A socio-legal analysis of the divergent approaches of the EU Data Protection Directive and individuals' attitudes towards novel uses of administrative data in social science research

Hannah Smith

St Cross College

M.St Socio-Legal Research

Michaelmas Term 2017

ABSTRACT

Governments around the world are encouraging social science research using administrative data to support policy development. These initiatives depend on wide-scale public acceptance to succeed and are often supported by a legal basis. The care.data initiative in the UK, which sought to open up routinely collected health data to researchers, is an example where societal expectations of privacy diverged from legally permissible data processing practices. This discord led to the closing down of the project. The factors influencing societal expectations and causing these divergences are currently under-theorised, and little understood, particularly in the field of administrative data.

The thesis argues that data processing utilising innovative technologies challenge current constructions of privacy and the notion of the public interest in data processing. As a result, the approaches of the EU Data Protection Directive and individuals' attitudes towards these practices diverge. In developing this argument, the contested nature of the interests of privacy and the public interest in data processing, which are interests present in the objectives of the Directive are explored. The thesis suggests that different values underpin the construction of these interests and further proposes that these different values are a potential source of the divergences between the Directive and individuals' attitudes.

This claim is tested by examining the Directive and the empirical findings from two focus groups to identify potential divergences. The analysis suggests the Directive constructs privacy by reference to its value to society and perceives research as a data processing activity in the public interest. The qualitative findings, however, suggest individuals ascribe less value to research as an activity in the public interest. Due to individuals’ uncertainty as to the risks generated by novel practices, they adopted a more individualistic construction of privacy, enabling greater control over their data. Considering these divergences, possible legal responses are explored, including the suitability of the law aligning with individuals’ expectations, the ability of the law to guide societal expectations, and the possibility of the law fostering deliberative dialogues between the actors involved in data processing.

Thesis Word Count: 30,000

Contents

TABLE OF ABBREVIATIONS AND SHORT TERMS

European Convention on Human Rights	ECHR
European Court of Human Rights	ECtHR
Court of Justice of the European Union	CJEU
European Data Protection Directive	The Directive
European Union	EU
Focus Group X, Participant Y	FGX, PY
General Data Protection Regulation	GDPR
Information Commissioner’s Office	ICO
United Nations Educational, Scientific and Cultural Organisation	UNESCO

TABLE OF CASES

TABLE OF PRIMARY LEGAL SOURCES

1 INTRODUCTION

The use of Big Data[1] analysis techniques on administrative data has been heralded as a technological advance that creates a 'rich new resource for research and policy-making and evaluation.'[2] Through its capacity to discover hitherto unknown patterns, links, and associations, its potential to provide insights into social phenomena and shed light on socio-economic issues is 'without question.'[3] The EU Data Protection Directive,[4] governing the processing of personal data,[5] including data processed for research purposes, seeks to promote the 'public good' arising from such research whilst also protecting the privacy interests of individuals. The importance of societal acceptance of the use of Government-held data in research is demonstrated by the Government's care.data data sharing initiative, which, notwithstanding a sound legal basis,[6] received such fierce public opposition that the project was cancelled.[7] The potential that this could happen in the field of administrative data is a real possibility. Despite this, only one empirical study[8] has thus far explicitly examined individuals' attitudes towards the

---

[1] Whilst there is no agreement as to a precise definition of Big Data, this thesis will use the definition proposed by Laney that emphasises its volume, variety, and velocity in Doug Laney, '3D Data Management: Controlling Data Volume, Velocity and Variety.' (2001) 6 META Group Research Note 70.

[2] Administrative Data Taskforce, 'Improving Access for Research and Policy' (2012) 59 <http://www.esrc.ac.uk/files/research/administrative-data-taskforce-adt/improving-access-for-research-and-policy/> accessed 24 November 2017.

[3] Graeme Laurie and Leslie Stevens, 'Developing a Public Interest Mandate for the Governance and Use of Administrative Data in the United Kingdom' (2016) 43 Journal of Law and Society 360.

[4] Council Directive 95/46/EC of 13 December 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data OJ L281/31

[5] Defined in Article 2(a) EU Data Protection Directive as 'any information relating to an identified or identifiable natural person ('data subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity'

[6] Health Care and Social Act 2012

[7] Rebecca Hays and Gavin Daker-White, 'The Care.Data Consensus? A Qualitative Analysis of Opinions Expressed on Twitter' (2015) 15 BMC Public Health 838.

[8] Daniel Cameron, Sarah Pope and Michael Clemence, 'Dialogue on Data: Exploring the Public's Views

use of administrative data in social science research. Its findings indicate the technological advances utilised in research has affected the understandings individuals ascribe to the interests of privacy and the public good, creating potential divergences between the respective approaches of the EU Directive and individuals. There is a likelihood that using of administrative data in social science research may be legally acceptable but lack societal acceptance.

Addressing this lacuna in the existing research, this thesis will identify the divergences between the Directive's construction of the interests of privacy and the public good arising from data processing for research purposes and the views collected from focus group discussions. In identifying these divergences, the thesis argues these may be attributable to differences in the values that underpin how the Directive and individuals construct their understandings of privacy and the public interest arising from research. Using theoretical frameworks that consider societal responses to technological innovations, the thesis proposes that novel practices that utilise technological innovations, such as the use of administrative data in social science research amplify these divergences. Particularly building on Nissenbaum's work,[9] this thesis utilises the theoretical framework of privacy as contextual integrity to achieve a more fine-grained analysis of the potential causes of the divergences in the approaches of the EU Directive and focus group participants. This framework and its construction of privacy will be situated in a wider context through theories of reflexive

---

on Using Administrative Data for Research Purposes' (2014) <https://adrn.ac.uk/media/1245/sri-dialogue-on-data-2014.pdf> accessed 11 October 2017.

[9] Helen Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (Stanford Law Books 2009).

modernisation to consider the impact of societal uncertainty and perceptions of risk on individuals' construction of the interests of privacy and the public interest.

Existing theories considering the relationship between law and society speak of the law 'mirroring'[10] social norms or of the law's ability to 'fix' societal understandings and to define certain activities as 'valuable.' [11]The empirical findings of this thesis, however, indicate these relationships are not always present. The use of administrative data in social science research, as a novel data processing practice, brings to the foreground the challenges of regulating areas undergoing significant technological innovations. In particular, the emergent nature of these technologies means a precise understanding of the benefits and risks remains elusive and the consequences of their use are often unknowable.[12] I will use these challenges to reflect critically upon the potential roles for data protection law in regulating innovative technologies. Whilst the use of two focus groups limits the generalisability of these findings, it still provides a basis upon which further research can build upon and is a method that supports the exploratory nature of this thesis.

The first section of the thesis introduces the issue that has shaped the approach of this research - that legal and societal constructions of the privacy interests and public interest in research diverge. I suggest that these divergences are linked to the use of different values to construct the interests promoted by data processing for research purposes, which prompt differences in the respective approaches of the Directive and

---

[10] Brian Tamanaha, *A General Jurisprudence of Law and Society* (Oxford University Press 2001)

[11] Roger Cotterrell, *Law's Community: Legal Theory in Sociological Perspective* (Oxford University Press 1997).

[12] Shawn Harmon, Graeme Laurie and Gill Haddow, 'Governing Risk, Engaging Publics and Engendering Trust: New Horizons for Law and Social Science?' (2013) 40 Science and Public Policy 25, 26

individuals towards novel data processing practices made possible by technological advances. The second section, through a close analysis of the Directive's provisions and the thesis' empirical findings, identifies divergences between their respective constructions of privacy and the public interest in research as the interests affected by data processing practices. The third section analyses these divergences, drawing upon Nissenbaum's proposed framework[13] and ideas present in theories of reflexive modernisation,[14] to understand better the driving forces behind the divergences. The final section considers potential legal responses to these divergences, including a closer alignment between the Directive and individuals' views expressed in the focus group discussions and the Directive's potential for guiding societal expectations regarding the use of their data in research. The thesis concludes with a consideration of its key findings and areas of potential future research.

1.1 APPROACHES TO DETERMINING APPROPRIATE DATA PROCESSING PRACTICES

1.1.1 Introducing the research problem: the legal and societal construction of interests

The practice of using administrative data in social science research is part of a wider trend of sophisticated data processing which uses novel analytical approaches on 'Big Data.' This approach to data processing increases the potential for both beneficial and harmful outcomes, requiring a legal response that can protect individuals from these harms whilst recognising that data processing may lead to benefits in the public interest.[15] This thesis focuses upon the approach is present in the objective of the EU

---

[13] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[14] Ulrich Beck, Wolfgang Bonss and Christoph Lau, 'The Theory of Reflexive Modernization' (2003) 20 Theory, Culture & Society 1.

[15] The Royal Society and The British Academy, 'Data Management and Use: Governance in the 21st

Data Protection Directive ("the Directive")[16] which seeks to protect individuals' right to privacy and promote the free flow of data as it is the current regulation in this area.[17] This latter objective may serve to limit the exercise of individuals' rights and, therefore, implicitly recognise that some data processing practices may promote the public interest. This thesis commenced before the UK Government confirmed that it planned to implement the provisions of the GDPR after the UK had left the EU so a decision was made to focus this thesis on the provisions of the EU Directive, as the regulation currently in force across the EU and the UK.

The Directive's dual objective, of protecting privacy and promoting the free flow of data, is perceived to create an inherent tension by incorporating ostensibly conflicting interests meaning the advancement of one of its objectives is only possible to the detriment of the other.[18] For example, the UK Academy of Medical Sciences[19] argued that measures designed to protect privacy must be considered against the societal cost of diminishing the quality of research or not doing it at all. Others,[20] however, have sought to move away from the presentation of privacy and the public interest as goals in zero-sum opposition. Instead, through alternative conceptions of privacy, which shifts away from a focus on individualistic values, and the public

---

Century' (2017) <https://royalsociety.org/~/media/policy/projects/data-governance/data-management-governance.pdf> accessed 6 October 2017.

[16] Council Directive 95/46/EC of 13 December 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data OJ L281/31

[17] Article 1, Council Directive 95/46/EC

[18] Paul Ohm, 'Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization' (2010) 57 UCLA Law Review 1701 at 1705: 'Because the utility and privacy of data are intrinsically connected, no regulation can increase data privacy without also decreasing data utility'

[19] Academy of Medical Sciences, 'Personal Data for Public Good: Using Health Information in Medical Research' (2006).

[20] Priscilla M Regan, *Legislating Privacy : Technology, Social Values, and Public Policy* (University of North Carolina Press 1995); Charles D Raab, 'Privacy, Social Values and the Public Interest' in Andreas Busch and Jeanette Hofmann (eds), *Politik und die Regulierung von Information* (Nomos 2012).

interest, which includes the protection of individuals' privacy interests as well as benefits to society as a whole, they argue it is possible to produce a 'win-win' situation.[21] These arguments suggest that the values, which underpin the construction of the interests of privacy and the public interest in data processing, can lead to differences in the perceived appropriateness of certain data processing practices. The term 'appropriate' reflects the influence of Nissenbaum's framework of privacy as contextual integrity[22] in determining when a data processing practice violates an individual's expectation of privacy. The 'norm of appropriateness'[23] governs the nature of information about individuals that is 'allowable, expected, or even demanded to be revealed.'[24] What remains unclear, however, are the values used by the Directive and individuals to underpin their respective constructions of the interests in privacy and the public interest in data processing, a gap this thesis seeks to address.

The thesis uses a socio-legal approach[25] to identify the Directive's and individuals' constructions of the privacy interests and public interest in research and analyse the divergences between their respective constructions for two reasons. Firstly, it emphasises the importance of the social context when analysing the legal construction of these interests. Whilst the 'right to privacy' is an established legal doctrinal term, individuals' privacy expectations existed long before its legal recognition. This history may help explain why, despite 120 years passing since Warren

---

[21] Ann Cavoukian, 'The 7 Foundational Principles' (Information and Privacy Commissioner of Ontario 2012).

[22] Helen Nissenbaum, 'Privacy as Contextual Integrity' (2004) 79 Washington Law Review 119.

[23] Helen Nissenbaum, 'Privacy as Contextual Integrity' (2004) 79 Washington Law Review 119, 138

[24] ibid

[25] Defined as 'applying social scientific methods to the study of law, legal behaviour and legal institutions in order to describe and analyse legal phenomena in their social, cultural and historical contexts' in Reza Banakar and Max Travers, *Law and Social Theory* (Hart Publishing 2013).

and Brandeis,[26] responding to new intrusions created by that era's technological advancements, conceived the legal right to privacy as 'the right to be let alone,' it is still a concept in 'disarray.'[27] Furthermore, aspects of the Directive appear to draw upon societal expectations when determining if a data processing practice complies with its requirements, such as requiring personal data to be 'processed fairly.'[28] In unpacking the requirement of 'fairness,' Bygrave[29] argues it 'undoubtedly' means that data controllers must take account of the interests and reasonable expectations of data subjects so that it does not unreasonably interfere or intrude upon their individual interests. The Information Commissioner's Office also links the processing of data to individuals' reasonable expectations by requiring personal data to be handled 'only in ways [individuals] would expect.'[30] This thesis proposes that, when analysing the construction of privacy and the public interest and the divergent approaches of the Directive and focus group participants, it is important to recognise the range of social norms, that operate within the law.[31] The term 'social norm' is contested but, for the purposes of this thesis, is used to indicate social phenomena play a role in regulating social behaviour.[32] The inclusion of social norms concurs with the approach of Brownsword who argues that, unless 'open to the full range of norms in play,'[33] it is

---

[26] SD Warren and LD Brandeis, 'The Right to Privacy' (1890) 4 Harvard Law Review 193.

[27] Daniel Solove, *Understanding Privacy* (Harvard University Press 2008).

[28] Article 6(1)(a) Council Directive 95/46/EC

[29] Lee Bygrave, *Data Protection Law: Approach Its Rationale, Logic, and Limits* (Wolters Kluwer Law & Business 2002).

[30] Information Commissioners Office, 'The Guide to Data Protection' available at http://ico.org.uk/for_organisations/data_protection/~/media/documents/library/Data_Protection/Practical_application/the_guide_to_data_protection.pdf

[31] Roger Brownsword, 'In the Year 2061: From Law to Technological Management' (2015) 7 Law, Innovation and Technology 1.

[32] Jing Hiah and Thomas Riesthuis, 'Studying Law in Society: Static and Dynamic Conceptions of Social Norms' (2016) 9 Erasmus Law Review 1.

[33] Brownsword (n 31).

not possible to understand why activities, such as data processing, may be lawful yet still provoke negative societal responses. Current research, however, has rarely explored individuals' attitudes towards the use of administrative data engendering an 'astonishing'[34] lack of clarity as to the values underpinning data protection law and the relationships between the interests promoted by its provisions.

Secondly, a more explicit consideration of the social context in which the law operates may help clarify how technological innovations, such as the application of novel analytical approaches to large and complex administrative datasets examined in this thesis, can create divergences between the legal construction of these interests and how individuals understand them. Nissenbaum[35] argues that technological advances challenge previous commitments to values and principles as technological innovations enable behaviour to be predicted and inferred, testing existing constructions of privacy. Such innovations, therefore, also challenge the traditional protections of privacy. For example, the ability to collect an increasing volume of data and advances in data matching techniques[36] means it is increasingly difficult, possibly impossible, to ensure the permanent anonymisation of data.[37] A failure to recognise the implications of the changes produced by technological innovations has practical implications. As outlined above, the cancellation of care.data[38] due to its negative societal response represents a missed opportunity to create an 'invaluable research resource and an important

---

[34] N Forgo, 'My Health Data--Your Research: Some Preliminary Thoughts on Different Values in the General Data Protection Regulation' (2015) 5 International Data Privacy Law 54.

[35] Helen Nissenbaum, 'How Computer Systems Embody Values' (2001) 34 Computer 119.

[36] Royal Society, 'Progress and Research in Cybersecurity. Supporting a Resilient and Trustworthy System for the UK.' (2016) 70 <https://royalsociety.org/~/media/policy/projects/cybersecurity-research/cybersecurity-research-report.pdf> accessed 7 November 2017.

[37] Ohm (n 18).

[38] Olivia Solon, 'A Simple Guide to Care.Data' *Wired* (7 February 2014).

nationally strategic dataset.'[39] The negative societal reception suggests, in these circumstances, that 'legal authority does not necessarily command social legitimacy'[40] and, as a result, there is a need to examine the drivers behind these divergent approaches to defining appropriate data processing practices.

This section introduced the problem this thesis will examine and justified a socio-legal approach to exploring the divergences between the legal construction of the interests of privacy and the public interest in research and those gained from the empirical work of this thesis. In doing so, reference was made to the concept of 'values' and how differences in these 'values' made lead to differing constructions of 'interests.' As key terms in this thesis, they require further elucidation which will be provided in the next section.

The role of values and interests in this thesis

It is recognised that 'values' and 'interests' are used in a wide range of disciplines, which employ different understandings to suit their varied theoretical orientations, which requires the elucidation of their interpretation for the purposes of this thesis. This section is not concerned with the particular values that may underpin the construction of privacy interests or the public interest in data processing. Rather, it acknowledges the role of values in this process of construction and explores how this may lead to divergences. In this thesis, the concept of 'values' underpins the construction of privacy and the public good used by the Directive and individuals and thus serves to elucidate the specific nature and scope of these interests. Hence, the use

---

[39] The Royal Society and The British Academy (n 15).

[40] Pam Carter, Graeme Laurie and Mary Dixon-Woods, 'The Social Licence for Research: Why *Care.data* Ran into Trouble' (2015) 41 Journal of Medical Ethics 404.

of different values in constructing an understanding of privacy may lead to very different constructions of a privacy interest but still allow for agreement on the importance of the interest.

The concept of an ‘interest’ is used to refers to an objective or aim that is perceived as worthy of protection or promotion, due to the values underpinning its construction. This thesis, therefore, in considering the divergences between the respective approaches of the Directive and individuals who participated in the empirical part of this research, will examine the construction of the privacy interests and public interest in data processing for research purposes. It is important to note that ‘interests’ can be expressed in legal provisions in several ways which are relevant to this thesis. Firstly, interests may be recognised through the objectives of legal provisions. For example, the Directive states its object is to protect the fundamental rights and freedoms of individuals and to ensure that the free flow of data are not unduly restricted.[41] In this thesis, the protection of individual rights and the promotion of the free flow of data thus are considered as interests that flesh out the objective of the Directive. The law may also recognise interests through affording them the status of legal ‘rights,’ which, due to their perceived importance and fundamentality to all individuals, are subject to different limitations and protections than interests not afforded the status of legal rights. The crucial point for this thesis is that, based on these terms, it is possible to have an agreement that something is an ‘interest,’ that it is an objective or a goal that should be pursued, but to disagree over the values underpinning this interest i.e. *why* an interest should be protected or promoted. To contextualise these

---

[41] Article 1 Council Directive 95/46/EC

terms further, the next section will consider the role of values and interests in the legal framework examined in this thesis – the EU Data Protection Directive.

Introducing the applicable legal framework: The EU Data Protection Directive

Adopted in 1995 to regulate the processing of personal data, the EU Data Protection Directive was an EU-level response information technology innovations that had provoked a diverse set of legislative responses at Member State level. The Directive, through harmonising national provisions, was developed to remove obstacles to the free movement of data which could impede the creation of the Internal Market without reducing the protection of personal data.[42]

Article 1 of the Directive[43] sets out the dual objective:

> *1. In accordance with this Directive, Member States shall protect the fundamental rights and freedoms of natural persons, and in particular their right to privacy with respect to the processing of personal data.*
>
> *2. Member States shall neither restrict nor prohibit the free flow of personal data between Member States for reasons connected with the protection afforded under paragraph 1.*

This suggests the Directive, in determining if data processing is compliant with its provisions, seeks to promote two potentially conflicting interests valued by society;

---

[42] European Commission, 'Data Protection in the European Union' available at http://ec.europa.eu/justice/policies/privacy/docs/guide/guide-ukingdom_en.pdf accessed 1 November 2017

[43] Article 1 Council Directive 95/46/EC

the right to privacy and the public interest that can arise from the processing of data,[44] including the processing of data for research purposes. The decision in *Lindqvist*[45] confirms the objectives 'may of course be inconsistent with one another'[46] but the CJEU suggested this was not a significant problem as the mechanisms to 'balance' these interests were in the Directive itself.[47] Nevertheless, it was left to the Member States to achieve a 'fair balance'[48] between the interests of privacy and the public interest in data processing with little guidance given as to how exactly this balance should be achieved. The extent of the Court's guidance was a statement that this balance was provided by the EU Directive's rules regarding the processing of data and requirements of safeguards and the subsequent national implementation.[49] Therefore, whilst the interests are clearly articulated by the Directive, this leaves two unresolved problems. Firstly, references to these interests give little indication as to the values that underpin them. Secondly, exactly how a balance is to be achieved remains unclear but the reference to a 'fair balance' suggests the expectations of society should be incorporated in these assessments, as some argue that references to fairness indicate an area where the expectations of individuals should be reflected.[50] The following sections

---

[44] Processing is defined broadly under Article 2(b) Council Directive 95/46/EC as 'any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction'

[45] C-101/01 *Bodil Lindqvist [2003] ECR I-12971*

[46] ibid para 79.

[47] ibid para 82

[48] ibid para 90

[49] ibid para 82

[50] Bygrave (n 29).

seek to elucidate the role of values by interrogating potential values that underpin different constructions of privacy interests and the public interest in research.

1.1.2 Different constructions of privacy.

The privacy interest underpinned by liberal ideological values

One of the earliest *legal* recognitions of a *right* to privacy, as opposed to its existence as a societal construct, was Warren and Brandeis' conception of privacy as the 'right to be let alone.'[51] This individualistic conception is influenced by liberal ideology, present in Mill's work,[52] and, through the enduring conception of privacy as a value pertaining to the individual, is still prominent in modern privacy discourse.[53] A key distinction underpinning this construction of privacy is the difference between self-regarding activities, which are an individuals' private concern, and other-regarding activities, which, due to their impact on others, the State can regulate. This distinction between self-regarding and other-regarding activities is at the root of the public/private dichotomy that remains influential in current discourses on privacy.[54] This construction of privacy links to 'restricted access' theories which arose from concerns regarding undesired physical access to individuals.[55] This construction presupposes the ability to delineate between public and private spheres, an assumption that has been heavily criticised.[56] This criticism is particularly applicable to uses of Big Data in research as

---

[51] Warren and Brandeis (n 26).

[52] John Mill and John Gray, *On Liberty and Other Essays* (Oxford University Press 1998).

[53] Raab (n 20).

[54] ibid.

[55] Herman Tavani, 'Informational Privacy: Concepts, Theories, and Controversies' in K Himma and HT Tavani (eds), *The Handbook of Information and Computer Ethics* (Wiley 2009).

[56] Colin Bennett and Charles Raab, *The Governance of Privacy : Policy Instruments in Global Perspective* (MIT Press 2006).

data can be combined, re-used and re-purposed in a number of ways. The ‘ability of technology to move information from one context to another as well as to aggregate data’[57] means there is virtually no limit to the amount of information that can be recorded and analysed[58] making it nearly impossible for individuals to create a truly private sphere.

Other theories link privacy to the ability of individuals to control information about themselves. Westin,[59] for example, defines privacy as the ability to determine when, how, and to what extent information about individuals is communicated to others. Support for this construction of privacy arises from its value in encouraging intimacy and forming and shaping relationships.[60] This construction of privacy perceives it as a necessary aspect of self-realisation[61] and requiring the protection of personality, recognised as a fundamental right in some countries.[62] As a result, it is more amenable to information being used for the public good than one promoting a completely closed-off private sphere. The German Census case,[63] for example, recognised the protection of personality was, in part, concerned with the ability of an individual to develop their personality that depended on their ability to communicate within a society. Tavani[64] observes, however, that these theories fail to explain which

---

[57] Lisa Austin, ‘Privacy and the Question of Technology’ (2003) 22 Law and Philosophy 119.

[58] ibid.

[59] Alan Westin, *Privacy and Freedom* (Bodley Head 1970).

[60] C Fried, *An Anatomy of Values* (Harvard University Press 1970); J Inness, *Privacy, Intimacy, and Isolation* (Oxford University Press 1992).

[61] James Whitman, ‘The Two Western Cultures of Privacy: Dignity versus Liberty’ (2004) 113 Yale Law Journal 1151.

[62] *See* The Census Act Case, BVerfGE 65, 1; The Microcensus Case, BVerfGE 27, 1.

[63] The Census Act Case, BVerfGE 65, 1

[64] H Tavani, ‘Philosophical Theories of Privacy: Implications for an Adequate Online Privacy Policy’ (2007) 38 Metaphilosophy 1.

types of personal information one can expect to control and how much control one can expect over one’s personal information.

These individualistically-focussed constructions of privacy have come under increasing criticism. Etzioni,[65] adopting a communitarian approach to privacy, criticises their roots in liberal ideology, arguing that it leads to an undue focus on the positive aspects of ensuring an individual’s privacy. A reliance on libertarian values has also been criticised as leading to privacy being constructed as a ‘reified concept…explained through a combination of individual psychological need and individual right.’[66] This construction has a powerful effect on those that utilise the law and leads to a society in which societal benefit is ‘forever playing second fiddle to individual desire.’[67] Raab contends that a definition of privacy premised on an individualistic basis opens it to ‘damaging challenges to rights-based defences of privacy.’[68] This supports Lindsay’s[69] claim that rights-based defences are a problem as, due to their focus on maximising the sum of utilities, they would require the interest of an individual to be sacrificed where it would maximise overall welfare. This fails to recognise the importance individuals attribute to the ability to keep their information private. These criticisms have led to the development of a distinct set of theories which propose a right to privacy underpinned by values that emphasise its importance to society, rather than the individual. These will be explored in the next section.

---

[65] Amitai Etzioni, *The Limits of Privacy* (Basic Books 1999).

[66] Philip Leith, ‘The Socio-Legal Context of Privacy’ (2006) 2 International Journal of Law in Context 105.

[67] ibid 106.

[68] Raab (n 20).

[69] David Lindsay, ‘An Exploration of the Conceptual Basis of Privacy and the Implications for the Future of Australian Privacy Law’ (2005) 29 Melbourne University Law Review 131.

A privacy interest underpinned by its value to society

Criticisms of individualistic constructions of privacy, combined with the influence of modern technology, have led to literature exploring the societal value of privacy. These recognise that advances in technology do not just lead to the loss of an individual's privacy but have further societal implications. The values underpinning this construction of privacy move away from an emphasis on rights that secure negative liberties and, instead, seek to secure individuals' ability to participate in the public sphere and democratic decision-making. Critical to this construction is the argument that 'a right should not be seen solely as an individual right simply because it is advanced by an individual - it may also still have wider implications, and benefits, for society as a whole.'[70]

Introduced by Regan,[71] this construction of privacy has three dimensions that make it an interest valuable to society, rather than the individuals within a society. Firstly, privacy is a common value because all hold it. Secondly, privacy has a public value due to its importance within democratic societies. This dimension is present in Bygrave's work where the values promoted by privacy are argued to have a broader social significance as the privacy's protection 'serves to constitute a society infused with civility, stability, pluralism, and democracy.'[72] The protection of privacy underpinned by these values maintains such a society by securing a diversity of opinion and dissipating the tensions inherent in social relations. Finally, a protection of privacy

---

[70] Gillian Black and Leslie Stevens, 'Enhancing Data Protection and Data Processing in the Public Sector: The Critical Role of Proportionality and the Public Interest' (2013) 10 SCRIPTed 93.

[71] Regan (n 20).

[72] Bygrave (n 29) 134.

underpinned by its value to society has a collective value because technologies make it difficult for individuals to have privacy unless a minimum level is guaranteed for all.

Both this construction of privacy and the construction underpinned by liberal values, however, have been criticised[73] for not recognising is the culturally and historically contingent nature of privacy. Moore[74] has sought to emphasise how obligations that arise from different cultures create differences in individuals' perceptions of privacy. The differences in the constructions of privacy that occur in different cultures have led to theories that construct a right to privacy underpinned by values that indicate privacy is a contextually dependent. This next section will examine these theories in more detail.

A contextually dependent construction of privacy

This construction of privacy arose in response to criticisms that existing accounts of privacy were ahistorical and regarded privacy as a 'universal human essence,'[75] mistakenly suggesting that privacy is natural and has always existed in all societies.,[76] This construction emphasises privacy's development arises as a 'socially created need' and thus varies based on the given society.[77] These accounts are influenced by Altman's work,[78] which constructs privacy as a dynamic process where individuals' accessibility is context-dependent. This construction of privacy is, therefore, the recognition that

---

[73] Lindsay (n 69).

[74] Adam D Moore, 'Privacy: Its Meaning and Value' (2003) 40 American Philosophical Quarterly 215.

[75] Lindsay (n 69).

[76] Christian Fuchs, 'Towards an Alternative Concept of Privacy' (2011) 9 Journal of Information, Communication and Ethics in Society 220.

[77] Barrington Moore, *Privacy. Studies in Social and Cultural History* (ME Sharpe 1984).

[78] Irwin Altman, *The Environment and Social Behavior* (Brooks/Cole Pub Co 1975).

individuals' privacy expectations are shaped by external factors, such as the context in which data are transmitted, and internal factors, including their preferences and own knowledge.

This construction is prominent in Nissenbaum’s conceptualisation of privacy as contextual integrity[79] which posits that the protection of privacy is ensured by an appropriate flow of information within a given context. The contextual element emphasises that individuals’ privacy expectations depend on the particular social setting in which information is transmitted. These social settings are characterised by their own roles in which people act, activities, norms which govern acceptable practices, and the internal values which denote the goals or purposes of a given context.[80] Nissenbaum posits that the contexts in which a data processing practice takes place are partly constituted by norms that determine and govern aspects of the data processing practice, such as the roles individuals play in a given context and the expectations individuals have regarding the data processing practice.[81] Among these context-dependent norms are ‘information norms’ that govern how information should be used in a given context. Nissenbaum outlines two information norms: norms of appropriateness and norms of distribution and that must be upheld for a contextual conception of privacy to be maintained.[82] The norm of appropriateness encompasses the type and nature of the information that is perceived as appropriate to reveal in a given context and norms of distribution govern information flows between the actors

---

[79] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[80] AD Selbst, ‘Contextual Expectations of Privacy’ (2013) 35 Cardozo Law Review 643.

[81] Nissenbaum, ‘Privacy as Contextual Integrity’ (n 22).

[82] ibid.

that operate within a given context.[83] Breaches of these are deemed to violate the values that constitute a context and thus breach the privacy expectations of individuals within that context.

The contextual aspect of this account of privacy recognises information norms will vary, depending upon the context in which they operate. Nissenbaum develops the concept of an information norm by outlining four key aspects that them; the context, which operates as the backdrop to the norm, the actors, the nature of information distributed in a norm, and the transmission principle that constrain the flow of information in a context and thus expresses the conditions under which information ought to be shared.[84]

Privacy as contextual integrity consists of a descriptive aspect, identifying when contextual integrity is violated, and a normative layer, evaluating if a new information flow is acceptable, even if it constitutes an individual having less privacy.[85] The normative aspect is useful in exploring which technological advances should be perceived as beneficial, based on external political and moral judgements that are contextualised to the specific context in which the information norm operates. The contextual nature of this construction of privacy makes it difficult to discuss its underpinning values because these depend on the specific context in which the data was processed. Depending on the values that operate within an information norm, this construction of privacy can be underpinned by liberal or societal values. In outlining different constructions of privacy and how these are influenced by different values, this

---

[83] ibid.

[84] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[85] Selbst (n 80).

section has emphasised the contested nature of privacy. Is the construction of the public interest in data processing any clearer?

1.1.3 The different constructions of the public interest

One difficulty in constructing the 'public interest' is defining the 'public' aspect of this interest. For Taylor,[86] this depends on which values underpin the definition of the 'public.' He distinguishes between a public interest underpinned by communitarian values, which would consider the 'public' to have its own interests and functions, and by libertarian values, which sees the 'public' as an aggregation of individuals. Values also influence the distinctions made by Brownsword who argues that decisions based on the public interest, must appeal specifically to 'moral or ethical reason if [decision makers] are to defend the legitimacy of their actions.'[87] In exploring the values that may shape the construction of the public interest, three potentially conflicting ethical positions are identified: a utilitarian perspective, a human rights perspective, and a dignitarian perspective. A construction of the public interest underpinned by utilitarian values would support whichever action that maximises utilities and minimises disutilities. Lindsay[88] criticises utilitarian approaches for enabling 'impersonal social goals [to] always outweigh the interests and values of particular individuals.' A human rights perspective moves away from the notion of the public interest being underpinned by the 'greater good' and considers the promotion of public interest as being fulfilled where human rights have priority over the sole interest of science or society.[89] Some

---

[86] Mark Taylor, *Genetic Data and the Law* (Cambridge University Press 2012) 30.

[87] Roger Brownsword, *Rights, Regulations and the Technological Revolution* (Oxford University Press 2008) 10.

[88] Lindsay (n 69).

[89] See Article 3(2) of the UNESCO Universal Declaration on Bioethics and Human Rights 2006.

argue, however, that a greater the emphasis on the individual, may compromise the benefits that could arise from research.[90] Furthermore, the right to privacy as recognised in Human Rights instruments, such as the European Convention for the Protection of Human Rights[91] is a qualified right. Qualified rights may legitimately be restricted in some circumstances where this advances other interests and values promoted by the law. The final perspective is the dignitarian perspective which constructs the public interest as one protecting human dignity, which Brownsword recognises as a contested concept and roots his discussion firmly in the bioethics context in considering human dignity in relation to the impact of technology on the human body.[92]

An intuitive link between the 'public interest' and 'commonly held interests'[93] is rejected by Sorauf[94] as it fails to indicate the threshold at which an interest becomes a 'public interest.' Whilst a universal consensus may be too demanding a standard, especially in pluralistic societies, anything less than a universal consensus leads to a quantitatively measured public interest. This approach has been criticised for not considering the intensity with which interests may be held[95] and may enable the 'tyranny of the majority.'[96] A majoritarian construction of a public interest could result in the oppression of minority interests and constrain an individual's 'right to difference'

---

[90] Academy of Medical Sciences (n 19).

[91] Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as Amended) 1950.

[92] Brownsword (n 87) 41.

[93] Taylor (n 86) 30.

[94] Frank Sorauf, 'The Public Interest Reconsidered' (1957) 19 The Journal of Politics 616.

[95] ibid.

[96] See Mill and Gray (n 52).

which Rouvroy[97] posits as essential for an individual's growth and the evolution of society. Despite these disagreements over the validity of 'commonly held interests' as underpinning the public interest, Taylor[98] argues 'commonly held interests' can be used in a way that responds to these issues by highlighting a salient point about the legitimacy of decisions taken to promote the public interest. This legitimacy is argued to depend on a decision's p*erceived* capacity to consider valued interests and ability to 'engender the belief that it is the most appropriate one for society.'[99] A decision that is taken in the public interest, therefore, need not correspond to individuals' values and interests but must demonstrate that these interests have been considered to appear reasonable to an individual.

It is unsurprising, therefore, that respect for the public interest has been perceived to 'mean many things. Some of which cannot always co-exist peacefully.'[100] This disagreement has led to the nature and the scope of the public interest being labelled as 'illusory.'[101] Though the 'public interest' is used throughout the law to override individuals' rights, a precise definition remains elusive. Commonalities in its uses are rare, making it difficult to extrapolate a general understanding[102] due to its

---

[97] Antoinette Rouvroy, 'Réinventer l'art d'oublier et de Se Faire Oublier Dans La Société de l'information?', *La protection de l'individu numérisé* (L'Harmattan 2008).

[98] Taylor (n 86) 30.

[99] ibid 64 referring to SM Lipset Political Man: The Social Bases of Politics (John Hopkins University Press, 2nd ed. 1981) .

[100] Matti Hayry and Tuija Takala, 'American Principles, European Values and the Mezzanine Rules of Ethical Genetic Databanking' in Matti Hayry and others (eds), *The Ethics and Governance of Human Genetic Databases* (Cambridge University Press 2007) 21.

[101] Graeme Laurie and others, 'Managing Access to Biobanks: How Can We Reconcile Individual Privacy and Public Interests in Genetic Research?' (2010) 10 Medical Law International 315, 321.

[102] David Townend, 'Overriding Data Subjects' Rights in the Public Interest' in David Townend and others (eds), *The Data Protection Directive and medical research across Europe* (Ashgate 2004); Irwin Altman, 'Privacy Regulation: Culturally Universal or Culturally Specific?' (1977) 33 Journal of Social Issues 66.

context-driven nature, drawing upon a range of variables to justify an activity or outcome as in the 'public interest.' This highlights the relevance of the context in determining which values underpin the construction of the interests promoted in a given context. The next section will, therefore, explore the use of administrative data in social science research to understand better its specific effect on the construction of the privacy interest and public interest in data processing.

1.1.4 The impact of novel uses administrative data in social science research on the construction of interests

As a large and complex quantitative information source, administrative datasets are an example of Big Data and heralded as a 'rich archive of information covering most aspects of socio-economic behaviour from birth to death.'[103] Attributes that make administrative data a 'powerful new resource for social science research'[104] include larger sample sizes than social surveys, fewer issues with non-response, and an inherently longitudinal structure that allow for the creation and long-term study of cohorts. Unlike data specifically created for research purposes, however, researchers have no input into the design, structure, or content of administrative datasets. This may cause public concern over privacy and the appropriateness of researchers accessing such data. The use of novel analytical approaches on Big Data exacerbates these concerns by potentially enabling new forms of intrusion in a technologically complex environment that individuals increasingly lack the capacity to understand.[105] The less

---

[103] D Card and others, 'Expanding Access to Administrative Data for Research in the United States' (*National Science Foundation White Paper 10-069,* 2010) 1 <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1888586>.

[104] Roxanne Connelly and others, 'The Role of Administrative Data in the Big Data Revolution in Social Science Research' (2016) 59 Social Science Research 1.

[105] The Gallup Organization, 'Data Protection in the European Union: Citizens' Perceptions Analytical Report' (*Flash Eurobarometer Series,* 2008) <http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_225_en.pdf> accessed 10 October 2017.

individuals understand how data are collected and used, and the benefits and risks these uses entail, the more likely these activities are to diverge from societal expectations.

The rapid developments in analysis techniques used on Big Data challenge the ability to determine precisely the consequences of these data processing practices. The difficulties in predicting the outcomes of the practice of using administrative data in social science research make it nearly impossible to determine how this affects the privacy interests and the public interest in research. This has led Allenby to conclude that 'any technology of any significance tends to be profoundly destabilizing of existing norms, institutions, employment patterns, firms, and power relationships.'[106] Specifically, the rapid acceleration of these technological advances accelerates changes in the structures which are used by individuals to understand their worlds so that assumptions about meanings can no longer be regarded as stable.[107] It is unsurprising, therefore, that Conger et al contend that society has struggled to confront the 'concerns and possibilities around technologies in an early, explicit, or effective manner.'[108] Whilst the risks are acknowledged, the uncertainty means that societal assessments are prone to exaggeration, affecting the reception of these technologies and clouding future debates.[109]

---

[106] Braden Allenby, 'Governance and Technology Systems: The Challenge of Emerging Technologies', *The Growing Gap Between Emerging Technologies and Legal-Ethical Oversight: The Pacing Problem* (Springer 2011).

[107] ibid.

[108] Sue Conger, Joanne Pratt and Karen Loch, 'Personal Information Privacy and Emerging Technologies' (2013) 23 Information Systems Journal 401.

[109] Graeme Laurie, Shawn Harmon and Fabiana Arzuaga, 'Foresighting Futures: Law, New Technologies, and the Challenges of Regulating for Uncertainty' (2012) 4 Law, Innovation and Technology 1.

Bennett Moses[110] argues the use of Big Data in research does not just produce societal uncertainty but also challenges current legal approaches to technology, including data protection law. Technological changes affect the law as technology may enable new forms of conduct and broaden the horizons of what is possible.[111] These new forms of conduct can cause uncertainty in the law because their permissibility will depend on the existing legal concepts but they may not be easily incorporated into the existing legal framework. Therefore, whilst the advancement of technology may occur at a rapid pace, the legal frameworks, including the Directive, do not evolve as rapidly. This lag between technological advances and legal responses has been described as the 'pacing problem'[112] which may impede research and innovation.[113] The Directive responds to this problem by being 'technology neutral,' meaning it does not attempt to adapt to different technological contexts. Though the purpose of this approach is to prevent the Directive being rendered obsolete by unanticipated technological innovations,[114] Bennett Moses criticises the technological neutral approach to legal regulation on that very basis. The unknowable nature of the path of technological change makes the drafting of future-proof legislation nearly impossible, as innovations may be incongruent with existing legal concepts.[115] This is supported by the findings

---

[110] Lyria Bennett Moses, 'Recurring Dilemmas: The Laws's Race to Keep Up with Technological Change' (2007) 2 University of Illinois Journal of Law, Technology & Policy 239.

[111] ibid.

[112] Gary E Marchant, 'The Growing Gap Between Emerging Technologies and Legal-Ethical Oversight', *The International Library of Ethics Law and Technology*, vol 7 (1st edn, Springer Netherlands 2011); Lyria Bennett Moses, 'Agents of Change: How the Law 'copes' with Technological Change' (2011) 20 Griffith Law Review 763.

[113] Marchant (n 112).

[114] Bennett Moses (n 110).

[115] Gary Marchant, Braden Allenby and Joseph Herkert, *The Growing Gap between Emerging Technologies and Legal-Ethical Oversight : The Pacing Problem* (Springer 2011).

in the Nuffield Council on Bioethics report,[116] which recognised the limited guidance given by existing technologies as to the regulatory pressures created by innovations.

In summary, the practice of using administrative data in social science research, as an example of the use of novel analytical approaches on Big Data may challenge the construction of interests that are protected and promoted by data processing due to the difficulties in identifying how this innovation affects the interests. The next section considers how best to understand these changes by outlining two theoretical frameworks which allow for a richer analysis of the issues created by this practice.

1.2 FRAMEWORKS FOR EVALUATING THE IMPACT OF NOVELTY IN DETERMINING THE APPROPRIATENESS OF DATA PROCESSING PRACTICES

1.2.1 The theoretical framework of privacy as contextual integrity

Information norms: how contextual integrity operates as a benchmark for privacy

Nissenbaum's[117] framework of privacy as contextual integrity seeks to identify the roots of the negative societal responses to certain forms of technological advances by building on previous literature which recognised the importance of contextually dependent norms in explaining individuals' understandings of their privacy expectations.[118] The framework argues negative reactions arise where advances in

---

[116] Nuffield Council on Bioethics, 'Emerging Biotechnologies: Technology, Choice and the Public Good' (2012) <http://www.nuffieldbioethics.org/sites/default/files/Emerging_biotechnologies_A4_overview_PDF.pdf>.

[117] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[118] See James Rachels, 'Why Privacy Is Important' (1975) 4 Philosophy & Public Affairs 323 who argues that privacy is valuable as it enables the ability to 'create and maintain different sorts of social relationships with different people' at p. 326 ; and Ferdinand Schoeman, 'Privacy and Intimate

technology, including the new practices these innovations generate, violate 'context-relative information norms.'[119] Nissenbaum defines context-relative information norms as the 'finely calibrated systems of social norms, or rules, which govern the flow of personal information in distinct social contexts.'[120] The contextual aspect of an information norm means that it is responsive to the historical and cultural backdrop of a society and can evolve in accordance with the distinct patterns of a given society. These information norms, therefore, operate to 'define and sustain essential activities and key relationships and interests'[121] within a given society. The term 'context' represents structured social settings that are characterised by roles, relationships, norms, and internal values and this recognises that people operate in a 'plurality of realms' each governed by distinct sets of norms.[122]

Nissenbaum argues that contextual integrity is the benchmark of privacy because individuals' perceive privacy violations to occur where informational norms are transgressed.[123] The framework considers the impact of new technologies or novel practices by examining how it affects the norms present within a given context. In applying this framework to this thesis, the use of administrative data in social science research is understood as a novel practice occurring in the research context. The actors within the informational norm governing research include the information sender, the information recipient, and the information subject and, therefore, this thesis will

---

Information', *Philosophical Dimensions of Privacy: An Anthology* (1984) who recognised the importance of the ability for individuals to maintain different relationships with different people.

[119] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[120] ibid 3.

[121] ibid.

[122] Nissenbaum, 'Privacy as Contextual Integrity' (n 22).

[123] ibid.

consider the roles played by the Government, researchers, and individuals. The inclusion of actors recognises that the capacities in which actors function are ‘crucial to the moral legitimacy of certain information flows’[124] and means the framework is a ‘more expressive medium for highlighting variables that are relevant to privacy.’[125] Transmission principles serve to constrain the flow of information, expressing the conditions under which information ought to be shared. Therefore, they may be used as a point of comparison between the Directive’s constraints, imposed within the context of data processing for research purposes, and the constraints that focus group participants perceived as necessary in ensuring the appropriate flow of information. This comparison may indicate areas of divergence in how the Directive and individuals constrain information flows to uphold the norm of appropriateness present in this context. The next section will explore how the use of administrative data in social science as a novel practice fits in with this framework.

The potential impact of novel data processing practices on information norms

This section will justify why privacy conceived as contextual integrity is apt to explore the differences in the values underpinning the respective approaches of the Directive and individuals towards the use of administrative data in social science research. Nissenbaum created the framework in response to technological advancements that have ‘radically altered the flow of information in societies and thereby affected institutions, power structures, relationships and more.’[126] This, she argues, means

---

[124] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9) 142.

[125] ibid.

[126] ibid 148.

constructions of privacy that ‘had served adequately’ are now unable to adapt and respond to ‘the ebb and flow of anxieties’ generated by novel practices.[127]

The key parameters of context, actors, attributes, and transmission principles in Nissenbaum’s theoretical framework enable a comparison between ‘entrenched’ and ‘novel’ practices. If a new practice generates a change in these parameters, this indicates that it violates an entrenched informational norm and constitutes a ‘prima facie violation of contextual integrity.’[128] If this novel practice can demonstrate its moral superiority to the entrenched practice, however, this presumption can be rebutted, based on its ability to promote the interests within a given context. This framework, therefore, accords with one of the aims of this thesis by facilitating the identification of divergences between the approach of the Directive and individuals towards the appropriateness of using administrative data in social science research. It also enables an analysis of why divergences may occur; to individuals, this novel practice may not promote the interests within the research context, identified as the interests of privacy and the public interest in research.

Individuals’ expectations will be drawn from the insights gained from focus group discussions. These explored participants’ attitudes and opinions towards the use of administrative data in social science research. Whilst these findings are not generalisable, due to the small sample size of the research, they provide a foundation upon which further empirical work may be carried out.[129] Does Nissenbaum’s framework of contextual integrity, however, truly incorporate all the factors that

---

[127] ibid.

[128] ibid 150.

[129] The methodological aspects of this research are discussed in more detail in the methodological annex.

influence individuals’ responses to novel practices? The next section will consider the impact of novel practices the construction of interests through the lens of reflexive modernity, focussing on how risk and uncertainty may shape individuals’ constructions.

1.2.2 The lens of reflexive modernity: Understanding the societal reception of technological advances

A socio-legal approach to analysing the impact of novel practices generated by technological advancements supports the thesis’ objective of understanding different approaches to the construction of the interests promoted by data protection law as it incorporates the legal and social in its analysis. Theories of reflexive modernity align with this approach to facilitate the development of a more sophisticated analysis of the impact of technological innovations by appreciating ‘the wider social and political context of which [these] technologies are a part.’[130] This enables a finely-tuned analysis of the role that the law should play in governing the use of administrative data in social science research by broadening the range of factors understood to potentially influence the societal reception of technological advances. It also enables an examination of societal responses that are not completely grounded upon the current state of data processing activities and does not immediately dismiss individuals’ fears as ignorance and flaws that require ‘fixing.’

Theories of reflexive modernity contend the success of technological developments has, as an unintended side effect of this progress, created risks to society. These risks have indeterminable origins that cannot be measured accurately meaning

---

[130] Anne Kerr and Sarah Cunningham-Burley, ‘On Ambivalence and Risk: Reflexive Modernity and the New Human Genetics’ (2000) 34 Sociology 283.

the certainties upon which current societal structures and individuals' lives were based upon can no longer be relied upon. This increasing uncertainty results in social structures and relationships being perceived as risky[131] and the nature of risk shifts from calculable probabilities to unknowable consequences.[132] The societal response to this change in the understanding of risk is that novel practices are associated with a heightened perception of risk. Such risks are not objectively comprehended but require definition and interpretation thus the construction of 'risk' is key to understanding the reception of these changes.[133] Theories of reflexive modernity contend that whilst the definition of 'success' and 'progress' may still be defined by the achievement of novelty, this novelty is now also perceived as challenging and disturbing.[134] Though societal uncertainty often arises where changes modify practices, Nowotny et al[135] see technological innovations to be even more radicalising as they are often bundled with other innovations. These create anxiety regarding their impact on current relationships between citizens, the State, and those involved in scientific enterprises.

Theories of reflexive modernity recognise the acceptance of technological innovations depends, in part, on the relationship between science and society. The shift towards a reflexively modern society leads to fluctuations in the categorisations of human enterprises around which contemporary society is organised. This means science, as a category of human enterprise, no longer occupies an autonomous space.

---

[131] Ulrich Beck, *Risk Society : Towards a New Modernity* (Sage Publications 1992).

[132] Tina Miller and Mary Boulton, 'Changing Constructions of Informed Consent: Qualitative Research and Complex Social Worlds' (2007) 65 Social Science and Medicine 2199.

[133] Scott T Fitzgerald and Beth A Rubin, 'Risk Society, Media, and Power: The Case of Nanotechnology' (2010) 30 Sociological Spectrum 367.

[134] Helga Nowotny, Peter Scott and Michael Gibbons, *Re-Thinking Science : Knowledge and the Public in an Age of Uncertainty* (Polity 2001).

[135] ibid.

As science, including social sciences, moves into more contextualised arenas,[136] straddling different enterprises, this challenges its ability to assert its authority because the criteria by which its 'success' is defined is no longer contested on grounds that can be opposed solely by facts but instead must respond to values.[137]

This resonates with the problems identified in using administrative data in social science research. As an activity falling within the scope of the Directive, data processing in social science research must comply with its requirements. These are based on the Directive's objective of protecting privacy and promoting the public interest in the processing of data and, as argued previously, these interests are constructed by using values which shape the meanings of these interests. These values, therefore, must be considered when ensuring that data processing practices comply with the Directive.

Furthermore, Giddens[138] contends that reflexive modernisation means that science has lost most of its authority due, in part, to societal disillusionment with technology and its supposed benefits. This chimes with some of the issues arising from the use of administrative data in social science research, as an example of research using Big Data. The characteristics of Big Data, including its volume, variety, and velocity,[139] means science can no longer provide an accurate insight into potential risks as these risks lack a clear origin. The origin of administrative data is clear, as it is the

---

[136] H Nowotny, P Scott and M Gibbons, *Re-Thinking Science : Knowledge and the Public in an Age of Uncertainty* (Polity 2001)

[137] H Nowotny, P Scott and M Gibbons, *Re-Thinking Science : Knowledge and the Public in an Age of Uncertainty* (Polity 2001)

[138] Anthony Giddens, 'Living in a Post-Traditional Society' in Ulrich Beck, Anthony Giddens and S Lash (eds), *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order* (Stanford University Press 1994).

[139] Laney (n 1).

data necessary for allowing the Government to fulfil its duties to provide services and keep records. The analysis techniques employed on Big Data, however, mean insights are generated from hitherto undiscovered patterns, links, and correlations, introducing an element of uncertainty in research employing novel analytical approaches on Big Data. This may risk violating the privacy of individuals whose information is held as part of an administrative dataset without the researchers intending, or even realising, the data could enable intrusive findings.

To summarise, the practice of the use of administrative data in social science research has an effect on both individuals' privacy interests and the public interest in data processing for research purposes. These interests must be reconciled to determine appropriate data processing practices. The approaches of the Directive and individuals suggest there are divergences in what is deemed an appropriate data processing practice. Drawing on existing literature, this Chapter has argued that these divergences can be attributed to different values underpinning the construction of these interests .Frameworks for analysing these divergences, including Nissenbaum's framework of privacy as contextual integrity and theories of reflexive modernity, have been discussed. These suggest that the novelty of using administrative data in social science research may be at the root of these differences, a claim that will be subject to empirical testing. Chapter 2, therefore, will compare the legal construction of these interests, identified through a close analysis of the EU Directive and drawing upon the literature discussed above, to individuals' construction based on the findings from two focus groups. It argues that the law and individuals construct privacy and the public interest in research differently and attempts to show the difference in values that lead to this.

2 IDENTIFYING DIVERGENCES: THE APPROACHES OF THE EU DATA PROCESSING DIRECTIVE AND FOCUS GROUP PARTICIPANTS

2.1 DIVERGENT CONSTRUCTIONS OF PRIVACY

2.1.1 The legal construction of privacy

The first chapter demonstrated that a widely accepted definition of privacy remains elusive. Despite the universal recognition of privacy's importance, significant disagreement over what it protects and the values it upholds[140] persists. This is partly attributable to privacy being a concept of importance in many different disciplines which approach it in ways suited to their own diverse methodologies and research processes. This section seeks to show that the legal construction of privacy present in the Directive is an interest underpinned by reference to societal values.

The privacy interest protected by the Directive diverges from liberal values which underpin individualistic constructions of privacy. Though the Directive contains several examples of individual rights, there is no absolute 'right to be let alone' and individuals are granted limited control over their data. For example, Article 14[141] of the Directive grants an individual the right to object to data processing but this requires the subject to have '*compelling legitimate grounds*' and will only be granted where the

---

[140] Lindsay (n 69); Daniel J Solove, 'Conceptualizing Privacy' (2002) 90 California Law Review 1087; M Hartley, 'The Concept of Privacy: An Analysis of the EU Directive on the Protection of Personal Data' in D Byeveld and others (eds), *The Data Protection Directive and Medical Research Across Europe* (Ashgate 2004).

[141] Article 14 Council Directive 95/46/EC

objection is deemed '*justified*.'[142] The lack of clarity as to what qualifies as a '*compelling legitimate ground*' hinders the ability to determine exactly how demanding these requirements are. Nevertheless, the ability to disapply this provision does not correspond to an individualistic conception of privacy. Article 7 of the Directive,[143] outlining the criteria for legitimate data processing, includes criteria where there is no scope for an individual's input. Whilst consent, included in the criteria for making data processing legitimate,[144] accords with an individualistic conception of privacy, Article 7 also allows data processing when it is '*necessary for the performance of a task carried out in the public interest*'[145] and '*for the purposes of the legitimate interests pursued by the controller.*'[146] These do not align with an individualistic construction of privacy as the data subject has no control over the use of their data, contrary to a construction of privacy based on the 'right to be let alone.'[147]

The Directive includes provisions that support a legal construction of privacy corresponding with theories that emphasise the contextual nature of privacy. These provisions may be argued to be 'contextual' in nature as they distinguish between different types of data and modifies the requirements for compliance with the Directive. For example, the distinction between personal and anonymous data determines the scope of the Directive.[148] Furthermore, the Directive approaches the processing of sensitive data differently to non-sensitive data by adopting a prohibitive approach to

---

[142] Article 14(a) Council Directive 95/46/EC

[143] Article 7 Council Directive 95/46/EC

[144] See Article 7(a) Council Directive 95/46/EC

[145] Article 7(e) Council Directive 95/46/EC

[146] Article 7(f) Council Directive 95/46/EC

[147] Warren and Brandeis (n 26).

[148] See Recital [26] Council Directive 95/46/EC

sensitive data.[149] Unlike the processing of non-sensitive data, here data controllers must demonstrate the processing falls within one of the exemptions to this prohibition. Based on the literature that elucidates the contextual nature of privacy, however, there are aspects of the 'context' that are not considered by the Directive. For example, in Nissenbaum's theoretical framework of privacy as contextual integrity, one of the key aspects of a 'context' is the actors that operate within a context. There are some contextual elements regarding the rights and responsibilities of data controllers and subjects, such as the ability for data subjects' rights to be limited in certain context, including national security[150] and defence.[151] These examples, however, do not fully reflect the breadth of realms individuals operate within and the range of contexts that shape the information norms and, consequently, individuals perceptions as to when their privacy has been violated.

Aspects of the Directive's construction of to privacy are underpinned by values that emphasise its societal importance and aligns with the literature that constructs privacy in this sense. The dual objective of the Directive corresponds to how the societal value of privacy shifts from the idea that the values underpinning the interests of privacy and the public interest in data processing are 'conflicting societal goals in zero-sum opposition.'[152] Taipale has criticised this as based on an apprehension of technology and a 'mythology of privacy that conflates secrecy with autonomy.'[153] Rather than proceeding on the assumption that only by weakening one interest can the

---

[149] See Article 8 Council Directive 95/46/EC

[150] Article 13(1)(a) Council Directive 95/46/EC

[151] Article 13(1)(b) Council Directive 95/46/EC

[152] Raab (n 20).

[153] Kim Taipale, 'Technology, Security and Privacy: The Fear of Frankenstein, the Mythology of Privacy and the Lessons of King Ludd' (2004) 7 Yale Journal of Law & Technology 125.

other be strengthened, this construction of the Directive's interests posits that a 'fair balance' may be achieved by reconciling the interests in the 'most optimal way.'[154] For Gutwirth et al[155] this 'most optimal way' emphasises a construction of the interests of privacy and the public interest in data processing that are mutually reinforcing. This approach, therefore, does not seek to balance interests but considers them when asking what kind of society individuals want to live in. Specifically, to what extent can the erosion of privacy, recognised as a fundamental right, be compatible with a State where fundamental rights are an important principle?[156] This construction of privacy is present in the Law Commission's report, which notes the protection of privacy as 'very much in the public interest as it gives individuals the confidence to provide information that is necessary to plan, improve, and provide public services.'[157] In the context of research, Beyleveld contends 'research, as a public good, can increase life choices and improve quality of life, which are privacy values. Furthermore, respect for privacy facilitates public trust, which is positively necessary for research and its societal understanding as a common good.'[158] These indicate that the values underpinning the Directive's construction of the interests seek to provide both the 'robust protection of individual privacy and uses of data that stand to result in wider public benefit.'[159] To

---

[154] Serge Gutwirth and others, 'PRESCIENT: Legal, Social, Economic and Ethical Conceptualisations of Privacy and Data Protection' (2011) 27 <https://www.prescient-project.eu/prescient/inhalte/download/PRESCIENT-D1---final.pdf> accessed 28 November 2017.

[155] Gutwirth and others (n 154).

[156] ibid.

[157] The Law Commission, *Data Sharing Between Public Bodies: A Scoping Report*, (Law Com No 351, 2014) para 2.22.

[158] Deryck Beyleveld and Roger Brownsword, 'Emerging Technologies, Extreme Uncertainty, and the Principle of Rational Precautionary Reasoning' (2012) 4 Law, Innovation and Technology 35, para 288.

[159] Laurie and Stevens (n 3) 387.

address the key objective of this thesis, this next section will analyse the empirical findings to determine if the focus group participants shared this construction of privacy.

2.1.2 Focus group participants' construction of privacy

This section, using the empirical findings of the thesis, seeks to show that many of the focus group participants, in contrast to the Directive's approach, indicated a construction of privacy underpinned by the values associated with liberal theories of privacy. Liberal theories of privacy emphasise the importance of privacy for the individual and are often based on the values of autonomy and self-determination. This leads to a construction of privacy promoting seclusion and control. This concurs with previous research[160] that suggested the level of autonomy and control individuals have over their data positively influences their response to the use of their data in research. It does not, however, correspond with the approach of the Directive, which was argued to be underpinned by more societally-focussed values.

Two sets of findings will be discussed in support of the identification of this divergence. Firstly, focus group participants' attitudes towards the criteria they perceived as legitimising data processing will be examined. Specifically, the focus group participants' view that only consent could legitimise the processing of their data will be contrasted with the Directive's approach, which provides a range of criteria for legitimising data processing.[161] Secondly, the section will discuss the empirical findings which indicated that individuals desired a greater use of anonymisation. This

---

[160] Nandini Saxena and others, 'Understanding Canadians' Attitudes and Expectations Citizens' Dialogue on Privacy and the Use of Personal Information for Health Research in Canada' (2006) <http://cprn3.library.carleton.ca/documents/43383_en.pdf> accessed 28 November 2017.

[161] See Article 7 Council Directive 95/46/EC

would permit researchers to have access to anonymous data in circumstances where the Directive would allow the processing of personal data.

Focus group participants expressed a preference for an 'anonymise or consent' paradigm

Heavily criticised as an outdated approach to data governance,[162] the 'consent or anonymise' paradigm refers to a prevalent norm in research that, where informed consent cannot be obtained, only allows research using anonymous data. This does not necessarily align with the approach of the Directive, which permits data to be legitimately processed where one of six processing criteria are fulfilled.[163] Whilst consent,[164] which gives the decision-making ability to individuals, is included, it is important to emphasise two points. Firstly, it is not the only criterion for legitimising data processing. Secondly, other criteria, including processing that is '*necessary for the performance of a task carried out in the public interest*'[165] envisage no direct participation for the data subject. In contrast to the Directive's approach, however, some focus group participants indicated that consent was the only criteria they perceived as legitimising the use of their personal data:

> *I think that if, for whatever reason, whatever topic or issue needs to be examined by researchers it should be carried out by directly obtaining consent of the target sample (FG2, P5)*

---

[162] Academy of Medical Sciences (n 19).

[163] Article 7 Council Directive 95/46/EC

[164] Article 7(a) Council Directive 95/46/EC

[165] Articles 6(e) Council Directive 95/46/EC

Where this was not possible, some were only comfortable with researchers accessing their anonymised data:

> *If* [their data] *were anonymised I don't care* [about researchers having access to their data], *if it's not anonymised or I'm identifiable, I do (FG1, P3)*

The importance of showing respect for the individual was suggested by some as a further justification for the consent or anonymise paradigm. Alternatives to consent or anonymisation were perceived as problematic as they could allow researchers to access data when individuals '*wouldn't have knowledge of who have access to their information and wouldn't be able to consent to it' (FG1, P9.)* Some participants supported the 'consent or anonymise' paradigm as researchers would still be able to carry out their research and also '*circumvent the issues of personal dignity' (FG1, P9.)* Previous research[166] has highlighted how the mechanisms of consent can operate as an act of courtesy and ensure an ongoing level of involvement and awareness. The value individuals attribute to consent diverges from the approach of the Directive, which includes a range of criteria for making data processing legitimate and does not perceive one criterion as intrinsically preferable.[167]

The attitudes of individuals indicated within these findings suggest the Directive's numerous criteria for legitimising data processing diverges from the values that underpin the focus group participants' constructions of the interests promoted by data processing. The findings suggest that the Directive places a much lower value on

---

[166] Susan Brown Trinidad and others, 'Informed Consent in Genome-Scale Research: What Do Prospective Participants Think?' (2012) 3 AJOB Primary Research 3.

[167] Article 7 Council Directive 95/46/EC

the individuals' ability to control who can access their data than that expected by the focus group participants in the context of using administrative data in research. The desire for greater control corresponds with a privacy interest underpinned by values that emphasise an individualistically focussed construction. This construction of privacy, suggested in participants' responses when considering the appropriateness of the use of administrative data in social science research, focuses on the use anonymisation which, linking to individualistic constructions of privacy, which helps secure individuals' 'right to be let alone.'[168] The desire for either anonymisation or consent suggests that focus group participants' construction of the public interest and its application to the use of administrative data in social science research diverges from the Directive's approach. As noted above, the Directive permits the use of identifiable data without consent where another criterion for legitimising data processing is fulfilled.[169] The use of consent and anonymisation emphasise an individual's ability to be in control and to seclude themselves from others, stressing the importance of individually focussed values to the participants. This suggests a construction of the public interest thus underpinned by liberal values.[170] The support for the 'anonymise or consent' paradigm expressed by some focus group participants was not the only example of a preference for anonymisation where the Directive would not require it. The next section will consider further examples that support the overall finding that individuals sought more control and the further use of anonymisation than required by the Directive.

---

[168] Warren and Brandeis (n 26).

[169] Article 7 Council Directive 95/46/EC

[170] See section 1.1.3

Focus group participants wanted their data to be anonymised in circumstances where it would not be required by the law

The Directive distinguishes between personal data, which falls within the scope of its provisions, and anonymous data, which does not. The distinction is based on the argument that processing anonymous data, defined as data that does not permit the identification of a data subject considering '*all the means likely reasonably to be used either by the controller or by any other person to identify the said person*,'[171] does not harm an individual's privacy interests. Aligning with the Directive's approach, a previous study[172] suggested the anonymisation of data was a sufficient measure for individuals to accept research as an appropriate use of their data. This distinction has also found academic support in arguments made by Manson and O'Neill that anonymised data cannot result in harm to the individual as 'nothing is done to the 'research subjects' to whom these data pertain.'[173]

Some of the focus group participants, however, expressed mixed opinions towards the suitability of anonymisation in determining the scope of data protection law. Several participants appeared to accept the use of their anonymised data for research purposes:

> *I'm fine with it* [my data] *being, you know, different bits and bobs being stored in different databases used for statistical analysis on the aggregate level (FG2, P4)*

---

[171] Recital [26] Council Directive 95/46/EC

[172] Cameron, Pope and Clemence (n 8).

[173] Neil C Manson and Onora O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge University Press 2007) 82.

In contrast to the bright line distinction in the Directive, however, other participants' responses suggested there was still a possibility of anonymous data processing violating their privacy expectations. In response to one participants' statement, where they could not understand why people would care about how their anonymous data would be used as it could not be linked back to them, another responded:

> *'I would feel some kind of affront if you used that data without my consent for something that I had a fundamental disagreement with' (FG2, P3)*

Such findings support the argument made by Capron[174] who utilises an individualistic construction of privacy, by emphasising its importance for ensuring an individual's autonomy and self-determination, to argue harms can arise even where anonymous data are used. This harm arises as the use of anonymous data may still hinder an individual's sense of seclusion. This participant's attitude indicates the purpose of anonymous data processing is an area where the Directive, through excluding anonymous data from its scope, diverges from how individuals determine if a data processing practice is appropriate. This leads individuals to perceive the existence of harms the Directive does not recognise, suggesting that it draws upon an incomplete set of values in its construction of privacy.

---

[174] AM Capron, 'Protection of Research Subjects: Do Special Rules Apply in Epidemiology?' (1991) 44 Journal of Clinical Epidemiology 81.

By stating uses of anonymous data could be an ‘*affront*’ to them, this participant also indicated the importance of emotion in shaping their construction of privacy. The use of emotive language supports Stark’s[175] claim that human emotion is a critical, yet undertheorised, element in societal misgivings about information. Responses based on emotive considerations support a construction of privacy where ‘affect and emotion are central elements facilitating and prompting our socialised sense of what is an appropriate privacy-preserving behaviour.’[176] These elements may be incorporated in the construction of privacy underpinned by contextual theories, but it is unclear as to the extent these underpin the approach of the Directive. These responses may feed into determinations as to whether data processing is ‘fair’ and if it aligns with individuals’ reasonable expectations. Nevertheless, the emotional responses of individuals are not explicitly included and thus it would depend on the data controller’s interpretation of ‘fair’ data processing. So, if the construction of privacy is a source of divergence between the focus group participants and the Directive, due to the use of different values to underpin its construction, is a similar divergence present in the way the public interest is constructed?

---

[175] Luke Stark, ‘The Emotional Context of Information Privacy’ (2016) 32 The Information Society 14.

[176] ibid 18.

2.2 CONSTRUCTING THE PUBLIC INTEREST PROMOTED BY RESEARCH

2.2.1 The Directive's construction of the public interest arising from research

The inherently innovative nature of research means it challenges many of the provisions of data protection law, which seeks to determine legal uses of data by reference to principles including certainty, transparency, and data minimisation.[177] By pushing the boundaries of current knowledge, there are difficulties in requiring research to express its purpose with the certainty required by the Directive[178] and in determining the minimum level of data required to achieve its purpose.[179] This section, therefore, will examine two means by which the Directive's approach may be understood as constructing data processing for research purposes as an activity in the public interest. Firstly, it will explore references to the 'public interest' in the Directive. Secondly, it will outline the exemptions within the Directive that are triggered where data processing is for research purposes.

The public interest is a ground for legitimising the processing of data[180] and provides an exemption to the prohibition of processing special categories of data.[181] The Directive, however, provides little clarification as to its definition. Instead, it provides several examples and leaves the further clarification of these interests to the

---

[177] David Erdos, 'Systematically Handicapped? Social Research in the Data Protection Framework' (2011) 20 Information and Communications Technology Law 83.

[178] Article 6(1)(b) Council Directive 95/46/EC requires Member States to provide that data are collected only for specified, explicit and legitimate purposes

[179] Article 6(1)(c) Council Directive 95/46/EC requires Member States to provide that personal data must be adequate, relevant and not excessive in relation to the purposes for which they are collected and/or further processed

[180] Article 7(e) Council Directive 95/46/EC

[181] Article 8 Council Directive 95/46/EC

national legislation of Member States.[182] The given examples do include the areas of ‘scientific research and Government statistics,’[183] indicating a construction of the public interest that perceives research as a beneficial activity and an appropriate use of data. Data processing for research purposes, however, even if in the ‘public interest’ still requires the implementation of ‘suitable and specific safeguards,’[184] thus limiting the scope of potential intrusions into individuals’ privacy interests. The exact scope of these limitations is difficult to determine because, again, the Directive gives no guidance or criteria for determining if the implemented safeguards are ‘suitable’ or ‘appropriate.’

Rather than requiring full compliance with its provisions, potentially hindering certain research, the Directive includes specific exemptions where data processing is for research purposes. This distinctive treatment of research suggests the values that underpin the Directive’s construction of the interests it promotes mean research is perceived as a valuable activity, justifying exemptions from some of the provisions that protect individuals’ privacy interests. The exemptions from the obligations in Article 11 of the Directive[185] stem from the perception that, as research may process the data of millions of people, upholding individuals’ rights under such circumstances would represent a burden disproportionate to the potential risks arising from data processing for research purposes. Therefore, Article 11 exempts data processing for research purposes from the requirement to inform individuals about the identity of the controller, the purposes of processing, and other information where the provision of such

---

[182] See Recitals [32] and [45] Council Directive 95/46/EC

[183] Recital [34] Council Directive 95/46/EC

[184] Recital [34] Council Directive 95/46/EC

[185] Article 11 Council Directive 95/46/EC

'*information proves impossible or would involve a disproportionate effort*.'[186] The construction of the objective of the Directive, informed by the interests it seeks to promote and underpinned by the values that shape these interests, suggests the contribution arising from data processing for research purposes is more valuable than ensuring individuals can always exercise their rights.

Article 6(1)(b) of the Directive[187] requires the Member States to ensure that data is collected only for specified and explicit purposes and that further processing can only take place where it is compatible with the original purpose it was collected for. This usually requires a data processor to demonstrate that this secondary purpose is compatible with the original specified and explicit purpose. Erdos[188] argues the value of certainty promoted by this requirement would require a researcher to outline, in some cases to an unrealistic degree of specificity, their reasons for collecting data, encouraging extensive data protocols that do not accord with the realities of research. The Directive takes a different approach where data are processed further for research purposes. It assumes research, as a further purpose, is compatible with the original purpose for which the data were collected without requiring a researcher to demonstrate the compatibility of the purposes. The approach of Article 6 of the Directive[189] thus suggests the values that underpin the Directive constructs research as an activity in the public interest because research, as a data processing activity, is perceived as a sufficient justification to reduce the burden of compliance on data controllers.

---

[186] Article 11(2) Council Directive 95/46/EC

[187] Article 6(1)(b) Council Directive 95/46/EC

[188] David Erdos, 'CONSTRUCTING THE LABYRINTH: The Impact of Data Protection on the Development of "ethical" Regulation in Social Science' (2012) 15 Information Communication and Society 104.

[189] Article 6 Council Directive 95/46/EC

The exemptions suggest that the Directive’s approach to reconciling the interests promoted by its dual objective in the ‘most optimal way’ is underpinned by the assumption that the erosion of individuals’ interests is compatible, in some instances, with the idea of a State that promotes such interests as fundamental rights. This assumption underlying this approach of the ‘most optimal way’ is evident where the Directive permits data processing for research purposes in circumstances where its construction of privacy and protection of individuals’ interests would prohibit such processing. This does not mean, however, that the Directive regards research as such a valuable activity as to warrant a complete forfeiture of the rights given to individuals by its provisions. The Directive does not provide a *carte blanche* for data processing for research purposes.

A further assumption underpinning the approach of the Directive is the lack of salient differences between types of research that are of relevance to the values underpinning the interests promoted by the Directive. The Directive’s definition of research encompasses both scientific and historical research and, by not defining these terms further, allows for a broad range of research purposes, including the use of administrative data in Social Science research, to benefit from the exemptions discussed. This assumption, however, appears increasingly shaky in light of significant developments in data processing and the analysis techniques that can be applied to data. The next section will elucidate the reasons why the specific data processing context of the use of administrative data for social science research may undermine the Directive’s assumption that research requires no further classification into sub-categories of research types such as medical research and social science research.

2.2.2 The focus group participants’ construction of the public interest in data processing did not always include the use of administrative data for social science

Focus group participants did not perceive social science research as a data processing activity that created benefits

When considering the value of using administrative data in social science research, some participants did identify the possibility of such data processing as aligning with their construction of the public interest:

> *[I]t’s the whole big data concept of looking at all of this aggregate information and then determining where policy changes need to be made (FG1, P9)*

The Directive specifically regulates the processing of data, which, though broadly defined,[190] does not incorporate an examination of the benefits or potential positive outcomes in determining the legality of a data processing practice. In contrast to the Directive’s approach, some focus group participants suggested the benefits arising from such research informed the values that shaped their attitudes towards the use of their data.

> *So long as it’s not just something that doesn't really have a benefit […] I want it to be something where they'd use that information to tackle an issue rather than see if there is a link for some arbitrary reason (FG1, P5)*

---

[190] See Article 2(b) Council Directive 95/46/EC

The concept of 'benefit' is recognised[191] as significantly influencing individuals' attitudes towards the acceptability of research using administrative data and its construction of being an activity in the public interest. The focus in empirical research on the use of medical data for health research, however, has potentially obscured the amorphous nature of what constitutes a benefit in this context. Haddow et al[192] have argued that there is a tendency to assume that individuals construct research as a beneficial activity. This assumption thus leads to the perception that the ability to do something is synonymous with data processors being justified in data processing for research purposes.[193] These findings suggest this elision between the ability to research and the activity of research is not generalisable to the use of administrative data in social science research. When examining the participants' discussion as to why they distinguished between different types of research, the findings indicate the value attributed to medical research may not generalisable to social science research utilising administrative data.

> *[T]he danger of having that data is that you use it without any kind of consideration for any kind of nuance going on within that…and how that then can be, in the wrong hands, interpreted as a particular group of people being more likely to perform crime and therefore everyone in that group of people being demonised (FG1, P3)*

---

[191] Cameron, Pope and Clemence (n 8).

[192] Gill Haddow and others, '"Nothing Is Really Safe": A Focus Group Study on the Processes of Anonymizing and Sharing of Health Data for Research Purposes' (2011) 17 Journal of Evaluation in Clinical Practice 1140.

[193] danah boyd and Kate Crawford, 'CRITICAL QUESTIONS FOR BIG DATA' (2012) 15 Information, Communication & Society 662.

This chimes with contextual accounts of privacy and suggests the use of medical data in health research is perceived as a different practice in the context of research, affecting the information norms of this context differently, meaning the construction of 'research,' without any further sub-divisions, as an activity in the public interest is questionable to some of the participants. These differences suggest that social science research using administrative data is not constructed as an activity in the public interest in the same way that studies[194] examining individuals' attitudes towards the use of health data in medical research indicate. Some of the statements made by the focus group participants, where they considered these types of research, support this. For example, whilst one participant (FG1, P1) was immediately supportive of the use of their data for medical research, their tone when discussing the use of administrative data in social science research suggested they were more cautious about the use of their data in this context. Their statements regarding the use of administrative data for social science research were more hesitant, with a significant number of pauses. Whilst their responses indicated clear support for health research and an acknowledgement of the benefits, this strong support was less evident in their discussions regarding other forms of research. When prompted by the moderator to consider their attitude towards social science research and if there was any perceived benefit to its outcomes, the participant gave only tentative support for social science research and restricted this research to using aggregate data *'yeah, I mean I guess...as long as it's like, in aggregate form' (FG1, P1.)* Furthermore, where participants discussed the benefits arising from the use of administrative data for social research

---

[194] Haddow and others (n 192) See, for example, ; Elizabeth Hill and others, '"'Let's Get the Best Quality Research We Can'": Public Awareness and Acceptance of Consent to Use Existing Data in Health Research: A Systematic Review and Qualitative Study.' (2013) 13 BMC medical research methodology 72.

purposes, these were carefully qualified, or discussed only in the context of their potential:

> *[I]n terms of receipt of benefits is a similar one where you...it could be done in a positive way, looking at correlations and causal factors that might result in somebody...needing to receive state support, welfare support. Equally, it could fall into the same trap...of building on stereotypes that we already have (FG2, P3)*

These findings suggest that, aligning with the framework of privacy as contextual integrity, focus groups participants appear to construct their understanding of 'benefit' as a concept that depends on the 'needs, the values, and the cultural priorities and expectations of that individual or that community.'[195] This distinction indicates the values underpinning individuals' acceptance of medical research as an appropriate data processing practice are not present to the same extent in their attitudes towards social science research. In this context, therefore, the focus group participants did not share fully the values underpinning the approach of the Directive. Instead, individuals' attitudes correlate with previous findings that specifically explored attitudes towards the use of administrative data for research purposes.[196] Whilst individuals could identify the potential harms that could arise from such research, including the profiling of certain areas and pigeonholing of certain demographics, they

---

[195] Lorraine Sheremeta and Bartha Knoopers, 'Beyond the Rhetoric: Population Genetics and Benefit-Sharing' (2003) 11 Health Law Journal 89, 96.

[196] Cameron, Pope and Clemence (n 8).

struggled to see the point of social research, believing that many of its findings were mere common-sense observations.[197]

A further example of divergences in the construction of the public interest in data processing for research purposes may be found in one participant's response within a discussion on how the process of anonymisation would influence their support for the use their data in this context. Their understanding of anonymisation and its purpose within data protection law did not align with the Directive's dichotomous typology of data. Rather than perceiving anonymous data as a single state, their responses suggested anonymisation was perceived as an attribute of data that could vary and exist upon a spectrum of 'more' or 'less' anonymous data.

> *I think if there were a way to make it* ***appropriately anonymised*** *then that would make me comfortable (FG1, P2) [emphasis added]*

This indicates a desire for context-specific safeguards, which can adapt to the purpose of the processing of data, supporting previous findings[198] exploring the factors that influence public support for research and chiming with the framework of privacy as contextual integrity. It suggests that the values underpinning individuals' approach to the use of their data for research purposes may be influenced by the type of research being undertaken and the purpose for which it is carried out for. The further research shifts from 'traditional' conceptions of research, where consent is paramount, participants actively participate, and are aware as to how their data will be used, participants appear to construct privacy using more individualistically focussed values.

---

[197] ibid 16.

[198] N Kass and others, 'The Use of Medical Records in Research: What Do Patients Want?' (2003) 31 Journal of Law Medicine & Ethics 429.

This supports the criticism that the Directive's typology of data is 'artificial' and fails to recognise the identifiability of a dataset may alter, depending on the context of the processing.[199]

This participant's response suggests they ascribe a definition to 'anonymisation' that indicates they understand it to be a context-specific form of privacy protection, in a way not present in the Directive. The influence of the extent to which data discloses information about an individual fits with the theoretical framework of privacy as contextual integrity as its assessment as to the appropriateness of an information flow includes the nature of the information.[200] It also rejects attempts to define information as a one-dimensional or binary concept and, instead, posits that the 'factors determining appropriateness are simultaneously variable.'[201] A context-specific approach was not just evident in the discussions about the benefits of the use of administrative data in social science research. The next section will analyse the empirical findings that suggest the actors that can access and use the data in this data processing practice influenced individuals' constructions of the public interest in research using this data.

Focus group participants perceived the ability of some actors to access their data as potentially harmful to the public interest

The Directive's approach does not distinguish between the types of actors that process data for it imposes obligations on 'data controllers.' These are defined in the Directive as any '*natural or legal person, public authority, agency or any other body*

---

[199] Mark J Taylor, 'Health Research, Data Protection, and the Public Interest in Notification' (2011) 19 Medical Law Review 267.

[200] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n14) 143.

[201] ibid 144.

which…determines the purposes and means of the processing of personal data.'[202] Lynskey[203] views this approach as influenced by the pre-existing provisions of Convention No. 108[204] which did not distinguish between the actors who may process data. Blume,[205] in discussing the differences between data processing in the public and private sector, notes the inclusion of distinctions between actors could hinder the Directive's aim of harmonising EU Member States' laws as, for example, different Member States may distinguish between the 'public' and 'private' sectors in different ways.

In examining the actors operating in this context, including researchers, the Government, and individuals, focus group participants' perceptions of this information flow seemed to be influenced somewhat by the role these actors played in sending and receiving data, as well as what they did with the data once they had received it. For example, the empirical findings from the focus groups suggested that there were concerns over how the Government would use the insights gained from this data processing activity:

> *[I]f research is being carried out within a given area, the pockets of areas where more poor people reside based on income data, that's concerning because then you can start profiling that area (FG2, P5)*

---

[202] Article 2(d) Council Directive 95/46/EC

[203] Orla Lynskey, *The Foundations of EU Data Protection Law* (Oxford University Press 2015).

[204] Council of Europe, Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data ETS No 108, 28 January 1981

[205] Peter Blume, 'The Public Sector and the Forthcoming EU Data Protection Regulation' (2015) 1 European Data Protection Law Review (EDPL) 32.

This chimes with the emphasis Nissenbaum[206] places on the context of data sharing as a factor that influences individuals' perceptions as to whether a data processing activity is appropriate.[207] The participant's response suggests the Government's ability to use data in this way would violate the values that underpin their construction of their privacy interests by potentially exposing individuals to harm arising from the profiling of individuals. The values underpinning the legal construction of privacy and the public interest in processing data for research purposes does not provide scope to consider the role of the actor in the context of a data processing activity. This indicates that the actors that process and receive data do not affect the Directive's construction of privacy and the public interest in research. The responses of the focus group participants, in contrast, suggest the actors do affect their construction of their privacy interests and the public interest in data processed for research purposes. In this example, this focus group participant appears to be suggesting the power held by the Government, through the information it could gain social science research that links and analyses administrative datasets, means it is in a unique position to cause harm to individuals.

Distinctions based on the actors involved in this data processing practice were also made by participants according to the different levels of trust participants had in them. The responses of some of the focus group participants indicated that they lacked trust in the Government to use the insights gained from social science research that links and analyses administrative data in a way that aligned with their construction of research as an activity in the public interest and an appropriate use of their data.

---

[206] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[207] Nissenbaum, 'Privacy as Contextual Integrity' (n 22).

> [B]a*sically* [Government researchers] *carry out research and if it doesn't further their policy aims they just sink it, they don't publish it, it disappears into a black hole… I suppose that is one of the problems; if you don't let external* [researchers] *access it you've just got the Government and they want to pursue certain policy aims and they want the evidence that supports that (FG2, P3)*

These findings support a previous study[208] that indicated individuals have a low level of trust in the Government to use their data appropriately. Furthermore, the concerns expressed by participants in the previous study that led to this low level of trust included the fear that data would not be used for an individual's benefit.[209] This resonates with the importance some focus group participants in this research ascribed to the role of benefit in determining if the use of administrative data in social science research was an appropriate use of their data. Further support for the influence of the actors that process and use the data as a source of divergence between the approach of the focus group participants and the Directive is the distinction that some participants made between the Government and researchers. Researchers, overall, received more support from participants.

> *Maybe it's not the actual research data scientists themselves that cause the problems but the people that read the reports that…under-interpret, right? So maybe the PREVENT strategy is maybe a good example of a policy that doesn't seem to, I mean that's starting to get a bit political, but of a policy*

---

[208] Royal Statistical Society, 'Public Attitudes to the Use and Sharing of Their Data' (*Research for the Royal Statistical Society by Ipsos MORI.*, 2014) <http://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers>.

[209] ibid.

> *that doesn't seem to be working, that was based on...I guess, so kinds of data and conclusions were drawn, that, you know, were actively harmful to certain people (FG1, P3)*

This suggests that focus group participants, when considering the actors involved in the specific data processing practice of using administrative data in social science research, considered researchers to be a more appropriate actor in this context, based on their construction of privacy and the public interest in research. The influence of different actors on the participants' attitudes was not the only finding that supported the argument that a key divergence between the approach of the focus group participants and the Directive is that the former is more contextually dependent. The next section will consider how the benefits of data processing for research purposes influenced the participants' construction of the public interest in data sharing for research as being more contextually dependent than the approach of the Directive allows for.

To summarise, I suggest that there are key divergences between the legal construction of privacy interests and the public interest in data processing for research purposes and the construction of these meanings by participants in the focus groups. Chapter 3, building on this finding, will analyse these divergences through the frameworks discussed in the first chapter. I will argue that the novelty of this data sharing practice contributes to these divergences through the changes it makes to the norms traditionally associated with research and creates greater uncertainty in individuals, prompting this practice to be perceived as risky.

3 ANALYSING DIVERGENCES: POTENTIAL REASONS FOR THE DIFFERENT CONSTRUCTIONS OF INTERESTS

3.1 NOVEL ASPECTS OF USING ADMINISTRATIVE DATA IN SOCIAL SCIENCE RESEARCH BREACH THE EXISTING INFORMATION NORMS GOVERNING THE RESEARCH CONTEXT

3.1.1 How novel uses of administrative data in social science research may breach the information norms of appropriateness and distribution

The empirical findings suggest some focus group participants perceived the use of administrative data in Social Science research, particularly where it involved linking datasets created by different Government departments to inform and evaluate Government policy, as enabling an inappropriate flow of information and thus violating the existing information norms of appropriateness and distribution. Nissenbaum argues that societal negative responses arise due to the breach of the values that shape the context of a given information norm.[210] These norms are defined by reference to four key parameters: contexts, actors, attributes, and transmission principles. Informed by Nissenbaum's approach to information norms, this section will examine these parameters to enable a more fine-grained analysis of potential reasons for some of the negative responses to the use of their administrative data in social science research given by the focus group participants.

The findings from the focus groups support Nissenbaum's argument that the capacities in which the actors operate within the context of data sharing for research purposes are relevant to an individuals' assessment of whether a practice violates privacy. As discussed in section 2.2.2., the Directive's treatment of the actors operating

---

[210] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

in a given context does not fully reflect the contextually dependent nature of privacy as conceived by Nissenbaum's framework. The actors operating within this information norm, in contrast, influenced participants' views as to the appropriateness of the use of administrative data in social science research. In considering the role of the Government in this information flow, the focus groups findings suggest some were concerned about how the Government would use the insights gained from the use of administrative data in social science research.

> [I]*f the Government suddenly see you're on that much income they might check on you on more often or check you for benefit fraud more often if you live in a certain area which leads to very simple but, you know, quite powerful stigmatisation of people (FG2, P4)*

This indicates that the Government's ability to use data in this way means this novel practice could potentially breach the existing information norm by allowing inappropriate i.e. harmful results to arise from research based on this data processing practice. The attitude some participants expressed towards the Government, as a key actor operating in this information norm, suggested they lacked trust in the Government to use their information appropriately. Participants attitudes, constructed through a focus on their beliefs regarding the Government's pre-existing agenda and ability to stigmatise individuals, cast doubt on the legitimacy of this novel practice as a result. This further corroborates the existing studies that have indicated that individuals have a low level of trust in the British Government to use their data appropriately and are particularly doubtful that their data would be used in a beneficial way. [211] The Government was not the only actor discussed by the focus group participants.

---

[211] Royal Statistical Society (n 208).

Researchers, as key actors in this information norm, were also discussed and participants drew distinctions between the contributions of researchers and the Government.

> *[M]aybe the original report or the original findings weren't jumping to those conclusions but the politicians who've read it clearly have (FG1, P3)*

The distinction that participants drew between the different actors provides further support for Nissenbaum's theoretical framework resonating with the empirical findings of this thesis, providing further insights into the participants' understanding of the appropriate use of data in the research context. This novel practice, due to the relationship it created between researcher's and the Government, was perceived to be inappropriate. Participants perceived it as enabling harmful consequences to be inflicted on individuals and did not allow researchers, the more appropriate actors in this context, to be able to influence how Government used the research or hold it to account over its use of the data.

Contextual integrity recognises that the 'factors determining appropriateness are simultaneously variable'[212] which emphasises the potentially complex nature of information. The importance of the nature of the information and a more nuanced view of information in shaping individuals' privacy expectations is supported by the findings outlined above where one participant referred to the concept of data being '*appropriately anonymised*' when considering if the use of administrative data in social science research could be an appropriate information flow. Transmission principles are a key parameter embedded within a context-relative information norm. These act as a

---

[212] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9) 144.

constraint on the flow of information between the actors in a given context. For example, the criteria for legitimising the processing of data in the Directive[213] operate as a transmission principle in this context. Participants' negative attitudes towards the use of criteria other than consent to legitimise the processing of administrative data in social science research, however, suggests these other grounds breach the information norm. Having shown that Nissenbaum's theoretical framework can shed some light on the empirical findings from the focus groups, this section will explore how the divergences can be analysed from the perspective of the 'duties'[214] imposed individuals as a result of the data processing practice. The ability for the use of administrative data in social science research to be compatible with the Directive suggests that the Directive perceives these duties as an appropriate burden for individuals to accept. The findings from the focus groups, however, do not fully support the assumption that individuals are willing to accept these duties.

3.1.2 The concept of 'duties' and their role in shaping attitudes towards data processing practices

The focus group discussions indicate how Nissenbaum's theoretical framework of privacy as contextual integrity can help to explain some of the negative responses of participants towards the use of administrative data in social science research. Nissenbaum[215] posits that where novel practices and the new information flows these may create new privacy intrusions, their acceptance depends on their ability to demonstrate their superiority and effectiveness over existing practices and information

---

[213] See Article 7 Council Directive 95/46/EC

[214] This term draws upon the work of Vezyridis and Timmons in Paraskevas Vezyridis and Stephen Timmons, 'Understanding the Care.Data Conundrum: New Information Flows for Economic Growth' (2017) 4 Big Data & Society 1.

[215] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

flows within a given context. The empirical findings suggest novel analytical approaches, using administrative data in social science research, have not demonstrated this required superiority and effectiveness over existing data processing practices. To explore this further, this section will build upon the work of Vezyridis and Timmons[216] who used Nissenbaum's framework to demonstrate how novel practices can impose new duties on individuals. These new duties would form part of an individuals' understanding of whether a novel practice is superior or more effective than existing practices, such as research that does not link together data sets from different Government departments or research that only takes place with the consent of individuals. The duties imposed by the novel data processing practice explored in this thesis expects individuals to accept the linking and sharing of their administrative data for a purpose it was not collected for and shared with a new set of actors i.e. researchers. Vezyridis and Timmons argue such duties shift the obligations on individuals away from their needs as an individual in society to those of bigger actors, including the State. This change in the nature of duties imposed by the use of administrative data in social science research chimes with the divergent constructions of privacy discussed in Chapter 2, which distinguished between constructions underpinned by individually-focussed and societal values.

The empirical findings suggest that the imposition of these duties: the duty to share their data, the duty to not opt-out, and the duty to accept the risks associated with this data processing activity are not considered appropriate and thus violate the values that shape the information norms operating in the research context. This section seeks to link the perceived inappropriateness of these duties, drawing upon data collected

---

[216] Vezyridis and Timmons (n 214).

from the focus group discussions, to the values that underpin individuals' constructions of their privacy and the public interest in research.

The imposition of a duty to share information

Individual's construction of privacy and the public interest in research suggest that novel analytical approaches, using administrative data in social science research, are novel practices that entail new information flows. This is partly due to the new relationship this practice creates between the Government and researchers and what such research could reveal about a person. According to the theoretical framework of privacy as contextual integrity, this greater intrusion upon individuals' privacy interests may be accepted where it demonstrates its moral superiority or greater effectiveness over existing information flows and practices. Applied to this novel practice, this would require the use of administrative data in social science to demonstrate to individuals that it would lead to improved services or better policies or some other outcome perceived as sufficiently beneficial to justify a greater intrusion into their privacy interests. The novel practice and the new information flows it creates would occur without the informed consent of an individual and, therefore, can be seen the imposition of a duty to share information. This is not a duty overtly imposed by the law but is a consequence of the limited ability for individuals to prevent their data being processed[217] and the practice's focus on the needs of society, rather than the needs of the individuals within a society. The responses of the focus group participants do not support the acceptance of this duty, suggesting that the use of administrative data in social science research has not demonstrated its effectiveness to individuals in society.

---

[217] Article 14 Council Directive 95/46/EC does give individuals the right to object but this requires 'compelling legitimate grounds relating to his particular situation to the processing of data relating to him' and the individual to show a 'justified objection' which is not defined further but suggests a very high threshold must be met.

Rather than linking the information shared during this data processing practice to beneficial outcomes, one participant appeared to take issue with these information flows on the basis that they were '*always'* being asked for their ethnicity and nationality and that they rarely saw the relevance in such information. This same participant indicated these requests caused them to be suspicious of the motives behind requests for such information:

> *[W]hy is that information needed by the Government? By repeatedly by different departments - to inform what? (FG2, P5)*

This differs from Vezyridis and Timmons'[218] application of this duty to the healthcare context where they argued that increased information flows in this context, despite being a prima facie privacy violation, are often expected by individuals as they often operate to support an individual's care.[219] This beneficial outcome enables this greater sharing to demonstrate its moral superiority over existing information flows. The focus group findings in this research, however, suggest this is not generalisable to other forms of research. This difference in attitude towards these different types of research provides further support for the argument that individuals' attitudes towards their privacy interest and the public interest arising from research are contextual. Previous research[220] indicates that, in contrast to medical research, few individuals place a high value on social research, leading to a lack of intrinsic support. This means individuals' construction of the public interest in the context of the use of administrative data in social science research does not justify the greater intrusion into

---

[218] Vezyridis and Timmons (n 214).

[219] ibid 2.

[220] Cameron, Pope and Clemence (n 8).

their privacy interests. Instead, as discussed in the previous chapter, individuals have a number of misgivings about the public interest in research that the use of administrative data in social science may promote. Instead, many perceived it as a practice that could harm the public interest. Are the other duties considered by Vezyridis and Timmons perceived as more appropriate by the focus group participants? The next section considers the imposition of a duty to accept the risks of data sharing practices.

The imposition of a duty to accept the risk inherent in this data sharing practice

Much of the debate regarding the greater use of Government-held Big Data, including medical and administrative data, has been triggered by calls for greater access to such data by those who argue that the current approach to data sharing fails to place sufficient ‘emphasis on the benefits derived from well-conducted research.’[221] Arguments based on the harms to the public interest arising from research due to the perceived over-emphasis of individuals’ do not, however, detract from the potential risks arising from research using novel approaches on Government-held Big Data. The centralised nature of these databases increases their susceptibility to direct malicious attacks.[222] Risks do not just stem from the nature of the databases that these novel practices use. As noted in the first chapter, the characteristics of Big Data datasets may challenge traditional mechanisms used to reduce the risk of harm to an individuals’ privacy, such as the anonymisation of data. Floridi[223] has argued that linking the acceptability of the analysis and re-use of data to anonymisation is problematic because

---

[221] Academy of Medical Sciences (n 19).

[222] Vezyridis and Timmons (n 214).

[223] Luciano Floridi, ‘Open Data, Data Protection, and Group Privacy’ (2014) 27 Philosophy & Technology 1.

the characteristics of Big Data increases the possibility of group-level harms arising from aggregated datasets. The risk arises because, despite the anonymisation of individuals' data, an individual may be harmed where a decision is targeted towards a group characteristic, such as those living in a certain geographical region or those from a certain ethnic background.[224]

The focus group findings indicate that some participants did not accept a duty to accept the risks arising from this context. One focus group participant's response suggested that they would only accept the information flows triggered by the novel practice of using administrative data in social science research where it would entail no risk to them:

> *As soon as you have individual data and the further that individual data gets spread, the greater the likelihood there'll be some human error that means that parts of it or most of it, get public…[and] I think it is very, very unlikely that you will ever create a system in which there is no room for any kind of human or computer or technological error (FG1, P3)*

Another participant, who seemed to accept an approach that minimised, rather than fully eliminated, the risks arising from the creation of such datasets, challenged this view. The first focus group participant, however, reaffirmed their view by emphasising the potentially sensitive nature of the data and the discomfort they felt about people they did not know accessing their data. This suggests that the duty to accept the risk that is inherent in this novel data processing practice is not accepted by

---

[224] Suparna Choudhury and others, 'Big Data, Open Science and the Brain: Lessons Learned from Genomics' (2014) 8 Frontiers in Human Neuroscience 239.

all the participants. The view that the imposition of this duty is inappropriate for individuals to bear aligns with the concept of a ‘privacy calculus.’ This assumes there is a situation specific trade-off of costs and benefits in an individual’s privacy decision-making[225] and research[226] indicates that the perceived sensitivity of information is a crucial aspect in determining an individual’s willingness to have their data disclosed. In this study, the participant’s calculation of the benefits and risks involved in this information flow caused them to perceive the data processing practice as inappropriate and capable of violating their privacy expectations. This, coupled with the expectations of a ‘consent or anonymise’ paradigm, discussed in section 2.1.2., challenges the ability to conduct the type of research envisaged by the using novel analytical approaches on administrative data for research purposes. The findings suggest that suggesting individuals’ constructions of privacy are not influenced sufficiently by its societal value to support this practice.

The more individualistic constructions of privacy instead used by some of the participants instead promote their ability to control their data and to decide who is allowed access. This level of individual control is not possible under this data practice. This lack of control may explain the reluctance to accept the risk inherent in this data practices. The construction of privacy underpinned by its values to society does not just lead to the imposition of a duty to accept the risk of data processing practices without an individual’s consent. They also impose a duty on individuals to participate in the practice which this next section will consider in more detail.

---

[225] Tamara Dinev and others, ‘Information Privacy and Correlates: An Empirical Attempt to Bridge and Distinguish Privacy-Related Concepts’ (2013) 22 European Journal of Information Systems 295.

[226] Flavius Kehr and others, ‘Blissfully Ignorant: The Effects of General Privacy Concerns, General Institutional Trust, and Affect in the Privacy Calculus’ (2015) 25 Information Systems Journal 607.

The imposition of a duty to participate in this data sharing practice

Using novel analytical approaches in social science research on administrative data can enhance the insights generated by reducing bias and enabling researchers to access populations that are marginalised or difficult to recruit.[227] Some participants, however, did not agree with the imposition of this duty in this context:

> *I don't know how I feel at all about any researcher being able to ask the Government for the release of that data, irrespective of its usage (FG2, P5)*

Existing research has recognised the link between researchers asking for consent and data subjects' perceptions of being respected in research[228] with research participants perceiving the asking of consent as important and an act of courtesy.[229] This chimes with the issues some participants in this research had with the use of opt-out consent, which assumes an individual gives their consent unless they explicitly refuse to participate. One participant stated:

> *I don't know we should be presuming everyone would give consent, I'm not sure that's the right starting point cos a lot of people would be uncomfortable with that (FG1, P8)*

---

[227] Connelly and others (n 104).

[228] S McLean, 'Commentary: No Consent Means Not Treating the Patient with Respect' (1997) 314 BMJ 1076.

[229] MR Robling, 'Public Attitudes towards the Use of Primary Care Patient Record Data in Medical Research without Consent: A Qualitative Study' (2004) 30 Journal of Medical Ethics 104.

This response aligns with existing empirical studies that have suggested individuals place significant value on having control over their data[230] and individuals' perceived control over their data was a crucial influence on their attitude towards when their privacy interests were violated.[231] This is a further potential example of how the different values underpinning the approach of the Directive and focus group participants can lead to different views as to the effectiveness and of the superiority of this novel data processing practice. Some focus group responses suggest the values underpinning their approach lead them to desire more control over their data than necessarily permitted under the Directive, corresponding to a construction of privacy underpinned by liberal, individualistic values. The arguments made by Manson and O'Neill[232] as to the role of consent suggest the focus group participants' rejection of the duty to participate by emphasising their preference for consent indicates a perceived lack of legitimacy in using administrative data in social science research. Their view of the role of consent suggests it lends legitimacy to actions that would otherwise be regarded as unacceptable.[233] The empirical findings, however, did not just suggest that the novelty of this data processing practice breached the contextual values of the existing information norm. The next section considers how the novelty of the practice fostered feelings of uncertainty and led individuals to perceive the practice as risky. It analyses how this influenced their construction of their privacy and the public interest in research as affected by using administrative data in social science research.

---

[230] Saxena and others (n 160).

[231] Trinidad and others (n 166).

[232] Manson and O'Neill (n 173).

[233] Mary Boulton and Michael Parker, 'Informed Consent in a Changing Environment' (2007) 65 Social Science & Medicine 2187.

3.2 ADMINISTRATIVE DATA IN SOCIAL SCIENCE RESEARCH AS A NOVEL PRACTICE THAT CREATES FEELINGS OF UNCERTAINTY AND PERCEPTIONS OF RISK

3.2.1 The role of risk in analysing divergences

One participant, in discussing their attitude towards the use of their administrative data in social science research, referred to recent political developments. They perceived the impact of these to have altered societal structures for the worse by increasing the risk of their privacy being infringed.

> *[W]hat does concern me is recent infringements into that without me noticing, like the Snooper's Charter that's been passed recently you know where [you] can just be made suspicious to the Government and they suddenly have a lot more rights to invade your privacy (FG2, P4)*

Such fears, stemming from risks created by societal changes, align with the 'information inequality' harm identified by Van der Hoven.[234] This harm is inflicted on individuals where data is used without their awareness ability to influence this process and may lead to individuals being singled out or discriminated. The participants' use of related examples of perceived privacy infringements to justify their attitude towards this data sharing practice also chimes with the work of Sunstein.[235] His findings indicate that individuals assess risk by reference to readily available examples of an outcome and perceive something to be a greater risk where it reminds them of a similar outcome. The lack of public attention given to the use of administrative data in

---

[234] Jeroen van den Hoven, 'Information Technology, Privacy, and the Protection of Personal Data' in Jeroen Van Den Hoven and John Weckert (eds), *Information Technology and Moral Philosophy* (Cambridge University Press 2008) 311.

[235] Cass R Sunstein, 'Probability Neglect: Emotions, Worst Cases, and Law' (2002) 112 Yale Law Journal 61.

social science research has received and the low understanding of what can be done with such research[236] means it is potentially vulnerable to these types of comparisons. This comparison is present in the participant's response where their attitude was informed by judging the use of administrative data in social science research to a more known piece of legislation that is perceived by this individual to have altered the relationship between individual's and the Government in a way that harms their privacy interests. This response also aligns with theories of reflexive modernisation which posit that the unintended side effects of modernisation, creating threats that are increasingly difficult to quantify, leads to a focus on the 'bads' of modernisation. This participant also identified a further source of risk that informed their views towards the use of data in research:

> *I'm less fine, which I don't think is yet happening but might be happening soon is Governments using data from different departmental sources to create a personal profile of the people they are meant to govern, right? So to infer from data they have already collected about me, erm, future or present behaviour about particular individuals (FG2, P4)*

This type of risk aligns with the 'information injustice' category of harm identified by Van der Hoven.[237] This harm arises where information is presented in one context and then used in another. The participants' consideration of these kinds of harms further corresponds to theories of reflexive modernisation. These posit that technological advances create unintended, negative side-effects as a result of their

---

[236] See Information Commissioner's Office, 'Data Protection Rights: What the Public Want and What the Public Want from Data Protection Authorities' (European Conference of Data Protection Authorities 2015).

[237] Hoven (n 234).

progress, leading to the creation of a ‘risk society.’[238] A risk society is one where the dangers arising from technological advances dominate and thus, in response, individuals seek to protect themselves from these dangers. As the sources of risk lack a clear origin, this leads to a construction of privacy that seeks as much individual control as possible and enables individuals to seclude themselves from society. Moreover, where risks lack a specific origin, this may help explain why using of administrative data in social science research is perceived as an activity that does not promote the public interest in a way that is present in medical research as it generates a level of uncertainty in individuals.

Taipale[239] argues that individuals’ responses to risk, influenced by negative media portrayals of information sharing initiatives, a mistrust in the Government to handle data appropriately, and anxiety relating to the disclosure of information, have created an anxiety that is out of proportion to the actual threats posed. He uses early public concerns about the use of credit cards online to show how the role of risk creates an ‘unreasonable fear based on unfamiliarity with technology.’[240] This aligns with some of the empirical findings of this thesis, supporting the argument that the divergence between the legal and individual constructions of privacy and the public interest is partially attributable to individuals’ perceptions of the risk of novel technologies. The novelty of these technologies leads individuals to evaluate them based their known experiences and, in the context of data sharing initiatives, this leads individuals to draw upon a number of high profile and negative media portrayals of

---

[238] Beck (n 131).

[239] Taipale (n 153) 135.

[240] ibid.

such initiatives.[241] This chimes with theories of reflexive modernisation whereby the media act as the lay public's access points to experts[242] and, due to the increasing complexities of the changes created by technological innovations, mean the lay publics become increasingly reliant on these access points in their attempts to understand these changes. Such links, therefore, heighten the perception of the use of administrative data in social science research as an inherently risky endeavour. This leads individuals to construct privacy to shield them from this type of data processing practice. Due the practice's novelty through the innovations it utilises, individuals are unable to determine exactly the outcomes of such research, leading them to adopt a cautious approach. The novelty of the technology, however, does not just create potentially heightened perceptions of risk in individuals. The next section will explore how the novelty of the data processing practice causes uncertainty in individuals and how the identified divergences may be attributable to this uncertainty.

3.2.2 The influence of uncertainty upon participants' attitudes

Participants' uncertainty towards novel uses of administrative data in research

Empirical studies suggest the public does not have a clear understanding of how personal data are defined[243] and have a low level of understanding as to how collected data is used.[244] Both academic[245] and grey literature both acknowledge that incomplete

---

[241] Laura Donnelly, 'Mass NHS Data Sharing Plan Will Not Allow "simple Opt out" despite Ministers' Pledges' *The Telegraph* (September 2017).

[242] Anthony Giddens, *The Consequences of Modernity* (Stanford University Press 1990).

[243] Jamie Bartlett, 'The Data Dialogue' (Demos, 2012).

[244] Information Commissioner's Office (n 236).

[245] Alessandro Acquisti, Laura Brandimarte and George Loewenstein, 'Privacy and Human Behavior in

information causes individuals to feel uncertain and influences their construction of the interests promoted by data protection law. The Law Commission has recognised that ‘a low public acceptance of data sharing and a low level of trust in the way it is undertaken by public services, along with negative media coverage’ create barriers to utilising the full potential of Government-held data.[246] Some of focus group discussions support the view that low public awareness can create feelings of uncertainty towards the use of data, particularly in the context of novel practices. Acquisti et al note that ‘advancements in information technology have made the collection and usage of personal data often invisible.’[247] This challenges the ability of individuals to have a clear understanding of how their data is collected, shared, and used in the context of social science research using administrative data. Participants in both focus groups raised concerns about their lack of knowledge and understanding as to current research practices. Furthermore, one participant suggested that this was not just an issue for them but that individuals throughout wider society shared this lack of knowledge.

> *I don't think anyone ever thinks, most people don't have cause to think of all the different pieces of their data that might be held against them and how they're being used (FG2, P3)*

This uncertainty arises due to a number of reasons. The lack of active participation by individuals, who are the data subjects in this novel practice, increases the likelihood that they will be unaware of the extent to which their administrative data may be processed beyond its original purpose of record-keeping and service provisions.

---

the Age of Information’ (2015) 347 Science 509.

[246] The Law Commission (n 157).

[247] Acquisti, Brandimarte and Loewenstein (n 245) 509.

O’Hara[248] has attributed this expressed uncertainty to the abstract nature of the concerns created by using data. This makes its use and the issues that can arise as a result, seem remote and hard to comprehend. This supports the findings of Robinson[249] who contends that the increasing opacity as to how information is used is one of the key challenges in regulating modern data processing. This opacity as to how information is used hinders individuals’ ability to exercise meaningful choice and, due to the difficulties in predicting future and secondary uses of data, harder to assign accountability. Furthermore, where data may be used for a number of purposes, this can lead to a complex and uncertain environment that individuals have to navigate, potentially leading to attitudes based on an erroneous underestimation as to the current state of technology. The re-use in research of Big Data datasets collected for other purposes and novel analytical techniques will serve only to potentially exacerbate these issues by exponentially increasing the ways that data can be linked, shared, and analysed.

Research utilising novel analytical approaches on Big Data makes it particularly challenging to explain all the potential risks, benefits, and uses. This is especially applicable where the consequences of data processing Big Data may not be completely knowable at the time of processing, which often occurs due to the innovative nature of research. Research utilising these advancements, therefore, align with both the innovations and problems associated with the shift to a reflexively modern society. The risk arises because of the progress made in data processing practices and the wide range

---

[248] Kieron O’Hara, ‘Transparent Government, Not Transparent Citizens: A Report on Privacy and Transparency for the Cabinet Office’ (2011) 28 <http://www.cabinetoffice.gov.uk/resource-library/independent-transparency-and-privacy-review>.

[249] Neil Robinson and others, ‘Review of the European Data Protection Directive’ (*Rand Europe*, 2009) 1 <https://ico.org.uk/media/about-the-ico/documents/1042349/review-of-eu-dp-directive.pdf> accessed 12 October 2017.

of possible re-uses of data, which hinder the ability to create clear solutions because the problems they must address are not always known at the time of processing. The risks arising in reflexively modern societies are defined by their unknowable consequences[250] which chime with the participant's view that individuals may not know how their data '*is held against them.' (FG2, P3)* Such language accords with theories of reflexive modernisation because the novelty of practices may be perceived as both a success but also as a disturbing development. This may lead to a focus away from the 'goods' of modernisation, here the ability to better inform and evaluate policies, to the 'bads' of this technological progress, such as the ability to profile individuals.[251] Participants did not just express uncertainty towards the practice of processing administrative data for social science research purposes and so this next section will consider the uncertainty some participants' expressed towards researchers and science in general.

Participants' uncertainty towards the authority of science and researchers

Theories of reflexive modernisation suggest that societal transformations that take place due to the unintended side effects of technological advancements. These lead to threats that cannot be entirely resolved by recourse to science, undermining the authority of science in society. The focus group findings do not support the argument that science has completely lost its authority over claims to knowledge as many participants still acknowledged their expertise:

---

[250] Miller and Boulton (n 132).

[251] Beck (n 131).

> *Researchers aren't the amateurs in these situations, they are the professionals at doing research (FG2, P1)*

Nevertheless, Giddens[252] contends that the new dimensions of risk may not necessarily lead to a loss of all authority but, instead, the meaning and understanding attributed to categories such as ‘expert’ become context dependent. Those deemed to be an ’expert,’ therefore, are granted only a provisional claim to authority. This chimes with the findings of this thesis and a previous study[253] that indicated some participants questioned the value of social science research and its outcomes. Cameron et al’s study on attitudes towards the use of administrative data in research found that some individuals perceived the outcomes of social science research to be little more than ‘common sense’ findings that were already known.[254] In this study, the sense of disillusionment individuals expressed towards social science research utilising administrative data may be underpinned by their perception that research in this area is not fully authoritative and its findings definitive:

> [R]*esearch based on current information held by the Government wouldn't necessarily enable you to get an accurate picture…there is a validity that comes from it being generated by a huge amount of data they may not be necessarily justified (FG2, P3)*

The changes reflexive modernisation cause to the relationship between science and society is not limited to an increased scepticism towards the authority of science.

---

[252] Giddens, *The Consequences of Modernity* (n 242).

[253] Cameron, Pope and Clemence (n 8).

[254] ibid 16.

Participants also expressed fears as to the outcomes arising from this data processing practice, due to the relationship it created between researchers and the Government.

> *I'd feel uncomfortable* [with researchers accessing administrative data] *as it means anything you've said or anything that you've participated in, that you almost have to defend that… because they* [researchers] *have access to who I am because they have access to who I am (FG2, P5)*

Such responses support Nowotny et al's arguments,[255] which build on this impact of contexts to argue that reflexive modernisation means science pushes into more 'contextualised arenas.' This increased contextualisation leads to a loss of clearly defined boundaries between it and other human enterprises which may not be judged solely on the basis of facts. The success of science, therefore, is no longer judged on grounds that can be debated by references to facts alone but also incorporates the values individuals use to orient themselves within society.[256] As a result, these changes mean that science can no longer be understood as a neutral referee in social conflicts.[257] This contextualisation is particularly challenging to the use of administrative data in social science as the empirical findings indicate that individuals draw upon individualistically focussed values in constructing their privacy interests, leading them to perceive this use of data as risky and harmful. Furthermore, some participants, because of recent negative news stories, challenged the value of the use of administrative research in social science

---

[255] Nowotny, Scott and Gibbons (n 134).

[256] ibid.

[257] B Latour, 'From the World of Science to the World of Research?' (1998) 280 Science 208.

> *we've just seen with the US institutions* [accessing data for a purpose it was not collected for] *and suddenly we see that data isn't as secure anymore and it's not something you can just erase with a click… once stored it's probably going to be there forever and to think that through political turmoil my data will be abused for political purposes is quite discomforting (FG2, P4)*

The influence of the media coverage of scandals that involve an aspect of data collection or data sharing means individuals' attitudes are shaped by the high-profile, yet not necessarily representative, news stories that enter the public discourse. Where the contextualisation of science means its success is based on both the factual outcomes it produces and the values used by society to judge its success, these scandals undermine the neutrality of science. These scandals can also have a significant impact on later projects which claim to have value because society now perceives research as an activity 'rich in potential for wrongs and harms for they demonstrate the violation of background, often implicit norms.'[258]

The empirical findings of this thesis, therefore, suggest many individuals had a number of problems with the use of administrative data in social science research. These problems appear to be rooted in divergences between how the respective approaches of individuals and the Directive in constructing the interests of privacy and the public interest. In analysing why such divergences had occurred, this thesis proposed the novelty of the data sharing practice of using administrative data in social science research had, for a number of reasons, led individuals to doubt the public interest arising from this practice. As a result, the focus group participants constructed

---

[258] Mary Dixon-Woods and Richard E Ashcroft, 'Regulation and the Social Licence for Medical Research' (2008) 11 Medicine, Health Care and Philosophy 381.

privacy that enabled a greater seclusion from participating in society than the Directive's approach. Therefore, individuals' attitude towards 'most optimal way' for reconciling their privacy interests with the public interest of data processing for research purposes entailed less erosion of their fundamental rights. It also suggested their view of society was one underpinned by more liberal theories of democracy. The identification of these divergences and potential reasons for their existence thus begs the question; where do we go from here?

4 RESPONDING TO THE DIVERGENCES: WHERE SHOULD THE LAW GO FROM HERE?

4.1 SHOULD THE LAW MIRROR THE VIEWS OF INDIVIDUALS?

Tamanaha[259] has identified the presence of a 'mirror thesis' in much of the existing literature[260] that considers the interactions between law and individuals in society. The 'mirror thesis' is premised on the law's ability to reflect social norms and argues that it should not be substantially out of sync with the customs and habits of the society it purports to govern.[261] Applied to this research, the mirror thesis would suggest the Directive should reflect the more individualistically focused constructions of privacy identified in this study's empirical findings and reduce the permitted level of erosion of individuals' rights where data processing is for research purposes.

Nevertheless, both the prudence and ability of the law to reflect the views of individuals in society have been questioned. Research drawing upon the mirror thesis has used different 'strengths' of mirroring and different 'dimensions' of mirroring, where the law draws upon economics, cultural aspects of a society, the political backdrop of a society, or a combination of these elements in its mirroring of social norms.[262] Watson[263] heavily criticises the mirror thesis and argues that 'the dynamic causal relationship between law and society which is often thought to keep the former

---

[259] Tamanaha (n 10) 1.

[260] See, for example, Lawrence Friedman, 'Borders : On the Emerging Sociology of Transnational Law' (1996) 32 Stanford Journal of International Law 65; HLA Hart, *The Concept of Law* (Clarendon Press 1994).

[261] Tamanaha (n 10) 13.

[262] William Ewald, 'Comparative Jurisprudence (II): The Logic of Legal Transplants' (1995) 43 American Journal of Comparative Law 489, 492.

[263] Alan Watson, 'Legal Change: Sources of Law and Legal Culture' (1983) 131 University of Pennsylvania Law Review 1121, 1136.

in a close harmony with the latter simply does not exist.' He contends that social, economic, and political factors determine legal developments only to the extent to which they permeate the legal consciousness.[264] This suggests that direct engagement between legal technocrats and wider society is required for the mirror thesis to apply but such interactions are rare. Moreover, this thesis supports previous research[265] that has found many individuals possess a low level of understanding as to how their data is collected, linked, and shared. This hinders their ability to contribute to debates as to how data processing should be regulated in an informed way.

In considering the low level of awareness individuals possess about some of the novel practices that the law regulates, some have questioned whether divergences between the approaches of the law and individuals in society are *ipso facto* problematic. Abel[266] argues that a degree of non-mirroring is normal in societies, particularly in light of their increasingly pluralistic nature. Edwards[267] contends that whilst the identification of divergences may often place pressure on the law to change, there are intervening factors that may cause persistent divergences. He posits that persistent divergences are neither intrinsically good nor bad but, instead, the cause of a divergence determines its appropriateness within society. In articulating a taxonomy of divergences, the 'bulwark,' as a force that buttresses the resistance of law against pressure to change, is of particular relevance to this thesis. He argues that bulwarks are caused either by elite capture or by the protection of fundamental rights through non-democratic institutions, particularly the courts. Whilst neither of these causes appears

---

[264] Alan Watson, *The Evolution of Law* (Johns Hopkins University Press 1985).

[265] Information Commissioner's Office (n 236).

[266] R Abel, 'Law Books and Books About Law' (1973) 26 Stanford Law Review 175.

[267] Mark Edwards, 'The Alignment of Law and Norms : Of Mirrors , Bulwarks , and Pressure Valves' (2015) 10 FIU Law Review 19.

particularly applicable here, the idea of a 'bulwark' may justify divergences that prevent the law being altered to reflect critically underdeveloped attitudes, such as those present in the empirical aspect of this research. The concept of divergences acting as 'bulwarks' could also justify a lack of mirroring where individuals' attitudes appear to be disproportionately influenced by a select number of high-profile media stories, which presents the sharing of data in a way that suggests it is nearly always harmful to both individuals and wider society.[268] This would help prevent the influence of 'negative information cascades' where expressed perceptions trigger 'a chain reaction that gives the perception increasing plausibility through its rising availability in public discourse.'[269] These can lead to minor risks engendering a high level of social anxiety, potentially leading to the imposition of regulation that fails to respond to the actual challenges presented by technological innovations.

Further justifications for the persistence of the divergences may be found where participants supported their views by reference to certain privacy-enhancing mechanisms that do not, in practice, operate in the way envisaged by the participants. For example, the faith some participants placed in the 'consent or anonymise' paradigm to protect their privacy interests does not correspond to the application of these mechanisms in practice. Participants' focus on anonymisation indicates a low awareness of the challenges made regarding the perceived infallibility of anonymisation.[270] This is especially pertinent in the context of research using Big Data

---

[268] Such examples would include the failure of the care.data initiative, the state use of federal records on immigrants to facilitate deportations in the US, and internet service providers being able to share individuals' data with third parties

[269] Timur Kuran and Cass R Sunstein, 'Availability Cascades and Risk Regulation' (1999) 51 Stanford Law Review 683, 684.

[270] Ohm (n 18).

datasets, where its potential to inflict harms on individuals, even where the datasets are anonymised has been recognised.[271] The ability of these technological innovations to encroach on an individual's privacy interest is a further challenge to its erroneous societal perception as a 'silver bullet' in preventing harms.[272] Matzner and Ochs[273] have noted that anonymisation may be insufficient as, 'in the right context, using an appropriate tool, any data can become personal information.' Consent has also been criticised for lacking in 'social salience' and that its ideation has led to misplaced assumptions,[274] supporting research that has shown it has negligible effects on participants' knowledge of research.[275] The increasing complexity of the ways research potentially shape an individual's life corresponds to an increasing uncertainty in individuals' attitudes towards this activity and desire for greater agency. The understanding that greater control will resolve these uncertainties, however, has been challenged on the basis that this ignores the actual conditions of data processing under which people make choices.[276] The perceived autonomy created by greater individual control is undermined where an individual is not aware of all the information that could potentially influence their decision. The awareness required in a technologically driven, innovative environment such as research using Big Data, however, makes this a near-

---

[271] Joshua Fairfield and Hannah Shtein, 'Big Data, Big Problems: Emerging Issues in the Ethics of Data Science and Journalism' (2014) 29 Journal of Mass Media Ethics: Exploring Questions of Media Morality 38.

[272] A McGuire and others, 'Perspectives on Human Microbiome Research Ethics' (2012) 7 Journal of Empirical Research on Human Research Ethics 1.

[273] Tobias Matzner and Carsten Ochs, 'Sorting Things out Ethically - Privacy as a Research Issue beyond the Individual' in Michael Zimmer and Katharina Kinder-Kurlanda (eds), *Internet Research Ethics for the Social Age* (Peter Lang 2017) 47.

[274] Kristian Pollock, 'Procedure versus Process: Ethical Paradigms and the Conduct of Qualitative Research' (2012) 13 BMC Medical Ethics 25.

[275] Susan Slaughter and others, 'Consent and Assent to Participate in Research from People with Dementia' (2007) 14 Nursing Ethics 27.

[276] PM Schwartz, 'Privacy and Democracy in Cyberspace' (1999) 52 Vanderbilt Law Review 1609.

impossible task. Furthermore, the use of Big Data in research specifically challenges the ability for consent to be a meaningful ground for legitimising processing. As the parameters of the research are unknown at the time the data are collected for their original administrative purposes, it would be a legal fantasy[277] to deem that individuals could assess the risks and benefits of the research, to comply with the Directive's definition of consent.[278] Research re-uses data collected for a different purpose and, therefore, it may 'discover correlations neither sought nor anticipated'[279] which further undermine the applicability of consent to this context.

The danger is the law mirroring the construction of individuals' interests present in the empirical findings this thesis may produce a regulatory 'whiplash effect.' This occurs where overly restrictive measures are proposed in reaction to perceived harms that are an over-reaction in lights of the actual practices.[280] This is exacerbated in this technologically driven context because of the heightened difficulties in understanding the complex and constantly evolving phenomena. A further challenge to the applicability of the mirror thesis is the Directive's ability to reflect individuals' constructions of their privacy interests and the public interest in research where these interests are significantly dependent upon the context of the data processing practice. This understanding of privacy draws attention to the law's limited ability to accommodate for 'the whole, interconnected innovation system and the rich, possibly

---

[277] Katherine Strandburg and others, 'Monitoring, Datafication, and Consent: Legal Approaches to Privacy in the Big Data Context' in J Lane and others (eds), *Privacy, Big Data, and the Public Good: Frameworks for Engagement* (Cambridge University Press 2014).

[278] Article 2(h) Council Directive 95/46/EC requires consent to be informed

[279] Solon Barocas and Helen Nissenbaum, 'Big Data's End Run around Anonymity and Consent' in J Lane and others (eds), *Privacy, Big Data and the Public Good: Frameworks for Engagement* (Cambridge University Press 2014) 60.

[280] Brent Mittelstadt and Luciano Floridi, 'The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts' (2016) 22 Science and Engineering Ethics 303.

transformative, lived experiences of actors involved in health research'[281] whilst still providing prescriptive guidance. These difficulties are particularly challenging in the context of data protection law, where its provisions are utilised within a wide range of organisations to regulate a variety of data processing activities, making the contexts it would have to address near infinite. Moreover, where the adequacy of privacy protection depends on the specific context, how can the law appropriately respond when the factors informing contexts evolve at such a rapid pace as to inhibit the ability to determine them with any precision? If it is not prudent for the Directive respond to the existence of divergences by mirroring the views of individuals, should it instead seek to lead societal attitudes and shape these attitudes in a way that reduces the existence of divergences? The next section will consider the applicability of this interaction between law and individuals in society to the use of administrative data in social science research.

4.2 SHOULD THE LAW SEEK TO LEAD SOCIETAL ATTITUDES?

The rapidly developing technologies in the context of data processing for research purposes, the inability for most individuals to develop a full understanding of such technologies, and the lack of an active role for individuals in data processing practices may require the law to 'lead' society in the areas where technological advancements have taken place. Vago [282] recognises that technology is one of the great moving forces of law and it changes exponentially in contrast to the incremental in law and society. Therefore, there may be risks or problems created by technological developments that

---

[281] Edward Dove and Vural Özdemir, 'What Role for Law, Human Rights, and Bioethics in an Age of Big Data, Consortia Science, and Consortia Ethics? The Importance of Trustworthiness' (2015) 4 Laws 515.

[282] Steven Vago, *Law and Society* (10th edn, Routledge 2015) ch 7.

mean the law cannot ‘wait’ for societal attitudes to catch up. Instead, he argues that the law must take the lead in shaping societal attitudes by determining what is and is not appropriate. This is supported by the arguments made by Sunstein[283] in his examination of public perceptions of risk. He argues that sometimes people can focus on the worst possible case, without inquiring into the probability that the worst case will occur and, as a result, it may not be suitable for the Government to ‘capitulate to unwarranted public fear.’[284]

Arguments that the law should ‘lead’ individuals and attempt to shape their attitudes in certain areas that the law regulates correspond to the understanding of law present in the work of Cotterrell.[285] He perceives the law’s power as deriving from its ability to influence the way individuals think and act. He posits that the law does not just coerce or empower individuals but also has the ability to fix the ‘common sense’ understandings of the nature of society and societal relationships. Therefore, the law is perceived as able to constitute a social reality that shapes the concepts used by individuals to describe and explain this reality. In the context of this research, this would entail the ability of the Directive to define the use of administrative data in social science research as a ‘valuable’ activity.[286] It is possible to discern examples of such attempts to fix understandings and shape the concepts used by individuals within the Directive through its use of terms such as ‘fair processing’ and justifications for data processing based on the ‘public interest.’ The use of these terms suggests the Directive attempts to define acceptable behaviour and assign values to certain social practices,

---

[283] Sunstein (n 235).

[284] ibid 66.

[285] Cotterrell (n 11).

[286] ibid.

including research. What Cotterrell also understands, however, is that the law alone cannot create such understandings and so aspects of society's views must feed into the law and its approach to reconciling different interests. By maintaining these 'common sense' understandings of the nature of society Cotterrell views the law as comprising of the more general structure of values and cognitive ideas and assumptions as to the nature of law and its appropriate functions. The empirical findings suggest a divergence between values underpinning the Directive's and the focus group participants' respective conceptions of privacy and the public interest in research. This questions the assumption that the Directive, in the context of the use of administrative data in social science research, comprises the values and assumptions as to the appropriate functions of law by indicating a failure to incorporate societal views. The empirical findings suggest that the practice of processing administrative data for social science research purposes, the law has not yet succeeded in shaping the social reality in determining the acceptable data processing practices and the level of erosion of privacy interests required for data processing in the public interest to take place.

Though Cotterrell[287] has attributed the existence of divergences to the remoteness of those that create the law from those that are purportedly governed by the law, the findings of this thesis suggest this may not fully explain the divergences identified. Attention must also be paid to the special context in which the Directive operates. Firstly, the Directive has to operate in a rapidly changing technological context. This makes it difficult for individuals to understand and thus articulate views that law can draw upon in its shaping of the understandings used by individuals in society. Secondly, the practice of data collection and processing does not require much

---

[287] ibid.

active input for members of society, particularly in the collection of administrative data, and thus there is little to spark the discussions and debates within society that the law can draw upon in giving further specificity to the general values that underpin the law. Where such instances do occur, they tend to arise from high profile data breaches discussed by the media. Due to their extreme nature, these are not the most suitable triggers for the creation of an understanding in the Directive. If the empirical findings oppose the argument that the law can shape and fix the understandings of individuals to deem certain activities as valuable, what alternative role can the law take in response? The next section will consider this issue.

4.3 OTHER POTENTIAL RESPONSES OF THE LAW

Tene and Polonetsky argue the rapid pace of technological innovations creates a need to 'recalibrate individual expectations, social norms, and, ultimately, laws and regulations.'[288] In this context, however, the law is perceived as a 'crude' tool that may struggle to distinguish appropriate data processing activities when social norms have hardly evolved.[289] This is reinforced by Taipale's argument that attempts to use of law alone to constrain technology are 'doomed to failure' [290] because of the tension between the interests of individuals' privacy and the public interest in data processing for research, imposes obligations that create a 'wicked problem.' A 'wicked problem' is characterised by a tension between two interests which can be resolved in an infinite number of ways because there is no fulcrum point upon which the interests can be

---

[288] Omer Tene and Jules Polonetsky, 'A Theory of Creepy: Technology, Privacy and Shifting Social Norms' (2014) 16 Yale Journal of Law & Technology 59, 73.

[289] ibid.

[290] KA Taipale, 'Technology, Security and Privacy: The Fear of Frankenstein, the Mythology of Privacy and the Lessons of King Ludd' (2004) 7 Yale Journal of Law & Technology 125, 127

balanced to achieve the 'correct' amount of protection and occur in a social context that involves a diverse range of interests. The resolution of such problems, therefore, requires a consideration of the problems understood in the context of the interests and the technologies at hand. His view influenced by Conklin, who argues the resolution of these issues is 'fundamentally a social process' that requires a 'shared understanding about the problem.'[291] This need to incorporate societal views is also present in theories of reflexive modernisation that consider how the law should respond to the heightened perceptions of risk present in society and the changes made to societal structures because of the success of technological innovations. Beck[292] argues that the changes that lead to the creation of a reflexively modern society require decision-makers to open up participation according to the social standards of relevance and take into account the views of the participants. There are, of course, challenges to this, and the incorporation of ethical and social issues into the law is fraught with difficulties. Marchant et al[293] have noted the intangibility and potential transience of the values that underpin these issues mean they do not easily lend themselves to their incorporation into a legal framework which has to embody sufficient permanence and specificity to enable the giving of prescriptive guidance.

Such arguments align with the increasing importance existing literature[294] has attributed to public engagement in fostering a sense of support for data-sharing

---

[291] J Conklin, *Dialogue Mapping: Building Shared Understanding of Wicked Problems* (Wiley 2005)

[292] U Beck, *Ecological Politics in an Age of Risk* (Polity Press, 1995)

[293] G Marchant, A Meyer and M Scanlon, 'Integrating Social and Ethical Concerns into Regulatory Decision-Making for Emerging Technologies' (2010) 11 Minnesota Journal of Law, Science & Technology 345

[294] See Mhairi Aitken, Sarah Cunningham-Burley and Claudia Pagliari, 'Moving from Trust to Trustworthiness: Experiences of Public Engagement in the Scottish Health Informatics Programme' (2016) 43 Science and Public Policy 713; Ian Welsh and Brian Wynne, 'Science, Scientism and Imaginaries of Publics in the UK: Passive Objects, Incipient Threats' (2013) 22 Science as Culture 540.

initiatives and the perception that research is an appropriate data-processing practice. One-off consultations at the start of data sharing projects, where it is not possible to anticipate effectively the future developments of such initiatives are unhelpful and create a lack of transparency that would further undermine individuals' trust in these projects. Nevertheless, as recognised by Harmon et al,[295] and aligning with theories of reflexive modernisation, it is equally important to acknowledge the relevance of risk in potentially influencing future debates and to reject 'possible Frankenstein futures which are driven by media hype.' Moreover, Fischer[296] has criticised Beck's focus on opening up the forum of deliberation to laypeople for failing to demonstrate that individuals in society have the ability to participate and underestimates the extent to which individuals are ambivalent towards experts.

Laurie[297] has perceived this challenge as signifying that whilst the law still has value and importance in this context, here it 'might play less of a legislatively grounded normative role' and instead should seek to be about space-creating and context-shaping that seeks to permit more self-regulation by the actors that adopt the technological advancements. This would allow the law to obtain information from a variety of actors to understand better the possibilities and issues created by technological innovations to determine how the law can be used to promote the best possible outcome.[298] A consideration of the potential governance mechanisms that can respond to the challenges identified not just in this chapter but also throughout this research is beyond

---

[295] Harmon, Laurie and Haddow (n 12).

[296] Frank Fischer, *Citizens, Experts, and the Environment : The Politics of Local Knowledge* (Duke University Press 2000).

[297] Laurie, Harmon and Arzuaga (n 109).

[298] ibid.

the scope of this thesis. It does, however, identify a key area upon which future research could build upon this work and further elucidate the relationship between law and society in this context.

5 CONCLUSION: IMPLICATIONS AND FUTURE RESEARCH

In analysing the identified divergences between how the Directive and focus group participants constructed the interests in privacy and data processing for research purposes this thesis has produced two key findings. Firstly, that different values can underpin the interests promoted by the objectives of the Directive, leading to divergent understandings of the interests of privacy and the public interest in research and different perceptions of appropriate data processing practices. Secondly, the empirical findings suggest the novelty of the use of administrative data in social science research, as an example of Big Data analytics and part of a move away from data subjects' active participation in research, influences only the focus group participants' views and not the Directive, due to its technology neutral approach.[299] This creates greater scope for divergences between the Directive's and individuals' respective approach to novel data processing practices.

Theories of reflexive modernity and Nissenbaum's contextual accounts of privacy elucidate how the context in which data processing practices occur influence individuals' construction of their interests. Consideration of these theories has enabled me to broaden the range of factors considered in this thesis that may contribute to shaping individuals' attitudes. Moreover, the theoretical material has emphasised the role of risk and uncertainty in shaping individuals' views. This concluding chapter will

---

[299] See Chapter 1, Section 1.1.4.

elaborate upon the implications of the respective approaches of the Directive and focus group participants towards the use of administrative data in social science research and outline potential areas for future research.

5.1 SPECIFIC FINDINGS

This thesis identified differences in the values underpinning the respective approaches of the Directive and the focus group participants towards the use of administrative data in social science research. The empirical findings suggested several differences in how the interests of privacy and the public interest in processing data for research purposes were conceived leading to significant divergences in determining if a data processing practice breached their respective understandings of privacy. Individuals employed a more contextual approach towards their evaluation of the use of administrative data in social science research. Their views incorporated a consideration of the benefits of such research, their attitudes towards the actors involved in the data processing practice, and the ways in which the transmission of information could be constrained, including the use of anonymisation and consent. Though the findings of this thesis are limited, due to the small scope of the qualitative empirical data collection, it does elucidate potential reasons for the divergences between the approach of the Directive and individuals towards the use of their data for research purposes.

The views of the focus group participants suggested the construction of their privacy interests were influenced by liberal values that promote individualistic conceptions of privacy and seek to promote an individual’s control over their data and enable their ability to seclude themselves. This construction of their privacy interest is contrasted with the approach identified in the Directive which suggested a privacy interest constructed upon more societally-focussed values. Privacy conceived in this way shifts away from giving individuals the ability to seclude themselves and exercise individual control over their data but recognising how privacy can help create a democracy built upon participatory, rather than liberal, values. The notion of the Directive promoting a democracy built on participatory values is particularly evident when one considers the nature of the duties imposed by the use of administrative data in social science research as discussed in Chapter 3. These duties entailed an obligation on individuals to share their administrative data with researchers and to accept the risks of this data processing practice to benefit society. This construction of privacy is protected due to its ability to encourage individuals to participate in society and to encourage civil debate that draws on varied opinions. This data processing practice could encourage participation and debate where it exposes previously unknown links and patterns that may indicate Government policies should be changed or where research findings suggest currently policies are not supported by empirical findings.

Similar issues arose in relation to the values underpinning the respective approaches of the Directive and focus group participants towards the use of administrative data in social science research as an activity that promotes the public interest. Whilst specific exemptions and assumptions that make further processing for research purposes less burdensome for data processors in the Directive suggest it perceives research as an inherently valuable activity, the focus group participants did not share this construction of the public interest. The empirical findings indicate that individuals did not necessarily view the use of administrative data in social science research as an activity in the public interest, comparing it unfavourably to medical research and questioning the benefits of research that used administrative data. These corroborate the findings of Cameron et al[300] and support the argument that individuals perceive the use of administrative data in social science research as a novel practice and, therefore, empirical research exploring individuals' attitudes towards medical research should not be generalised. The findings also accord with Caulfield's[301] warning that opportunities presented by Big Data should not lead to the use of convenient solutions based on rationales with an intuitive appeal, such as the public interest in research. This thesis has demonstrated that, in this context, the ability to comply with the Directive's requirements when processing administrative data for research purposes does not mean such processing has secured societal acceptance as an appropriate data processing practice.

These divergences in the construction of privacy and the public interest in research, therefore, led to different approaches to the appropriateness of the use of administrative data in social science research. Whilst the thesis proposes that the values that underpin the construction of these interests are crucial in understanding these divergences, they were not the only variable identified in this thesis as a potential source of the divergences. Though the novelty of the use of administrative data in social science research as a data processing practice does not influence the approach of the Directive, the empirical findings indicated this novelty provoked uncertainty in those who participated in the focus group discussions. This uncertainty influenced the focus group participants' approaches towards using administrative data in social science research, leading it to be perceived as a risky practice and, therefore, potentially not in the public interest. The effect of this uncertainty and the perception of such research as

---

[300] Cameron, Pope and Clemence (n 8).

[301] Timothy Caulfield, 'Biobanks and Blanket Consent: The Proper Place of the Public Good and Public Perception Rationales' (2007) 18 King's Law Journal 209.

inherently risky in shaping the construction of the interests and privacy and the public interest in research does not just potentially lead to divergences between the respective approaches of individuals and the Directive towards novel data processing practices. It may also have implications for the possible responses to these divergences.

In identifying potential divergences, this thesis has sought to demonstrate that the use of administrative data in social science research is an area where the law does not 'mirror' societal expectations regarding the appropriateness of this data processing practice. The lack of mirroring arises from the differences in the respective constructions of appropriate privacy protections and the value of research as an activity in the public interest. This has been attributed to the contrast between the exponential changes in technology and the incremental changes in both the social and legal systems. Vago has used this to argue that the law may be both reactive and proactive, by seeking to induce broad social changes where it may not be possible to determine societal expectations.[302] Whilst the concept of the law as an instrument for social change has pragmatic appeal and receives support in existing literature,[303] this does not completely absolve the need for societal support.[304]

The findings have implications for the role of law in reconciling privacy interests and the public interest in research in the context of the use of administrative data in social science research. Theories of reflexive modernisation[305] and literature

---

[302] Vago (n 282) ch 7.

[303] W Friedmann, *Law in a Changing Society* (2nd edn, Colombia University Press 1972); Yehezkel Dror, 'Law as a Tool of Directed Social Change' (1970) 13 American Behavioral Scientist 553.

[304] Edwin Schur, *Law and Society: A Sociological View* (Random House 1968).

[305] U Beck, A Giddens and S Lash, 'Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order', *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order* (1994).

examining the sociology of science[306] have emphasised the importance of gaining public acceptance through forms of public engagement[307] to empower individuals.[308] This suggests forms of governance that seek to include individuals in society in the decision-making process should be considered, possibly in the form of ‘bottom-up’ approaches to governance and the law may potentially seek to play a more ‘space-creating’ role.[309]

5.2 FUTURE RESEARCH

Further research could build on the current empirical findings to increase their generalisability. Practical limitations, including a tight timeframe, hindered the ability to collect data from a diverse range of individuals. Further empirical work is therefore required to explore the values underpinning the approach of individuals in their attitudes towards the use of administrative data in social science research. Future research would seek to include a more diverse age range and individuals from different socio-economic backgrounds to explore if these attributes may influence individuals’ constructions of their interests.

Greater generalisability may also be gained by using different empirical methods and modifying the approach of the focus groups. In particular, the use of vignettes within focus groups discussions[310] could be used to enhance the

---

[306] Nowotny, Scott and Gibbons (n 134).

[307] It is argued this term corresponds to Beck’s argument for the demonopolisation of expertise in Beck (n 131).

[308] Anthony Giddens, *Modernity and Self-Identity : Self and Society in the Late Modern Age* (Stanford University Press 1991).

[309] Laurie, Harmon and Arzuaga (n 109).

[310] Sue Wilkinson, ‘Focus Group Methodology: A Review’ (1998) 1 International Journal of Social Research Methodology 181.

understanding gained from this thesis to consider aspects of the context of research[311] that would benefit from greater exploration. This would enable attempts to determine more precisely which specific aspects of the use of administrative data in social science research provoke the most concern and lead to the widest divergences between the approach of individuals and the Directive. Qualitative methods could also be utilised in future research. For example, the use of surveys employing a Likert Scale could facilitate the collection of data from a greater number of individuals and enable a better understanding of factors that influence their opinion and to what extent these factors are an influence. This could allow for the creation of a hierarchy of influences, based on the extent to which their influence an individual's opinion, which may be of relevance in examining potential legal responses. Previous work has suggested that younger individuals are more open sharing their data[312] but this thesis' findings do not fully support this contention and some of the focus group participants were uncomfortable with many aspects of this form of data sharing and usage.

Furthermore, this thesis examined the legal framework using the current EU legislation but, in May 2018, the General Data Protection Regulation[313] will replace this. This requires a close analysis of the differences in values underpinning the approach of the new law to explore the extent to which it aligns with the empirical findings of this thesis and future work that builds upon it.

---

[311] Used in the sense proposed by Nissenbaum's theory of privacy as contextual integrity

[312] TNS Opinion & Social, 'SPECIAL EUROBAROMETER 359 Attitudes on Data Protection and Electronic Identity in the European Union' 330 available at http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_359_en.pdf accessed 27 Oct. 17.

[313] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (GDPR) [2016] OJ 2 119/1

The implications for the role played by the law, discussed in the previous section, illustrate the potential importance of examining different ways of regulating the processing of data for research purposes, shifting away from the law attempting to reflect or guide societal constructions of the interests of privacy and the public interest to one that seeks to engage individuals. The findings suggest there is a need to explore more reflexive forms of governance, which encourage actors, including the governing and the governed, to interact in deliberative ways and engage in collaborative forms of enquiry[314] to encourage a culture of cooperation[315] and facilitate appropriate responses to the concerns of individuals. This is not to advocate always changing the approach of research when faced with concerns but rather that these concerns should not be viewed as errors arising from ignorance that must be 'fixed.' Of interest are methods of public engagement that seek to demonstrate trustworthiness,[316] the notion of responsible innovation, which understands that science is partially socially and politically constituted.[317]

---

[314] Jacques Lenoble and Marc Maesschalck, 'Renewing the Theory of Public Interest: The Quest for a Reflexive and Learning-Based Approach to Governance' in Olivier de Schutter and Jacques Lenoble (eds), *Reflexive Governance : Redefining the Public Interest in a Pluralistic World* (Hart Publishing 2010).

[315] Graeme Laurie, 'Reflexive Governance in Biobanking: On the Value of Policy Led Approaches and the Need to Recognise the Limits of Law' (2011) 130 Human Genetics 347.

[316] Aitken, Cunningham-Burley and Pagliari (n 294).

[317] Jack Stilgoe, Richard Owen and Phil Macnaghten, 'Developing a Framework for Responsible Innovation' (2013) 42 Research Policy 1568.

6 METHODOLOGICAL ANNEX

6.1 INTRODUCTION

Two focus groups were conducted to investigate the values underpinning individuals' attitudes towards the use of administrative data in social science research and enable a comparison between the values underpinning the approach of individuals and the Directive. Of particular interest to this research were the collection of data on the focus group participants' views on privacy, the public interest in social science research, and their reconciliation of these interests in the specific context social science research using Government-held administrative data.

Existing empirical studies[318] have demonstrated the context, a term drawn from Nissenbaum's[319] work to connote the structured social settings that are characterised by roles, relationships, norms, and internal values, may influence individuals' attitudes towards the use of their data in research. Based on this framework and informed by theories of social change,[320] the research sought to explore if the use of administrative data in social science research could be distinguished from other types of research and the impact of its novelty and unfamiliarity.

Focus groups were chosen for this research as they utilise complementary and argumentative interactions[321] and forms of communication such as anecdotes to gather

---

[318] Haddow and others (n 192); Hill and others (n 194).

[319] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[320] Beck, Giddens and Lash (n 305).

[321] Jenny Kitzinger, 'The Methodology of Focus Groups: The Importance of Interaction between Research Participants' (1994) 16 Sociology of Health & Illness 103.

a variety of attitudes and opinions. This allows individuals to explore and clarify their thoughts and researchers to capture ideas that participants may struggle to encapsulate in a reasoned response to a question.[322] It also enables researchers to observe how the opinions of the focus group participants alter during the discussions.[323] These features make them an effective means of gathering data on phenomena that are not well understood and where questions of the acceptability of the researched phenomenon are relevant.[324]

6.2 RESEARCH DESIGN

6.2.1 Recruitment and setting

Practical constraints confined the geographic scope of recruitment to Oxford. Seven Community Centres in the Oxford area were contacted as part of the recruitment efforts; all agreed to display recruitment posters, four agreed to post the information online, either on their website or their Facebook Page, and three were visited in person to engage directly with individuals and pre-existing groups that used the Centres. Despite some initial displays of interest by individuals who had been engaged with actively, however, these recruitment attempts did not produce responses. As a result, the recruitment strategy was altered to focus on the recruitment of students as their timetable was considered to be more flexible, increasing the likelihood a sufficient

---

[322] Jenny Kitzinger, 'Introducing Focus Groups' (1995) 311 BMJ 299.

[323] James Kahan, 'Focus Groups as a Tool for Policy Analysis' (2001) 1 Analyses of Social Issues and Public Policy 129.

[324] Richard Powell and Helen Single, 'Focus Groups' (1996) 8 International Journal for Quality in Health Care 499.

number could attend a Focus Group discussion. Furthermore, the researchers' status as a student was hypothesised to make this group more accessible.

Initial reluctance to recruit students arose from studies that suggested age and educational background were factors that influenced individuals' openness towards the sharing of their data.[325] Students were still difficult to recruit but the introduction of a small amount of financial compensation and the use of snowball sampling, where referrals from initial subjects generated additional participants,[326] led to a focus group of nine students in June 2017. My initial findings did not support the hypothesis that this population would be significantly more open to their data being shared and, therefore, a further round of recruitment led to a second Focus Group in July 2017 with six participants.

The focus groups were conducted at St Cross College, an accessible, central location, and lasted two hours. Physical copies of the Participant Information Sheet and Consent Form, previously sent by email, were available for participants to read and complete and to encourage them to start forming views about research.

Though ideally, the moderator should be a 'neutral person' that can stimulate the discussion without any personal impact,[327] the researcher acted as the moderator, a not uncommon occurrence in Social Science research.[328] This required an awareness of the researcher's background, their assumptions, and how these may influence the focus

---

[325] TNS Opinion & Social (n 312).

[326] John Dudovskiy, 'Snowball Sampling' <http://research-methodology.net/sampling-in-primary-data-collection/snowball-sampling/> accessed 17 September 2017.

[327] Pranee Liamputtong, *Focus Group Methodology : Principles and Practices* (SAGE 2011).

[328] Janet Smithson, 'Focus Groups' in Pertti Alasuutari, Leonard Bickman and Julia Brannen (eds), *The SAGE handbook of social research methods* (SAGE 2008).

group participants. Where participants directed questions to the moderator, they were answered succinctly and responses aimed to encourage a discussion among focus group participants.

6.2.2 Questioning route

Can you think of a time you’ve given, or shared, your data in exchange for something like a product or a service?
My research looks specifically at administrative data, the information that the Government collects on people; what kinds of data do you think Government departments hold on people?
Thinking about all the kinds of data we’ve just discussed; how do you feel about the Government departments holding this much information about people?
Can you think of any benefits to the Government departments and public bodies having this information about individuals? What about any downsides?
How would you feel about a cleaner in a Government department being able to access your data?

What about someone accessing data stored in one department from a different Government department? What about a researcher?
Can you think of any purposes you wouldn’t like your data to be used for? How do you feel about your data being used for research purposes?
Thinking back to the start of today, you all read through these information sheets and signed a consent form – how do you feel about this being required every time a researcher wants to access your data? How would you feel if your information could be used without your consent if it was decided by someone else that it would be good for researchers to use your data?
How would you feel if researchers could use data that identified who you were?
Is there anything that could be done to make you feel more comfortable with this happening?

Do you feel that you have enough control over your own data?

A structured questioning route was used to minimise the potential impact of the moderator's inexperience on the data collected and to facilitate cross-group comparisons during the data analysis stage. The questioning route was guided by the research aims and a review of the literature linked to exploring the values underpinning individuals' attitudes towards the use of administrative data in social science research. The use of legal terminology was minimised for two reasons: to encourage participants to discuss the questions based on the meanings they ascribed to the concepts they felt were relevant. This allowed data to be collected on the values that underpinned participants' attitudes rather than their use of specific terms. Exceptions were made for terms that prominent in public discourse in a range of contexts, increasing the probability that participants would have experiences they could draw upon during the discussions.[329] Typically, focus groups employ only open-ended questions because they encourage extended answers from which individuals' attitudes and opinions can be determined.[330] In response to concerns that participants were largely unaware of the research area led to the use of questions with a 'yes or no' answer but also created space for participants to share their experiences in their own words[331] and considered points still relevant to the research aims.

---

[329] For example, questions explored participants' attitudes towards consent

[330] Kitzinger, 'Introducing Focus Groups' (n64).

[331] See the first Focus Group question

6.3 DATA ANALYSIS

The Focus Groups were recorded using a small Dictaphone and, immediately after each Focus Group, the moderator took notes on the participants' physical reactions and other physical cues that were identified in each session. The transcripts were transcribed verbatim using Express Scribe Transcription[332] to enable familiarity with the data and the pauses, reputations, and false starts made by participants were included. These structural elements can give insights into a participant's strength of feeling or indicate where were responses were moderator whilst a participant spoke. The transcripts were initially analysed with NVivo[333] but attempts to code using this software were unsuccessful in providing insights relevant to the research aims. Instead, physical copies of the data were printed and coded using post-it notes which could easily be modified or removed. This form of analysis assisted with gaining familiarity with the data and allowed the researcher to consider the data in small chunks whilst still considering its coherence within the context of the entire transcript.

The data were analysed thematically,[334] with a theoretical approach that interpreted the data through the lens of the existing theories of privacy as contextual integrity[335] and reflexive modernisation[336] to draw out the values and influences underpinning the participants' responses. A desire to explore these values and logic

---

[332] Available at http://www.nch.com.au/scribe/index.html

[333] See http://www.qsrinternational.com/nvivo/what-is-nvivo for further information about this software

[334] Victoria Clarke and Virginia Braun, 'Thematic Analysis' (2016) 12 The Journal of Positive Psychology 297.

[335] Nissenbaum, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (n 9).

[336] Beck, Giddens and Lash (n 305).

frameworks led to the use of latent codes,[337] based on the researcher's interpretation of the values and logic framework underpinning the responses gathered which were reviewed to develop themes informed by these codes and the existing theories that informed this study's approach.

6.4 LIMITATIONS

The small sample sizes of focus group and tendency not to use probability methods to select participants may challenge the validity and generalisability of findings.[338] In response, Hopkins[339] emphasises the importance of the inferences drawn in judging the validity. Focus groups methods have also been criticised for providing a shallower understanding of participants' views than individual interviews. [340] My research aims, however, meant the process of how meanings were shaped and debated among participants were important and these shared understandings cannot be accessed through individual interviews. Focus groups also assign more control to participants who can shape the discussion according to the areas they consider of importance which aligns better with the exploratory nature of my research.

The empirical findings from this thesis have two limitations, arising from the recruitment issues outlined above. Firstly, the exclusive use of students further limits the generalisability of the findings and hinders the ability to explore the impact of personal attributes, including age and educational background, on the values

---

[337] Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3 Qualitative Research in Psychology 77.

[338] Edward Fern, *Advanced Focus Group Research.* (Sage 2001).

[339] Peter E Hopkins, 'Thinking Critically and Creatively about Focus Groups' (2007) 39 Area 528.

[340] Fern (n 338).

underpinning the participants' responses. Secondly, time constraints meant only two Focus Groups were conducted, making it unlikely that sufficient data was collected to enable the saturation of the themes identified which is a crucial aspect of the research design. Therefore, further empirical is needed to address these issues.

BIBLIOGRAPHY

Abel R, 'Law Books and Books About Law' (1973) 26 Stanford Law Review 175

Academy of Medical Sciences, 'Personal Data for Public Good: Using Health Information in Medical Research' (2006)

Acquisti A, Brandimarte L and Loewenstein G, 'Privacy and Human Behavior in the Age of Information' (2015) 347 Science 509

Administrative Data Taskforce, 'Improving Access for Research and Policy' (2012) 59 <http://www.esrc.ac.uk/files/research/administrative-data-taskforce-adt/improving-access-for-research-and-policy/> accessed 24 November 2017

Aitken M, Cunningham-Burley S and Pagliari C, 'Moving from Trust to Trustworthiness: Experiences of Public Engagement in the Scottish Health Informatics Programme' (2016) 43 Science and Public Policy 713

Allenby B, 'Governance and Technology Systems: The Challenge of Emerging Technologies', *The Growing Gap Between Emerging Technologies and Legal-Ethical Oversight: The Pacing Problem* (Springer 2011)

Altman I, *The Environment and Social Behavior* (Brooks/Cole Pub Co 1975)

——, 'Privacy Regulation: Culturally Universal or Culturally Specific?' (1977) 33 Journal of Social Issues 66

Austin L, 'Privacy and the Question of Technology' (2003) 22 Law and Philosophy

Banakar R and Travers M, *Law and Social Theory* (Reza Banakar and Max Travers eds, Hart Publishing 2013)

Barocas S and Nissenbaum H, ‘Big Data’s End Run around Anonymity and Consent’ in J Lane and others (eds), *Privacy, Big Data and the Public Good: Frameworks for Engagement* (Cambridge University Press 2014)

Bartlett J, ‘The Data Dialogue’ (2012)

Beck U, *Risk Society : Towards a New Modernity* (Sage Publications 1992)

Beck U, Bonss W and Lau C, ‘The Theory of Reflexive Modernization’ (2003) 20 Theory, Culture & Society 1

Beck U, Giddens A and Lash S, ‘Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order’, *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order* (1994)

Bennett C and Raab C, *The Governance of Privacy : Policy Instruments in Global Perspective* (MIT Press 2006)

Bennett Moses L, ‘Recurring Dilemmas: The Laws’s Race to Keep Up with Technological Change’ (2007) 2 University of Illinois Journal of Law, Technology & Policy 239

——, ‘Agents of Change: How the Law ‘copes’ with Technological Change’ (2011)

20 Griffith Law Review 763

Beyleveld D and Brownsword R, ‘Emerging Technologies, Extreme Uncertainty, and the Principle of Rational Precautionary Reasoning’ (2012) 4 Law, Innovation and Technology 35

Black G and Stevens L, ‘Enhancing Data Protection and Data Processing in the Public Sector: The Critical Role of Proportionality and the Public Interest’ (2013) 10 SCRIPTed 93

Blume P, ‘The Public Sector and the Forthcoming EU Data Protection Regulation’ (2015) 1 European Data Protection Law Review (EDPL) 32

Boulton M and Parker M, ‘Informed Consent in a Changing Environment’ (2007) 65 Social Science & Medicine 2187

boyd danah and Crawford K, ‘CRITICAL QUESTIONS FOR BIG DATA’ (2012) 15 Information, Communication & Society 662

Braun V and Clarke V, ‘Using Thematic Analysis in Psychology’ (2006) 3 Qualitative Research in Psychology 77

Brownsword R, *Rights, Regulations and the Technological Revolution* (Oxford University Press 2008)

Brownsword R, ‘In the Year 2061: From Law to Technological Management’ (2015) 7 Law, Innovation and Technology 1

Bygrave L, *Data Protection Law: Approach Its Rationale, Logic, and Limits* (Wolters Kluwer Law & Business 2002)

Cameron D, Pope S and Clemence M, ‘Dialogue on Data: Exploring the Public’s Views on Using Administrative Data for Research Purposes’ (2014) <https://adrn.ac.uk/media/1245/sri-dialogue-on-data-2014.pdf> accessed 11 October 2017

Capron AM, ‘Protection of Research Subjects: Do Special Rules Apply in Epidemiology?’ (1991) 44 Journal of Clinical Epidemiology 81

Card D and others, ‘Expanding Access to Administrative Data for Research in the United States’ (*National Science Foundation White Paper 10-069*, 2010) 1 <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1888586>

Carter P, Laurie G and Dixon-Woods M, ‘The Social Licence for Research: Why Care.Data Ran into Trouble’ (2015) 41 Journal of Medical Ethics 404

Caulfield T, ‘Biobanks and Blanket Consent: The Proper Place of the Public Good and Public Perception Rationales’ (2007) 18 King’s Law Journal 209

Cavoukian A, ‘Privacy by Design: The 7 Foundational Principles’ (*Privacy by Design*, 2011) 7 <https://www.ipc.on.ca/wp-content/uploads/Resources/7foundationalprinciples.pdf> accessed 16 November 2017

Choudhury S and others, ‘Big Data, Open Science and the Brain: Lessons Learned from Genomics’ (2014) 8 Frontiers in Human Neuroscience 239

Clarke V and Braun V, ‘Thematic Analysis’ (2016) 12 The Journal of Positive Psychology 297

Conger S, Pratt J and Loch K, ‘Personal Information Privacy and Emerging Technologies’ (2013) 23 Information Systems Journal 401

Connelly R and others, ‘The Role of Administrative Data in the Big Data Revolution in Social Science Research’ (2016) 59 Social Science Research 1

Cotterrell R, *Law’s Community: Legal Theory in Sociological Perspective* (Oxford University Press 1997)

Dinev T and others, ‘Information Privacy and Correlates: An Empirical Attempt to Bridge and Distinguish Privacy-Related Concepts’ (2013) 22 European Journal of Information Systems 295

Dixon-Woods M and Ashcroft RE, ‘Regulation and the Social Licence for Medical Research’ (2008) 11 Medicine, Health Care and Philosophy 381

Donnelly L, ‘Mass NHS Data Sharing Plan Will Not Allow “simple Opt out” despite Ministers’ Pledges’ *The Telegraph* (September 2017)

Dove E and Özdemir V, ‘What Role for Law, Human Rights, and Bioethics in an Age of Big Data, Consortia Science, and Consortia Ethics? The Importance of Trustworthiness’ (2015) 4 Laws 515

Dror Y, ‘Law as a Tool of Directed Social Change’ (1970) 13 American Behavioral Scientist 553

Dudovskiy J, ‘Snowball Sampling’ <http://research-methodology.net/sampling-in-primary-data-collection/snowball-sampling/> accessed 17 September 2017

Edwards M, ‘The Alignment of Law and Norms : Of Mirrors , Bulwarks , and Pressure Valves’ (2015) 10 FIU Law Review 19

Erdos D, ‘Systematically Handicapped? Social Research in the Data Protection Framework’ (2011) 20 Information and Communications Technology Law 83

——, ‘CONSTRUCTING THE LABYRINTH: The Impact of Data Protection on the Development of “ethical” Regulation in Social Science’ (2012) 15 Information Communication and Society 104

Etzioni A, *The Limits of Privacy* (Basic Books 1999)

European Commission, ‘Data Protection in the European Union’ <http://ec.europa.eu/justice/policies/privacy/docs/guide/guide-ukingdom_en.pdf> accessed 1 November 2017

Ewald W, ‘Comparative Jurisprudence (II): The Logic of Legal Transplants’ (1995) 43 American Journal of Comparative Law 489

Fairfield J and Shtein H, ‘Big Data, Big Problems: Emerging Issues in the Ethics of Data Science and Journalism’ (2014) 29 Journal of Mass Media Ethics: Exploring Questions of Media Morality 38

Fern E, *Advanced Focus Group Research.* (Sage 2001)

Fischer F, *Citizens, Experts, and the Environment : The Politics of Local Knowledge* (Duke University Press 2000)

Fitzgerald ST and Rubin BA, 'Risk Society, Media, and Power: The Case of Nanotechnology' (2010) 30 Sociological Spectrum 367

Floridi L, 'Open Data, Data Protection, and Group Privacy' (2014) 27 Philosophy & Technology 1

Forgo N, 'My Health Data--Your Research: Some Preliminary Thoughts on Different Values in the General Data Protection Regulation' (2015) 5 International Data Privacy Law 54

Fried C, *An Anatomy of Values* (Harvard University Press 1970)

Friedman L, 'Borders : On the Emerging Sociology of Transnational Law' (1996) 32 Stanford Journal of International Law 65

Friedmann W, *Law in a Changing Society* (2nd edn, Colombia University Press 1972)

Fuchs C, 'Towards an Alternative Concept of Privacy' (2011) 9 Journal of Information, Communication and Ethics in Society 220

Giddens A, *The Consequences of Modernity* (Stanford University Press 1990)

——, *Modernity and Self-Identity : Self and Society in the Late Modern Age* (Stanford University Press 1991)

——, 'Living in a Post-Traditional Society' in Ulrich Beck, Anthony Giddens and S

Lash (eds), *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order* (Stanford University Press 1994)

Gutwirth S and others, ‘PRESCIENT: Legal, Social, Economic and Ethical Conceptualisations of Privacy and Data Protection’ (2011) <https://www.prescient-project.eu/prescient/inhalte/download/PRESCIENT-D1---final.pdf> accessed 28 November 2017

Haddow G and others, ‘“Nothing Is Really Safe”: A Focus Group Study on the Processes of Anonymizing and Sharing of Health Data for Research Purposes’ (2011) 17 Journal of Evaluation in Clinical Practice 1140

Harmon S, Laurie G and Haddow G, ‘Governing Risk, Engaging Publics and Engendering Trust: New Horizons for Law and Social Science?’ (2013) 40 Science and Public Policy 25

Hart H, *The Concept of Law* (Clarendon Press 1994)

Hartley M, ‘The Concept of Privacy: An Analysis of the EU Directive on the Protection of Personal Data’ in D Byeveld and others (eds), *The Data Protection Directive and Medical Research Across Europe* (Ashgate 2004)

Häyry M and others, *The Ethics and Governance of Human Genetic Databases: European Perspectives* (Matti Hayry and others eds, Cambridge University Press 2007)

Hays R and Daker-White G, ‘The Care.Data Consensus? A Qualitative Analysis of Opinions Expressed on Twitter’ (2015) 15 BMC Public Health 838

Hiah J and Riesthuis T, ‘Studying Law in Society: Static and Dynamic Conceptions of Social Norms’ (2016) 9 Erasmus Law Review 1

Hill E and others, ‘“‘Let’s Get the Best Quality Research We Can’”: Public Awareness and Acceptance of Consent to Use Existing Data in Health Research: A Systematic Review and Qualitative Study.’ (2013) 13 BMC medical research methodology 72

Hopkins PE, ‘Thinking Critically and Creatively about Focus Groups’ (2007) 39 Area 528

Hoven J van den, ‘Information Technology, Privacy, and the Protection of Personal Data’ in Jeroen Van Den Hoven and John Weckert (eds), *Information Technology and Moral Philosophy* (Cambridge University Press 2008)

Information Commissioner’s Office, ‘Data Protection Rights: What the Public Want and What the Public Want from Data Protection Authorities’ (European Conference of Data Protection Authorities 2015)

Information Commissioners Office, ‘The Guide to Data Protection’ (2015) 15 <http://ico.org.uk/for_organisations/data_protection/~/media/documents/library/Data_Protection/Practical_application/the_guide_to_data_protection.pdf>

Inness J, *Privacy, Intimacy, and Isolation* (Oxford University Press 1992)

Kahan J, ‘Focus Groups as a Tool for Policy Analysis’ (2001) 1 Analyses of Social Issues and Public Policy 129

Kass N and others, ‘The Use of Medical Records in Research: What Do Patients Want?’

(2003) 31 Journal of Law Medicine & Ethics 429

Kehr F and others, ‘Blissfully Ignorant: The Effects of General Privacy Concerns, General Institutional Trust, and Affect in the Privacy Calculus’ (2015) 25 Information Systems Journal 607

Kerr A and Cunningham-Burley S, ‘On Ambivalence and Risk: Reflexive Modernity and the New Human Genetics’ (2000) 34 Sociology 283

Kitzinger J, ‘The Methodology of Focus Groups: The Importance of Interaction between Research Participants’ (1994) 16 Sociology of Health & Illness 103

——, ‘Introducing Focus Groups’ (1995) 311 BMJ 299

Kuran T and Sunstein CR, ‘Availability Cascades and Risk Regulation’ (1999) 51 Stanford Law Review 683

Laney D, ‘3D Data Management: Controlling Data Volume, Velocity and Variety.’ (2001) 6 META Group Research Note 70

Latour B, ‘From the World of Science to the World of Research?’ (1998) 280 Science 208

Laurie G, ‘Reflexive Governance in Biobanking: On the Value of Policy Led Approaches and the Need to Recognise the Limits of Law’ (2011) 130 Human Genetics 347

——, ‘Managing Access to Biobanks: How Can We Reconcile Individual Privacy and

Public Interests in Genetic Research?' (2010) 10 Medical Law International 315

Laurie G, Harmon S and Arzuaga F, 'Foresighting Futures: Law, New Technologies, and the Challenges of Regulating for Uncertainty' (2012) 4 Law, Innovation and Technology 1

Laurie G and Stevens L, 'Developing a Public Interest Mandate for the Governance and Use of Administrative Data in the United Kingdom' (2016) 43 Journal of Law and Society 360

Leith P, 'The Socio-Legal Context of Privacy' (2006) 2 International Journal of Law in Context 105

Lenoble J and Maesschalck M, 'Renewing the Theory of Public Interest: The Quest for a Reflexive and Learning-Based Approach to Governance' in Olivier de Schutter and Jacques Lenoble (eds), *Reflexive Governance : Redefining the Public Interest in a Pluralistic World* (Hart Publishing 2010)

Liamputtong P, *Focus Group Methodology : Principles and Practices* (SAGE 2011)

Lindsay D, 'An Exploration of the Conceptual Basis of Privacy and the Implications for the Future of Australian Privacy Law' (2005) 29 Melbourne University Law Review 131

Lynskey O, *The Foundations of EU Data Protection Law* (Oxford University Press 2015)

Manson NC and O'Neill O, *Rethinking Informed Consent in Bioethics* (Cambridge

University Press 2007)

Marchant G, Allenby B and Herkert J, *The Growing Gap between Emerging Technologies and Legal-Ethical Oversight : The Pacing Problem* (Springer 2011)

Marchant GE, 'The Growing Gap Between Emerging Technologies and Legal-Ethical Oversight', *The International Library of Ethics Law and Technology*, vol 7 (1st edn, Springer Netherlands 2011)

Matzner T and Ochs C, 'Sorting Things out Ethically - Privacy as a Research Issue beyond the Individual' in Michael Zimmer and Katharina Kinder-Kurlanda (eds), *Internet Research Ethics for the Social Age* (Peter Lang 2017)

McGuire A and others, 'Perspectives on Human Microbiome Research Ethics' (2012) 7 Journal of Empirical Research on Human Research Ethics 1

McLean S, 'Commentary: No Consent Means Not Treating the Patient with Respect' (1997) 314 BMJ 1076

Mill J and Gray J, *On Liberty and Other Essays* (Oxford University Press 1998)

Miller T and Boulton M, 'Changing Constructions of Informed Consent: Qualitative Research and Complex Social Worlds' (2007) 65 Social Science and Medicine 2199

Mittelstadt B and Floridi L, 'The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts' (2016) 22 Science and Engineering Ethics 303

Moore AD, 'Privacy: Its Meaning and Value' (2003) 40 American Philosophical

Quarterly 215

Moore BJ, *Privacy. Studies in Social and Cultural History* (ME Sharpe 1984)

Nissenbaum H, ‘How Computer Systems Embody Values’ (2001) 34 Computer 119

——, ‘Privacy as Contextual Integrity’ (2004) 79 Washington Law Review 119

——, *Privacy In Context: Technology Policy And The Integrity Of Social Life* (Stanford Law Books 2009)

Nowotny H, Scott P and Gibbons M, *Re-Thinking Science : Knowledge and the Public in an Age of Uncertainty* (Polity 2001)

Nuffield Council on Bioethics, ‘Emerging Biotechnologies: Technology, Choice and the Public Good’ (2012) <http://www.nuffieldbioethics.org/sites/default/files/Emerging_biotechnologies_A4_overview_PDF.pdf>

O’Hara K, ‘Transparent Government, Not Transparent Citizens: A Report on Privacy and Transparency for the Cabinet Office’ (2011) <http://www.cabinetoffice.gov.uk/resource-library/independent-transparency-and-privacy-review>

Ohm P, ‘Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization’ (2010) 57 UCLA Law Review 1701

Pollock K, ‘Procedure versus Process: Ethical Paradigms and the Conduct of

Qualitative Research' (2012) 13 BMC Medical Ethics 25

Powell R and Single H, 'Focus Groups' (1996) 8 International Journal for Quality in Health Care 499

Raab CD, 'Privacy, Social Values and the Public Interest' in Andreas Busch and Jeanette Hofmann (eds), *Politik und die Regulierung von Information* (Nomos 2012)

Rachels J, 'Why Privacy Is Important' (1975) 4 Philosophy & Public Affairs 323

Regan PM, *Legislating Privacy : Technology, Social Values, and Public Policy* (University of North Carolina Press 1995)

Robinson N and others, 'Review of the European Data Protection Directive' (*Rand Europe*, 2009) 1 <https://ico.org.uk/media/about-the-ico/documents/1042349/review-of-eu-dp-directive.pdf> accessed 12 October 2017

Robling MR, 'Public Attitudes towards the Use of Primary Care Patient Record Data in Medical Research without Consent: A Qualitative Study' (2004) 30 Journal of Medical Ethics 104

Rouvroy A, 'Réinventer l'art d'oublier et de Se Faire Oublier Dans La Société de l'information?', *La protection de l'individu numérisé* (L'Harmattan 2008)

Royal Society, 'Progress and Research in Cybersecurity. Supporting a Resilient and Trustworthy System for the UK.' (2016) 70 <https://royalsociety.org/~/media/policy/projects/cybersecurity-research/cybersecurity-research-report.pdf> accessed 7 November 2017

Royal Statistical Society, ‘Public Attitudes to the Use and Sharing of Their Data’ (*Research for the Royal Statistical Society by Ipsos MORI.*, 2014) <http://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers>

Saxena N and others, ‘Understanding Canadians’ Attitudes and Expectations Citizens’ Dialogue on Privacy and the Use of Personal Information for Health Research in Canada’ (2006) <http://cprn3.library.carleton.ca/documents/43383_en.pdf> accessed 28 November 2017

Schoeman F, ‘Privacy and Intimate Information’, *Philosophical Dimensions of Privacy: An Anthology* (1984)

Schur E, *Law and Society: A Sociological View* (Random House 1968)

Schwartz PM, ‘Privacy and Democracy in Cyberspace’ (1999) 52 Vanderbilt Law Review 1609

Selbst A, ‘Contextual Expectations of Privacy’ (2013) 35 Cardozo Law Review 643

Sheremeta L and Knoopers B, ‘Beyond the Rhetoric: Population Genetics and Benefit-Sharing’ (2003) 11 Health Law Journal 89

Slaughter S and others, ‘Consent and Assent to Participate in Research from People with Dementia’ (2007) 14 Nursing Ethics 27

Smithson J, ‘Focus Groups’ in Pertti Alasuutari, Leonard Bickman and Julia Brannen (eds), *The SAGE handbook of social research methods* (SAGE 2008)

Solon O, 'A Simple Guide to Care.Data' *Wired* (7 February 2014)

Solove D, *Understanding Privacy* (Harvard University Press 2008)

Solove DJ, 'Conceptualizing Privacy' (2002) 90 California Law Review 1087

Sorauf F, 'The Public Interest Reconsidered' (1957) 19 The Journal of Politics 616

Stark L, 'The Emotional Context of Information Privacy' (2016) 32 The Information Society 14

Stilgoe J, Owen R and Macnaghten P, 'Developing a Framework for Responsible Innovation' (2013) 42 Research Policy 1568

Strandburg K and others, 'Monitoring, Datafication, and Consent: Legal Approaches to Privacy in the Big Data Context' in J Lane and others (eds), *Privacy, Big Data, and the Public Good: Frameworks for Engagement* (Cambridge University Press 2014)

Sunstein CR, 'Probability Neglect: Emotions, Worst Cases, and Law' (2002) 112 Yale Law Journal 61

Taipale K, 'Technology, Security and Privacy: The Fear of Frankenstein, the Mythology of Privacy and the Lessons of King Ludd' (2004) 7 Yale Journal of Law & Technology 125

Tamanaha B, *A General Jurisprudence of Law and Society* (Oxford University Press 2001)

Tavani H, 'Philosophical Theories of Privacy: Implications for an Adequate Online

Privacy Policy' (2007) 38 Metaphilosophy 1

Tavani H, 'Informational Privacy: Concepts, Theories, and Controversies' in K Himma and HT Tavani (eds), *The Handbook of Information and Computer Ethics* (Wiley 2009)

Taylor M, *Genetic Data and the Law* (Cambridge University Press 2012)

Taylor MJ, 'Health Research, Data Protection, and the Public Interest in Notification' (2011) 19 Medical Law Review 267

Tene O and Polonetsky J, 'A Theory of Creepy: Technology, Privacy and Shifting Social Norms' (2014) 16 Yale Journal of Law & Technology 59

The Gallup Organization, 'Data Protection in the European Union: Citizens' Perceptions Analytical Report' (*Flash Eurobarometer Series*, 2008) <http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_225_en.pdf> accessed 10 October 2017

The Law Commission, 'Data Sharing Between Public Bodies: A Scoping Report' (2014)

The Royal Society and The British Academy, 'Data Management and Use: Governance in the 21st Century' (2017) <https://royalsociety.org/~/media/policy/projects/data-governance/data-management-governance.pdf> accessed 6 October 2017

TNS Opinion & Social, 'SPECIAL EUROBAROMETER 359 Attitudes on Data Protection and Electronic Identity in the European Union' 330

Townend D, ‘Overriding Data Subjects’ Rights in the Public Interest’ in David Townend and others (eds), *The Data Protection Directive and medical research across Europe* (Ashgate 2004)

Trinidad SB and others, ‘Informed Consent in Genome-Scale Research: What Do Prospective Participants Think?’ (2012) 3 AJOB Primary Research 3

Vago S, *Law and Society* (10th edn, Routledge 2015)

Vezyridis P and Timmons S, ‘Understanding the Care.Data Conundrum: New Information Flows for Economic Growth’ (2017) 4 Big Data & Society 1

Warren S and Brandeis L, ‘The Right to Privacy’ (1890) 4 Harvard Law Review 193

Watson A, ‘Legal Change: Sources of Law and Legal Culture’ (1983) 131 University of Pennsylvania Law Review 1121

——, *The Evolution of Law* (Johns Hopkins University Press 1985)

Welsh I and Wynne B, ‘Science, Scientism and Imaginaries of Publics in the UK: Passive Objects, Incipient Threats’ (2013) 22 Science as Culture 540

Westin A, *Privacy and Freedom* (Bodley Head 1970)

Whitman J, ‘The Two Western Cultures of Privacy: Dignity versus Liberty’ (2004) 113 Yale Law Journal 1151

Wilkinson S, ‘Focus Group Methodology: A Review’ (1998) 1 International Journal of Social Research Methodology 181

Case C-101/01 *Bodil Lindqvist* ECR I-12992

Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR) 1950

Council Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data [1995] OJ L281/31

Council of Europe, Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data ETS No 108, 28 January 1981

UNESCO, Universal Declaration on Bioethics and Human Rights (adopted 19 October 2005