically confirm their hypothesis (see for instance: (Shaw, 2016; Metcalf and Crawford, 2016)).

This is not to argue that theoretical analysis is not necessary to uncover harmful practices. Conceptual and philosophical analysis is essential to appropriately tackle the nuances of the ethical issues of Big Data. Nevertheless, the principle of *beneficence* requires that an appropriate balance between harm and beneficial outcomes of a study is made by investigators. Without thorough empirical investigation that clarifies the type and level of harm that derives from different research projects, such balance becomes hard to make. Therefore, strategies should be implemented to enhance more evidence-based studies on the pitfalls and promises of Big Data studies.

9.2 Beyond the Belmont Report: the need of a new ethical framework for research involving human subjects?

9.2.1 The (lack of a) definition of Big Data and its implications for research

Although there is no widely accepted definition of Big Data (De Mauro et al., 2015; Mittelstadt and Floridi, 2016a), the results of Chapter 5 have highlighted some important terminological and definitional elements that could have consequences for research practices and the creation of suitable ethical frameworks.

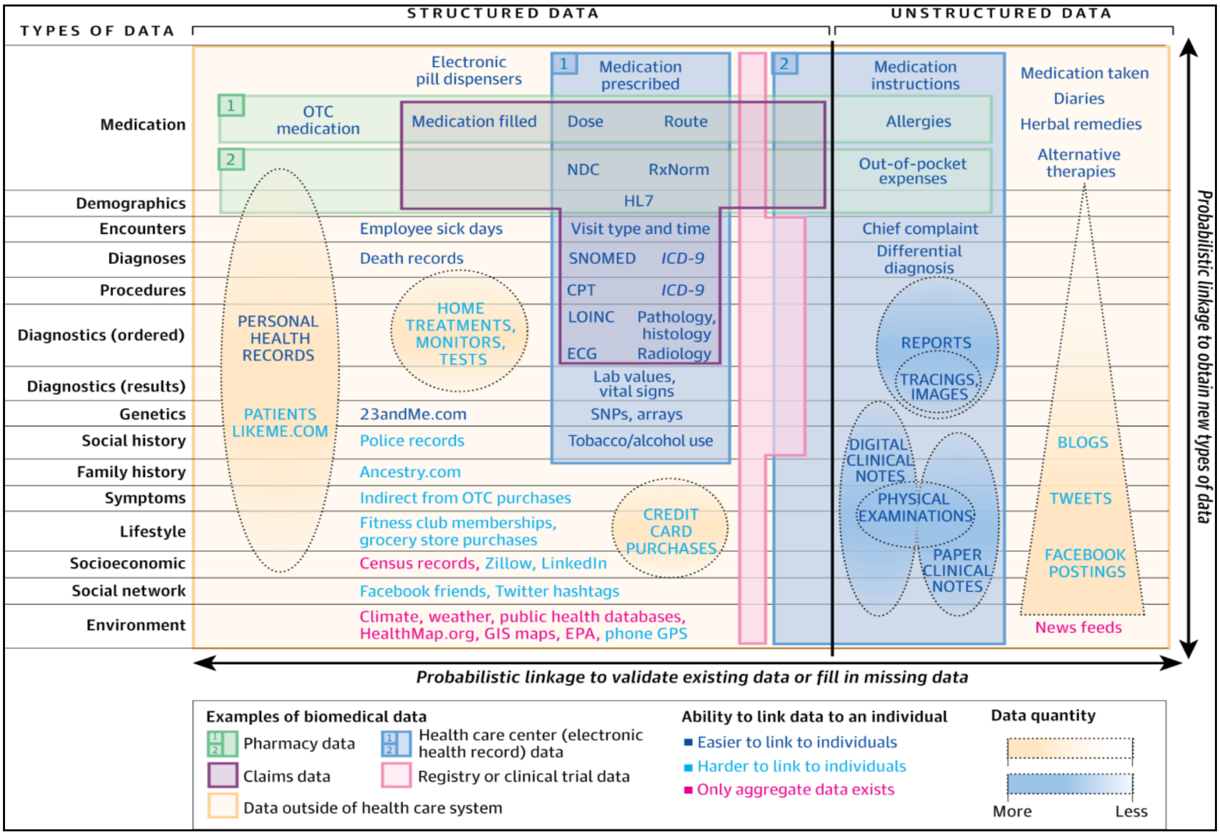
First of all, there seem to be a widespread recognition among researchers from the behavioral sciences that Big Data is in some way personal data or data that keeps a link with the person whose data is gathered. In line with definitions from policymaking bodies such as the EU commission that focus on the human component of Big Data (EU Commission, 2016), many of the researchers in this study defined Big Data as data generated by people through their daily activities and interactions with digital technologies. This finding becomes particularly important when linked with the current debate over the definition of the human subject in Big Data research. The concept of human subject, in fact, is becoming increasingly opaque with the introduction of Big Data methods in research. This is partly due to the fact that even though algorithmic analysis, statistical measurements and mathematical predictions ultimately represent people, the precursor disciplines related to Big Data – such as computer science, applied mathematics and statistics – are not traditionally considered as a conduction of human-subjects research (Metcalf and Crawford, 2016). In addition, data collection and other interactions between investigators and their research subjects are increasingly mediated and filtered by technological and digital tools (e.g. social media profiles, data networks, and transaction logs etc.). The worry that comes from such a “technological mediation is that researchers are increasingly detached from their participants and that their perception of human subjects becomes diluted (Zimmer, 2018). The recognition of the human component highlighted in Chapter 5 demonstrates that such detachment is not yet felt by the participants of the present study. In fact, their focus on the human factor in the definition of Big Data, together with the acknowledgement of their responsibility to protect data subjects from harm (Chapter 6), shows that our investigators are aware of and attentive about the strategies to protect research subjects in digitalized research.

Secondly, the difficulty of pinning down a definition of Big Data highlight the implicit need to adopt a more flexible understanding of the term as a socio-culturally evolving concept. It also questions the usefulness of the term towards the creation of ethical frameworks, if policymakers and scholars alike do not have a comprehensive grasp of the extent of the epistemological and socio-cultural nuances that the term embeds. The findings in Chapter 5 underline how Big Data is a tremendously vast and context-dependent concept that includes different subcategories and specificities which might give rise to very different ethical and regulatory challenges. Despite the common characteristics embedded in the traditional definition of Big Data (like volume and variety), there are many data specificities that must be considered when evaluating a research project. If we take volume for instance, high volume can be both related to a) high amounts of data points from a single individual or b) one data point from millions of participants. Hence, studies that qualify as Big Data studies might be essentially very different. For instance, a research study in psychology that analyzes streams of vast amounts of different data from smartphones of thirty participants has the characteristics of velocity, variety and volume, however such study is inherently different from an online study that scrapes data from millions of users on Twitter. Technical differences aside, also the ethical challenges and the potential harm for research participants differ consistently between these two studies: the first might encounter issues of data security and re-identification of research participants; the second might face concerns related to informed consent and awareness of research participants.

When it comes to the definition of Big Data, in order to build a framework that appropriately handles its ethical dilemmas, it might then be necessary to deconstruct or unfold the term into its different constituents, thus shifting from broad generalities – such as considering Big Data as an umbrella term – to specific qualities relevant for each specific subcategory of Big Data. This interesting approach suggested by Kitchin and McArdle (2016), that focuses on a more nuanced analysis of the concept of Big Data, proposes to consider Big Data as an analytical category that needs to be further unpacked and delineated and its various subcategories identified.

The sub-terms that are emerging in the academic milieu (such as Biomedical Big Data (Mittelstadt and Floridi, 2016a) and Big Social Data (Olshannikova et al., 2017)) and the attention that different disciplines are paying to narrower Big Data uses and technologies both on a methodological and ethical level (Woo et al., 2020; Salganik, 2019; franzke et al., 2019), are the first steps towards an appropriate clarification of the different Big Data types. However, even within those broad categories a more nuanced specification regarding the type of data and their core characteristics is needed. For instance, Weber, Mandl and Kohane (2014) provide a brilliant overview of the taxonomy of Biomedical Big Data (see Figure 9-1) that could be taken as a useful classification for other disciplines and fields as well.

Figure 9-1: *Taxonomy of Biomedical Big Data*



Source: Weber, G.M., Mandl, K.D., and Kohane, I.S. (2014) Finding the missing link for big biomedical data. Reproduced with permission from [The Journal of the American Medical Association, 2014. 331(24): 2479-2480]. Copyright©(2014) American Medical Association. All rights reserved."

Such clarification of the context and characteristics of the different Big Data types could provide important insight about the "Big Data" used in different fields, gain conceptual clarity about what constitutes Big Data, and generate insight on how to appropriately make sense of its ethical issues.

9.2.2 Interdisciplinarity: collaboration, education and the need of ethical reflection in Big Data research

Another relevant theme that emerged from this study is the inherent interdisciplinary nature of Big Data. The results delineated in Chapter 6 and Chapter 7, have highlighted that Big Data, by being an intrinsically interdisciplinary field, challenges the appropriate design and ethical evaluation of Big Data studies. On the one hand, there are investigators trained in philosophy, social science, and psychological research that do not always fully understand the implications of algorithmic modelling and the technical subtleties of data science (Schermer, 2011), on the other we have researchers coming from more technical fields, such as data science, who lack the expertise and tools to proactively think about ethical issues when designing or performing a research project (Vitak et al., 2016). Overcoming the challenges posed by this interdisciplinarity is one of the core element towards the design of appropriate ethical frameworks. Two strategies could be implemented towards this goal.

First, as the technical needs of Big Data projects need to be accommodated by the presence of skilled data scientists, there is an urgent need to enhance interdisciplinary collaborations between different fields. Research projects that use Big Data methods should be carried out by teams with interdisciplinary backgrounds, such as ethics, social science, psychology, data science, in order to cover both the technical aspects and the more conceptual and ethical conundrums (Lazer et al., 2009). Should this not be possible, especially when projects are carried out by a team mainly composed of data scientists, increased consultation and collaboration with experts in ethics should be sought to guarantee the ethical design and follow up of a research project.

Second, due to the fact that investigators are more and more called to critically reflect on the design of their studies and the consequences they might have for research participants (Goel, 2014), it becomes paramount to construct a "culture for ethics" (Tractenberg, 2016). In such an environment, on top of the development of appropriate ethical guidelines for investigators, researchers from all fields should be educated and trained in the development of skills of ethical reasoning and be prepared to address the ethical and societal issues that are of primary concern for those engaging with Big Data analytics and management (Tractenberg, 2016). For this reason, even in the scholarly formation of data scientists and more technical curricula, space should be given for the integration of coursework in ethics and ethical reasoning. Educating professionals towards ethical reflection will not only promote ethical decision-making in research and in practice, but it will also assist in establishing a responsible research community of ethical practitioners that are equipped with the tools to raise appropriate ethical questions when reviewing or developing different research projects (Tractenberg, 2016; Zook et al., 2017).

9.2.3 Traditional ethical principles, context dependency and ethical decision making

The results described in Chapter 6 demonstrate that the traditional research ethics principles, such as *respect for persons* in the practice of informed consent, *beneficence*, minimization of harm through protection of privacy and anonymization, stated by documents like the Belmont Report and the Declaration of Helsinki are still considered a relevant guidance by academic investigators. This finding is in line with current theoretical analysis on the creation of appropriate ethical guidelines for researchers in the digital age (Anabo et al., 2018; Vitak et al., 2016). For instance Salganik (2019) argues that the flexibility that characterizes these principles makes them an adequate framework where investigators can clarify trade-offs by appropriately balancing the different principles and bring about ethical reasoning.

At the same time however, Chapter 6 also demonstrates how investigators, while placing great importance on traditional ethical principles and practices, recognize the challenges that digital methods and Big Data are introducing. For instance, scholars admitted that informed consent is increasingly difficult to obtain and, in some cases, for example when performing online media studies, it might no longer be ensured (Metcalf and Crawford, 2016). When it comes to protecting the privacy and anonymity of research participants, this study registered a widespread recognition regarding the difficulty of ensuring anonymity and prevent re-identification of participants. In addition, some of the characteristics of Big Data outlined in section 1.3.1 of this dissertation clash with some of the practices valued by the interviewed researchers. For instance, *persistency* could be in contrast with the participants' right to withdraw from a research study.

The fracture that this dissertation registered between the recognition of the importance of traditional ethical principles, and the awareness of the limitations of such a purely principlistic approach in research ethics, that Big Data has reinforced, underlines the need of an updated ethical framework that stays true to the principles embedded in the Belmont Report, but at the same time accommodates the needs and changes introduced by Big Data methods.

First of all, on the same line as Steinmann et al. (2016), this study has highlighted that a one-size-fits-all approach is not appropriate to face the multifaceted ethical dilemmas of Big Data research. As a consequence, ethical reflection should be introduced within the analysis of research projects on a case by case scenario.

Emphasis on contextually driven decision-making is becoming a central point of many of ethical frameworks and guidelines that are emerging for Big Data studies (Anabo et al., 2018). Such frameworks place great importance on ethical deliberation and balanced trade-off analysis that investigators involved in the development of research projects have to demonstrate. For instance, the Ethical Guidelines for Internet Research by the Association of Internet Researchers (AoIR) emphasizes that the adequate process approach for ethical internet research is one that is reflective and dialogical "as it begins with reflection on own research practices and associated risks and is continuously discussed against the accumulated experience and ethical reflections of researchers in the field and existing studies carried out" (franzke et al., 2019: 9). Instead of defining a widespread overarching set of norms or rules for protecting research participants, applying context specific assessments increases the chances of solving ethical issues and appropriately deal with research participants.

For instance, it is recognized as problematic to consider privacy as a binary concept (private vs public data). Through data linkage, even publically available data could breach individuals privacy and cause them harm by revealing sensitive information about them (Zook et al., 2017), as happened in the examples detailed in Chapter 6 such as the New York City Taxi & Limousine Commission scandal in 2013 (Franceschi-Bicchierai, 2015) or the "Tagging Banksy" project (Hauge et al., 2016). By recognizing privacy as contextual, situational and changing over time (Zook et al., 2017; Nissenbaum, 2009; Salganik, 2019), researchers are asked to consider key factors such as the context in which the data were created and obtained, and the expectations of those whose data is used, in order to make ethical and balanced decisions regarding privacy of the participants. To give an example, in a research project that analyses voting trends in a country, investigators, although they might be analyzing only publically available data (e.g. social media and voter data), will have to ensure enhanced protection for the privacy of research subjects: users might not have expectations of privacy over their publically available information when taken singularly or separately, but they might have privacy concerns regarding the information revealed by the linkage of these two streams of data (their voting preferences).

When it comes to practices of informed consent, Salganik (2019) suggests to move beyond the "informed consent for everything" ideal towards a more complex rule: "some form of consent for most things". Researchers should interrogate themselves about what forms of consent are needed for the type of research they are performing. Heavy reliance on informed consent, although as demonstrated by Chapter 6 is still preferred by investigators, encounters a number of technical limitations in the Big Data context. Data might be recombined and linked across ecosystems far removed from the original source of data, making it impossible to re-contact participants or fully inform them about the range of uses their data will undergo (Xafis et al., 2019). Informed consent might also pose increased risk to research participants in certain contexts: Salganik (2019) for instance provides an example of a research project where investigators monitored Internet censorship through access from computers of people living under repressive governments. Asking them to provide consent would have resulted in placing individuals at increased risk, reason why the investigators opted for different forms of consent by contacting Non-Governmental Organizations. Finally, even before the advent of Big Data, consent already presented challenges. It is not an uncommon practice in social and psychological research to withhold information from participants or to deceive them, as there are cases where full informed consent would compromise the scientific validity of certain studies (Marzano, 2007). There are some strategies and alternative solutions to obtain weaker or alternative forms of informed consent such as informing the public about the research, enabling an opt-out, seeking consent from third parties, debriefing and so on (Salganik, 2019). In addition, as discussed in Chapter 6, forms of dynamic consent, a model where online tools are developed to have individuals engage in decisions about how their personal information should be used, are being developed to deal with the challenges posed by Big Data research (Abdul Aziz and Mohd Yusof, 2019; Dankar et al., 2020).

Big Data uses and methodologies are forcing the regulatory and ethical debate away from standardized norms and tools, demanding investigators to actively and continuously reflect on what type of strategies and ethical practices are better suited for their own research projects.

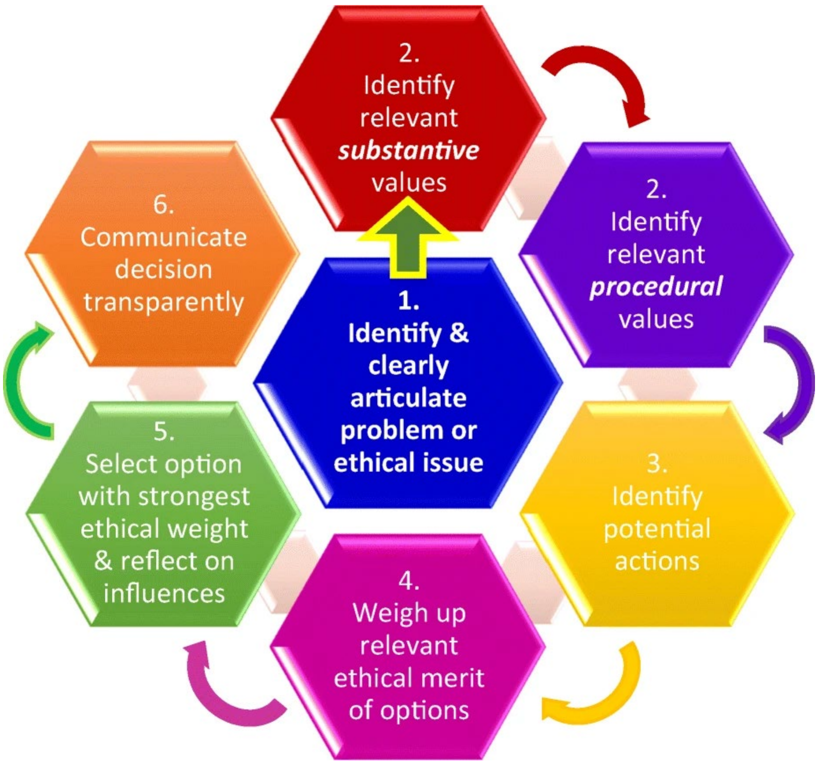
9.2.4 Promising ethical frameworks

The question remains however regarding what should drive investigators' ethical reflection other than the respect for the principles of the Belmont Report. Currently several scholars are developing frameworks that focus on a shift from a principlistic perspective to different paradigms for ethical research practices. Based on the preferences voiced by the researchers interviewed in this study for the values embedded by the Belmont Report (eg. respecting the subjects of research, non-maleficence and protection from harm), I will highlight three promising frameworks for Big Data studies.

The first framework is a value laden approach to ethics proposed by Xafis et al. (2019) and Steinmann et al. (2016). The main goal of these two approaches is to support decision makers in identifying key values related to a range of Big Data uses and providing them with tools and examples to appropriately balance such values towards ethical decision making. In this context, Xafis et al. (2019) provide a list of 16 values relevant for many Big Data uses divided in substantive – considerations that should be realized through the outcome of a decision – and procedural – values that guide the process of deliberation. Substantive values are overarching principles such as justice, public benefit, solidarity or minimization of harm, while procedural values are those that can assist in realizing some substantive values such as accountability, consistency, transparency and trustworthiness.

This set of values should then be used by investigators to solve the ethical issues identified within a research project by applying a *deliberative balancing* approach to decision making (See Figure 9-2).

Figure 9-2: *Deliberative balancing approach to decision-making in Big Data contexts*



Source: Xafis V, Schaefer GO, Labude MK, et al. (2019) An Ethics Framework for Big Data in Health and Research. Asian Bioethics Review 11: 227-254.

Similarly, Steinmann et al. (2016) propose a methodological approach to ethical reflection that identifies a set of values or, or principles (non-maleficence, beneficence, justice, autonomy, and trust), that cannot be further subsumed under one over-arching value, and provide a "privacy matrix" (Steinmann et al., 2015) as an heuristic tool in order to assist investigators to assess ethical issues under specific contexts (social, governmental, commercial, scientific). Their point is that that the same ethical concerns of privacy can become more or less manageable according to each context since in each context the amount of disclosure, the nature of disclosure, and the ultimate effects of disclosure vary in gravity. Therefore, investigators are asked to evaluate and balance what concerns are the most relevant in each context.

Figure 7-3: *Key drivers for Big Data Ethics*

Zimmer (2018), while introducing Nissenbaum's theory of contextual integrity[5] (Nissenbaum, 2009) as a tool to guide Big Data researchers towards the evaluation whether a given practice represents a violation of privacy in the context of their research study, suggests to switch the focus that drives frameworks for Big Data research from "human subject research" to "human harming research". Following Carpenter and Dittrich's suggestion to transition "from an informed consent driven review to a risk analysis review that addresses potential harms stemming from research in which a researcher does not directly interact with the at-risk individuals" (Carpenter and Dittrich, 2011: 14), the fundamental questions that drive investigators in their decision making in this framework would be: what type of harm could this

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[5] Nissenbaum's theory of privacy as contextual integrity is a conceptual framework that links the protection of personal information to the normative restraints of personal information flow within specific contexts. According to this theory, information should not be considered as inherently public or private, but its appropriate use is contextual to the norms and expectations connected to the appropriate flow of personal information. In the context of Big Data research, protection of privacy is then seen as preservation of informational norms within specific contexts. In each context the decision maker will be required to evaluate the flow of information between agents to identify why certain patterns of information flow are acceptable in one context, but problematic in another (Nissenbaum, 2009).

research inflict? Are there any ethical implications or harm for broader populations stemming from this research project?

Finally, an interesting approach that is only recently emerging is to apply care ethics to, Big Data studies (Suomela et al., 2019). The ethics of care is a normative ethical theory inherent to feminist bioethics that finds application as a framework for research ethics (Held, 2006). Such framework, created as a criticism of the principlist approach, has the aim of shifting the focus from enforcing rights and norms to the contextual analysis of the dynamics of relationships within the research study in order to protect and take care of the most vulnerable categories. Such approach prioritizes research relationships and is driven by questions such as: “What are the relationships between the people involved in a project? Who possesses the power or authority in a given situation?” and it “recognizes the differences in vulnerability and need among stakeholders between those studying and those being studied” (Suomela et al., 2019: 8). Practically, this translates in the Big Data context as the incorporation of a coherent discussion over research ethics during the early stages of planning and data collection and an attentive analysis of the relationships upon which the work of the investigators depends upon in order to anticipate possible conflicts, ethical issues and harms.

9.3 Who’s responsibility? Between overview and collaborative efforts in Big Data research

The *multi-entity governance* characteristic of Big Data that we have described in Section 1.3.1, together with the challenges encountered by researchers in properly addressing the ethical issues stemming from Big Data, opens the question of what the roles and responsibilities of the different actors involved in academic Big Data research are.

Collmann et al. (2016) identify two mirrored inter-related concepts for ethical responsibility for data stewardship: ethical horizon and ethical provenance. “Ethical horizon refers to the perspective of investigators at the time of data creation who look to future uses of the data, their own and all subsequent investigators. Ethical provenance refers to the perspective of an investigator who looks to the past from which data comes” (Collmann et al., 2016: 143). These concepts, according to the authors, refer to the responsibility of investigators to ensure ethical management and privacy protection for Big Data across its whole lifecycle (collection, compilation, analysis and application), making them the main responsible actors of the protection of human subjects. On the same line, current research guidelines in the field of social sciences and psychology that cover internet mediated and other Big Data research, place the responsibility for the ethical concerns of research projects mainly on the shoulders of investigators (Anabo et al., 2018).

However, from the interviews it has become clear that, due to the changes in the traditional research subject/investigator dynamic caused by the introduction of diverse factors/actors in the scholarly research environment (such as social media platforms and private firms), scholars are starting to interrogate themselves whether Big Data research and methodologies generate a shift of responsibility in protecting research participants. Many interviewees in fact, while admitting that part of such responsibility should fall on researchers themselves, pointed out that also other actors involved in the research process could and should share some of these obligations. They identified at least two such actors: data owners, in the personification of private firms in case research projects make use of corporate data, and overview bodies, such as Ethics Committees and Institutional Review Boards.

This perceived shift points to an implicit need to reconsider the responsibility dynamics in scholarly research on the part of researchers. In doing so, crucial questions open up such as 1) who should bear the responsibility of protecting the research subject in Big Data studies, 2) how much should data owners, data holders, ethics committees and even users be involved in sharing such responsibility, and 3) how to appropriately design and regulate its re-distribution.

It is important that academic investigators are not left alone in bearing all the responsibility of the ethical design and follow-up of research projects (Raymond, 2019) since, as highlighted multiple times in this dissertation, they might not possess the skills or even the power to appropriately safeguard research participants.

As a consequence, an analysis regarding the role and position that these two identified actors, companies and RECs, assume within the ecology of Big Data research has been carried out in this dissertation. These findings, together with additional research on the topic, will assist in identifying some of the appropriate strategies to assist researchers in facing the ethical issues of Big Data research.

9.3.1 The expansion of RECs’ role and purview

The results in Chapter 7 point out to an ambiguity in the participants’ perception regarding the role and functions of RECs as they were defined both as stewards of ethical research practices and as mere legal protectors of institutions and researchers. As suggested by a number of soft law documents and guidelines reviewed by Ferretti et al. (2020), ethics committees’ purview and role should be expanded and re-evaluated as a consequence of Big Data research. According to these documents, RECs should monitor the ethical soundness of Big Data projects though their whole data lifecycle; they should be able to audit each phase of the project, including research planning, data collection, analytics, and dissemination of results and should also examine the ethical safeguards in place to protect research participants and ensure transparency and quality of data management. As a consequence, ethics review, as some of the interviewees underlined, should not be considered a one-time waiver or a mere liability check, but an essential part of ethical research processes.

This is a relevant finding, especially in Switzerland, in light of the current implementation of ethics review boards at an institutional level. As mentioned in Section 1.4.2, Swiss universities are independently establishing IRBs in order to overcome the regulatory gaps left by the definition of human subject research from the HRA and to complement cantonal ethics review (Mitroff and Sharpe, 2017).

At the same time, measures and precautions should be taken towards a sustainable revaluation of the role of ethics reviews globally. In fact, expanding the purview of RECs could become an overbearing task for committees and fall within what Gunsalus et al. (2006) have referred to as the mission creep of American IRBs. According to the authors, bureaucratic burdens create a backlog of requests that make the approval process an excessively lengthy process and at the same time increase the possibilities of having unethical research being approved due to oversight and inattention. Based on the preferences expressed by the interviewees three are the considerations that should be addressed to appropriately implement ethics reviews' processes.

First, participants associated positive experiences with RECs in terms of support, contact and dialogue with committee members. RECs should therefore engage more with researchers and support them throughout the evaluation of their research projects, by means of nudges, comments, and responses to queries (Ferretti et al., 2020; Laurie et al., 2018). Some good practices suggested by the participants were a) the organization of Q&A sessions, where investigators could discuss the ethical design of their projects with experts and members of the ethics commission; and b) the establishment of an official intermediary to be reached by investigators in case of doubts or need for clarifications. These strategies could be suitable solutions to shorten the time needed for approval. If appropriate support is obtained in the early phases of the approval request, investigators will be more likely to submit complete and more pertinent research proposals, both ethically and bureaucratically, thus limiting the RECs effort towards their evaluation.

Second, participants reported problems in the current composition of ethics committees in terms of lack of appropriate expertise to evaluate and regulate increasingly digitalized research. As discussed in Section 1.2.1, the new methods introduced by Big Data call for the introduction and integration of more computational expertise in order to appropriately evaluate the design of Big Data research projects. Institutions should therefore seriously consider updating and diversifying RECs' composition by appointing individuals with expertise in computer science, data analytics, statistics and data ethics (Chapter 7). Furthermore, as suggested by Ferretti et al. (2020), RECs should also contemplate educational strategies for committee members and investigators in the form of training programs or capacity-building activities.

Third, due to the reported lack of both coordination between RECs and guidelines for appropriate ethics evaluation of Big Data studies, it has been argued that harmonized and coherent set of practices should urgently be implemented by RECs, research institutions, and science regulators to improve ethics review processes (Ferretti et al., 2020). As demonstrated in Chapter 7, standardization of the expertise required from board members could be a first step towards harmonization among different RECs and the formulation of coherent evaluation practices for Big Data studies. In addition, Collman (2016) suggests to contemplate the introduction of DMPs (Data Management Plans) as part of Big Data research proposals that are presented to RECs for approval. DMPs would be compiled by scholars in the form of a decision tree that contains information about a) the data; b) how it will be stored or managed during and beyond the project period; and c) how access to the data will be managed, granted, rescinded, and otherwise controlled during and beyond the project period. Such document would assist in the active estimation and forecasting of possible harm for research subjects deriving from the project by RECs. It would also accommodate the context-dependency nature of Big Data studies as both investigators and committee members would have to actively reflect upon the ethical concerns that might emerge from heterogeneous DMPs and consequent projects. Such a proposal is still at the embryonic stage of development, however it could be one of the possible ways towards coherent harmonization of RECs practices globally that also guarantees the appropriate level of flexibility required from Big Data ethics regulation.

9.3.2 The role of private companies in academic research

In the analysis of the role of private companies within the ecosystem of academic research, Chapter 8 has highlighted some of the tensions that are emerging in academic-company collaboration.

On the one hand, from the interviews it emerged how Big Data research is currently incentivizing partnership with private firms. The advent of Big Data is growingly entwining industry and academic interests (Leetaru, 2018): scholars are in fact attracted by the prospect of monetary and infrastructural resources that companies are willing to invest, the pragmatic impact that their research could make for society and individuals through the channels of corporate dissemination, and by the possible numerous uses for research of heterogeneous data that companies are gathering in high amounts. On the other hand however, scholars expressed numerous multifaceted concerns and reservations towards possible collaborative endeavors with private partners.

First, many concerns were of a methodological nature and mainly pointed towards issues of data quality and the limitations of data driven research. As highlighted in Section 1.2.1, scholars are generally not in favor of the loss of theoretical depths that data driven methods might imply (Woo et al., 2020) and, while they might have the interest to deliver scientifically sound and reproducible research based on theory rather than correlations, Chapter 8 has demonstrated how, from the point of view of university-based researchers, companies are mainly moved by for-profit motives and therefore not too keen in providing additional time, resources or data to academic scholars.

A second tension was associated with a perceived imbalance or inequality between public and private research entities in terms of regulatory overview. Scholars considered the lack of ethical evaluation for corporate research practices as extremely problematic since private firms are collecting and analyzing increasingly sensitive data from their users. Due to the evidence of harm caused by corporate research that did not underwent ethical evaluation - such as in the case of the Facebook Emotional Contagion Study (Shaw, 2016) and the studies carried out by the OK Cupid platform (Rothstein, 2015; Zimmer, 2018) analyzed in depth in previous chapters of this dissertation – the private sector needs to take on the responsibility of respecting and protecting their users (Kahn et al., 2014). As a consequence, regulatory practices and ethical overview should be expanded also to corporate research through the institution of structures similar to RECs for academic research either internal to the corporation (Bowser and Tsai, 2015) or instituted by third parties (Polonetsky et al., 2015).

Finally, scholars seem to have numerous ethical reservations towards the inclusion of corporations in the academic research environment. The impairment of research integrity as a consequence of for-profit incentives creeping into academic work and the perceived lack of transparency of corporate motives and practices were seen as important hindrances towards collaborations with private companies. Some authors have advocated for the introduction of ethical inquiry in business sectors that deal with Big Data. Davis (2012), for instance, has described many of the benefits that asking ethical questions could bring in the business context: being an organization "fluent in Big Data ethics" would provide the company a leadership role when compared to others; it would attract more consumers by reducing the fear of the unknown and providing reassurance to its users; and reduce the risk of unintended consequences and possible subsequent legal and reputational repercussions for the company. Introducing ethics in the management of corporate practices could mitigate some of academic scholars' reservations and reputational risks in being associated with private corporations described in Chapter 8.

9.3.3 Towards a paradigm of collaboration and shared responsibility in Big Data research

This dissertation has demonstrated how much collaboration between different actors is important, if not essential, in the Big Data research environment. Investigators are calling upon enhanced involvement of RECs in the ethical design of research projects; companies are asked to share some of the responsibilities in the protection of data users; and finally academic scholars are increasingly interested in accessing data from private companies.

As a consequence, paramount importance should be given to the implementation of strategies for sustainable collaboration between the aforementioned actors. Enhanced collaboration will set up the creation of a paradigm of shared responsibility among stakeholders that could, in turn, provide appropriate safeguards to Big Data research participants and also promote sustainable and beneficial Big Data research.

When it comes to the role of RECs, this dissertation has demonstrated that investigators consider ethics review boards to be the best suited as consultants to research rather than mere post-hoc gatekeepers. As a consequence, models of increased consultancy and collaboration between committees and scholars should be designed to enhance appropriate protection for human participants in Big Data research, and assist investigators in having more flexibility and certainty about their research practices (Chapter 7).

With regard to the relationship between researchers and companies, a sustainable place for partnership should be actively created. Strategies towards its establishment are numerous and must be appropriately investigated such as a) the implementation of policies to govern possible conflict of interests and find a balance between scholar's ethical reservations and industry's motives and desires; b) the establishment of review practices for corporate research that will assist in levelling the current inequality in oversight between corporations and academic research, promote transparency, trust and assist investigators and companies to set common goals for partnership (Chapter 8), c) the introduction of ethical inquiry in corporate practices in order to enhance collaboration through the generation of explicitly shared ethical values.

9.4 Limitations and implications for further research

9.4.1 Limitations

The presented research has several limitations. I will first go through the limitations of the systematic reviews (Chapters 3 and 4) and secondly through those of the interview study (Chapters 5, 6, 7 and 8).

For Chapters 3 and 4, the systematic review only included peer-reviewed articles from academic journals. Studies in other languages and the relevant grey literature might have therefore been overlooked. These limitations aside, Chapter 3 represents the first comprehensive and multidisciplinary examination of the relation between Big Data and discrimination and Chapter 4 the first study that systematically evaluates different ethical issues raised by Big Data in the field of dentistry.

With regards to the interview study, this dissertation only included researchers from the fields of psychology and sociology, and might therefore have overlooked the perspectives of other disciplines involved in Big data research (medicine, architecture, geography, etc.). Secondly, given that Big data research is intrinsically an interdisciplinary field, it has been extremely difficult to pinpoint the background of some of the participants as most of them have a heterogeneous academic career that qualifies them as experts in more than one field. Finally, since this study is qualitative in nature and the findings are based on a modest sample size, they are not generalizable. Additional specific limitations are discussed in the respective chapters (see Chapters 5, 6, 7 and 8).

9.4.2 Implications for further research

This study opens up numerous possibilities and paths for additional research. As mentioned in the limitation section, this study covered only experts from the field of behavioral sciences. As a consequence, future research could expand to other disciplines in order to acquire a more comprehensive understanding of the opinions and attitudes of researchers from diverse disciplines.

Secondly, this research project has only covered the opinions of academic investigators, thus omitting the inputs of other relevant stakeholders in the ecology of Big Data research. Future investigation should focus on different actors. For instance, as the contextual evaluation of ethical issues is becoming the main framework to assess Big Data research, more analysis should be performed on the contextual preferences of individuals (the subjects of research) on matters of privacy, autonomy, anonymity and informed consent. For instance, Rainie (2016) has analyzed privacy preferences of US citizens in the context of Big Data research uses. It would be relevant to expand such analysis both regarding different ethical concepts (such as consent and autonomy) and different countries with different cultures (UK, Switzerland, India, Japan, just to mention a few). Future research could also aim for comprehensive analysis of the perspectives of REC members worldwide, an endeavor that has been set off both in the United States (Vitak et al., 2017) and Switzerland (Ienca et al., 2018). Finally, although it might be difficult for organizational reasons, it would be exceptionally significant to obtain the perspective of researchers working within or in collaboration with Big Data corporations (eg. Google, Facebook, IBM and the like). Insights from their researchers could definitely shed some light over their ethical practices and therefore assist both the creation of actually sustainable and practicable Big Data ethics frameworks and also enhance appropriate collaboration with academic institutions.

9.5 Conclusions

This dissertation has analyzed the impact of Big Data methodologies on Big Data research. In doing so it has explored some of the most under-investigated fields of Big Data ethics and investigated the perceptions of academic scholars of ethical research practices, ethics review and the sustainability of collaborations with private firms.

The ethical issues that Big Data raises for society and research subjects in terms of unpredictable harm – such as discrimination and breach of privacy – should push investigators and institutions towards the development of appropriate infrastructures and strategies to ensure the proper protection of research participants. In order to do so, due to the interdisciplinary and multi-entity governance nature of Big Data, collaborative efforts should be brought about to create a paradigm of shared responsibility between the different stakeholders involved in the Big Data research ecology, such as academic investigators, data holders and overview bodies.

Furthermore, this dissertation has demonstrated that the contextual dependency of Big Data severely challenges ethical research practices and the formulation of suitable ethical frameworks for research. For this reason, the very definition of Big data should be reconsidered and expanded. By adopting a more nuanced definition of Big data that unpacks and articulates the specific characteristics of the data types used in a particular project or context, it will become easier to generate insight on how to appropriately make sense of the heterogeneous ethical issues it raises.

In addition, the development of ethical frameworks for Big Data research should integrate to a purely principlist approach that currently lacks the tools to appropriately address Big data ethical issues. Since there seem to be a preference both within the literature and by our research participants for the principles reported by the Belmont Report, ethical frameworks should be explored that stay true to its principles and perceived flexibility. Promising frameworks place great emphasis on contextually driven decision making where researchers are called to attentively and continuously reflect upon the different strategies and ethical practices/values that are better suited for their own research projects. As a consequence, education towards ethical reflection becomes paramount to appropriately assess the ethically problematic nuances of different research projects.

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Appendix

Interview guide for researchers

1) Introduction:

- Can we begin with exploring your most recent research projects?/ Are you currently working on any Big Data research project?

- Which one(s) of your research project(s) would you consider as involving Big Data methods or related to Big Data?

2) Methodology and Data:

- Are you integrating data from non-academic/commercial provider (like Cumulus/Facebook/Insurance) in your project?

- Are you integrating also data from sensing devices (such as Smartphones or Fit Bit) to acquire large data sets for your research?

- One definition of big data is on the procedural level. This definition sees big Data as a set of methods for prediction. Neural networks play a key role. Have you used such algorithms? Could you elaborate on it?

Anonymization

- So as I understood it, you used personal data from participants/individuals during your project. How did you anonymize the samples?

3) Regulation/Guidelines and Ethics Approval:

Regulation/Guidelines

- Would you consider your research as Human Subject Research?

- Was it clear to you which kind of guidelines you would have to apply to your research? Are there any specific guidelines that you applied to conduct your research?

- Do you find the guidelines that you are currently using useful? Anything that bothers you about them? Do you have any suggestion on how to improve them?

Ethics Approval

- Did you have to ask approval to an Ethics committee to perform your research?

- Did you have to ask for approval at an institutional level (IRB)? Did you have to ask it also at a Cantonal (EC) or federal level?

- How would you describe your experience with the ethics approval process?

- Did you find your experience with this digital project in any way different from other non-digital research projects with regards to the ethics approval?

- Do you have any suggestions on how to improve the ethics approval process?

4) Societal Aspects, Ethical Considerations and Barriers:

- Have you encountered any particular challenges when conducting your research project?
    - with receiving ethics approval due to the type of data you were using?

  - With anonymization of the data?
  - Additional ethical dilemmas or challenges that came up during the various stages of the project?
  - Legal challenges? Are there any barriers created by the law?

- How do you think data research should be ideally ethically regulated?

- What are in your opinion the minimal requirements that the law should enact to ensure that data research is carried out with minimal challenges but fulfilling ethical requirements?

<u>The concept of Hypothesis and the influence of Big Data on research</u>

- In light of the ease of obtaining data with growing technological innovations, we now have the possibility to carry out data driven studies and discard the concept of hypothesis driven research. The idea is that “the numbers talk for themselves”. What is your opinion on the matter?

  - is this situation changing the way research is performed in your field?
  - do you feel that data driven research has an added value for science and society?
  - do you think such studies should be conducted differently from other more classical research?

- What do you think is the main difference between Big Data research and more conventional research in your field? Do you think this has any implications for the guidelines?

- Considering the complexity involved in accessing and managing data research from different sources, who in your opinion, owns the data?

- How would you define Big Data?