

# Chapter 3

Values and interests in  
data initiatives

## Chapter 3 – Moral values and interests in data initiatives

### Chapter overview

This chapter discusses the significance and nature of information privacy norms and the relationship between privacy and public interests.

The concept of privacy and the distinction between public and private have evolved throughout history. Privacy is important in the formation and maintenance of individual and group identities. Norms of confidentiality and information sharing characterise different relationships between people and groups. Medical confidentiality allows information sharing that might otherwise infringe privacy norms to take place for specific professional purposes.

Consent provides a mechanism to make controlled exceptions to an existing privacy norm for specific purposes. However, consent does not itself ensure that all of the interests of the person giving consent are protected nor does it set aside the moral duty of care owed to that person by others who are given access to the information. On its own, consent is not always necessary, nor always sufficient for ethical extensions of data access.

While individuals have privacy interests in the use of data, they also share group interests in the wider use of data for health research. The broader public interest may come into conflict with individual privacy but the relationship is usually complex. This complex relationship leads to a need to reconcile the articulation of the private within the public and the public within the private. A fundamental moral question facing data initiatives is therefore: 'How may we define a set of morally reasonable expectations about how data will be used in a data initiative, giving proper attention to the morally relevant interests at stake?'

### Introduction

- 3.1 In this chapter we consider the morally relevant values and interests engaged by the use of data in biomedical research and health care. Our aim will be to understand what is at stake when claims are made about whether it is right or wrong to allow or to make particular disclosures of information. While data initiatives involving computerised data analysis have developed mainly in the late 20<sup>th</sup> and early 21<sup>st</sup> Century, many of the core moral questions they raise have been debated in some form for at least two-and-a-half millennia. We shall nevertheless try to formulate as clearly as possible the questions that must be addressed when ethical concerns are raised about current and future data initiatives.

### The value of privacy

#### Proposition 9

Privacy is fundamentally important to individuals (and groups) in the establishment and maintenance of their identity, their relationships and their sense of personal well-being.

## The public and private spheres

- 3.2 Human beings, as the philosopher Aristotle observed, have the capacity to form political communities and do so almost everywhere they exist.<sup>146</sup> The benefits of cooperative action are obvious: people working together can achieve what one person alone might never achieve. Nevertheless, just as human beings are born into, and drawn into, communities that advance their individual and common aims, they simultaneously value and preserve a sphere of ‘private’ thought and action.
- 3.3 The concept of privacy has a long and evolving history in Western social and political philosophy. In the fourth century BCE, Aristotle described the distinction between the spheres of private life – the life of the household – and public life – the free life of citizens in the *polis*, the Greek city state.<sup>147</sup> The private household was rigidly organised in order to supply the necessary conditions of life efficiently. In contrast, the public or political sphere was characterised not by necessity and toil but by freedom and discourse.<sup>148</sup>
- 3.4 The public/private distinction, as it would have been understood by the ancient Greeks, is transformed in modernity when labouring activities formerly constrained to the private realm of the household are transferred to the public sphere and organised through economic cooperation within societies. In the modern age, private life became increasingly important for the flourishing of individuality, for personal development and the cultivation of intimate relationships, both inside and outside the home.<sup>149</sup>
- 3.5 The vigorous defence of a sphere of free individual action to which society had no claim was a central preoccupation of modern liberal philosophers such as John Stuart Mill. “The only part of the conduct of any one, for which he is amenable to society,” wrote Mill in *On Liberty*, “is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.”<sup>150</sup> This conception of a protected sphere was important, however, not only as a defence from society, but as a source of free moral action. According to Isaiah Berlin’s famous distinction, freedom can be thought as having negative (‘freedom from’) and positive (‘freedom to’) aspects.<sup>151</sup> The first is the protection of a sphere of action from interference by others; the second concerns

<sup>146</sup> Aristotle, *Politics*, book I, available at: <http://classics.mit.edu/Aristotle/politics.html>.

<sup>147</sup> Ibid. In the ancient Greek *polis*, privacy is connected with the body, with manual labour necessary for the maintenance of life and with reproductive labour necessary for the continuation of the species.

<sup>148</sup> The freedom of the *polis* meant an equal freedom for citizens, although this has little in common with our contemporary understanding of equality: it presupposed the existence of (an inevitable majority of) ‘unequals’ – women, children, servants and slaves, whose labour was subordinated to the freedom of the male head of the household. A more recent critique in the feminist tradition argues that the defence of privacy can provide cover for the abuse and degradation of women and others. For a critical survey of some feminist writing on privacy, see Gavison R (1992) Feminism and the public/private dimension *Stanford Law Review* 45(1): 1-45.

<sup>149</sup> The political theorist Hannah Arendt argued that modern society inverts the norms of behaviour characteristic of the ancient Greek political realm, so that public behaviour becomes highly regulated, with the home life becoming a private refuge of ‘intimacy’. Arendt H (1958) *The human condition*, 2nd Edition (Chicago: University of Chicago Press). See also Habermas J (1991 [1962]) *The structural transformation of the public sphere: an inquiry into a category of bourgeois society* (Cambridge MA: MIT Press) for an extensive analysis of the concept of the public sphere.

<sup>150</sup> Mill JS (1859) *On liberty*, available at: <http://www.gutenberg.org/files/34901/34901-h/34901-h.htm>, at page 18. This thought is embodied in Mill’s ‘harm principle’.

<sup>151</sup> See: Berlin, I (1969 [1958]) Two concepts of liberty, in Berlin I (1969) *Four essays on liberty* (Oxford: Oxford University Press), available at: <http://spot.colorado.edu/~pasnau/seminar/berlin.pdf>.

the freedom expressed by being the ‘author’ of one’s actions, and an active agent in the formation of one’s social world.

### Informational privacy

#### Proposition 10

Control of certain information is generally viewed by individuals as an important aspect of maintaining their privacy; access to or disclosure of information contrary to their wishes can affect individuals’ well-being and infringe their rights.

#### Proposition 11

Not all personal information is private and some personal information is legitimately public. Privacy norms depend on the nature of the relationship between individuals or between individuals and institutions, including the state.

- 3.6 Some philosophers argue that having the opportunity to be free from observation by others is essential to the formation and maintenance of individual identity and ‘personhood’. A variety of arguments, all tending to this general conclusion, are offered in the literature. For example, privacy is claimed to be psychologically essential for personhood because the possibility of withdrawing from observation is necessary in order to assimilate and reflect on life experiences, and to identify one’s unique individuality.<sup>152</sup> Privacy is said to be practically necessary because observation by others inevitably transforms the conditions in which the person chooses and acts, and, by placing external constraints on their moral choices, denies respect for them as a moral agent.<sup>153</sup> Privacy is said to be necessary, furthermore, because it is through the ritual of respecting privacy that the social group recognises the entitlement of an individual to their own moral existence.<sup>154</sup> Finally, privacy is necessary for intimacy, which is nurtured by a process through which people progressively share hidden aspects of themselves.
- 3.7 Disclosure and withholding of information between people has an important function in establishing the structure of social relationships, as a means by which particular people are included or excluded. Family, group, community – even national – identities may be formed and confirmed by norms of information sharing. The fact that someone shares intimate information with one person and not with others, can function as a token of friendship, cement social bonds, promote trust, and encourage reciprocal sharing, all of which lay the foundation for future cooperation.<sup>155</sup> The sharing of information has been said to establish ‘moral capital’ that is a currency for interpersonal relationships.<sup>156</sup> Breaching such norms (reading someone’s private diary without their permission, for

<sup>152</sup> See, for example, Van Manen M and Levering B (1996), *Childhood’s secrets: intimacy, privacy, and the self reconsidered* (New York: Teachers College Press), available at: <https://archive.org/details/childhoodssecret00vanm>.

<sup>153</sup> Benn SI, Privacy, freedom, and respect for persons, in Schoeman FD (Editor) (1984) *Philosophical dimensions of privacy: an anthology* (Cambridge: Cambridge University Press), pp223-44.

<sup>154</sup> Reiman JH (1976) Privacy, intimacy, and personhood *Philosophy and Public Affairs* **6(1)**: 26-44.

<sup>155</sup> See: Fried C (1970) *An anatomy of values: problems of personal and social choice* (Cambridge MA: Harvard University Press).

<sup>156</sup> Fried C (1970) *An anatomy of values: problems of personal and social choice* (Cambridge MA: Cambridge University Press). See also Gavison R (1992) Feminism and the public/private dimension *Stanford Law Review* **45(1)**: 1-45.

example, or ‘hacking’ into their telephone messages) both has the practical consequence of undermining trust and exhibits a moral attitude of lack of respect for them as a person. On the other hand, enforcing non-disclosure norms (such as ‘keep it in the family’ in cases of domestic abuse) can be equally morally unacceptable. We therefore have to ask whether the norms themselves are morally appropriate, as well as who has the authority and the power to modify or transgress them.<sup>157</sup>

- 3.8 Different norms of disclosure and withholding of information will apply to different kinds of relationship. A disclosure (e.g. infection with a stigmatising disease) that might be expected in one context (e.g. between close family members or clinical professionals) might be surprising in another (e.g. among work colleagues). A person may participate simultaneously in many different relationships, governed by different norms, for example, distinct personal, social and professional networks. The norms governing these relationships, along with the membership of the networks themselves, may change over time.<sup>158</sup> In the contemporary world, control of access to and disclosure of information has become increasingly significant in measure with the role played by information exchanges in the conduct of life. The presence of information technology – giving the capacity to store, replicate and communicate data indefinitely – has acted as an exponent to this. People may consider public buildings (swimming baths, for example) public places where anyone might observe or overhear them but they might consider the presence of CCTV or a ‘webcam’ an ‘invasion of privacy’.<sup>159</sup> To answer the question whether such behaviours should be considered an ‘invasion’ of privacy, or whether disclosures of personal confidences are a ‘breach’ of privacy, we must define not only the nature of the expectations that have been frustrated, but what people are entitled to expect in these circumstances.

## Confidentiality and consent

### Proposition 12

Expectations of privacy relating to norms of access to and disclosure of information may be formalised and enforced, for example, through rules of confidentiality. These rules and expectations may be modified by individuals in specific cases, for example through explicit consent procedures.

<sup>157</sup> Ruth Gavison, for example, argues for the importance of a critique of the deployment of a public/private distinction rather than of the distinction itself. Gavison R (1992) Feminism and the public/private distinction *Stanford Law Review* **45(1)**: 1-45.

<sup>158</sup> Mark Taylor uses the term ‘norms of exclusivity’ to describe how the conditions of information access are deployed between different people in different social contexts: “Privacy is established by norms regulating access to individuals or groups of individuals: it represents a relevant state of separation defined and mediated by particular standards. In order to capture more fully the idea that relevant separation can only be assessed according to particular norms, I suggest that privacy concerns ‘norms of exclusivity’.” Taylor M (2012) *Genetic data and the law: a critical perspective on privacy protection* (Cambridge: Cambridge University Press), at page 25. See also Helen Nissenbaum, who posits ‘contextual integrity’ as a benchmark for privacy ‘to capture the nature of challenges posed by information technologies’: “Contexts, or spheres, offer a platform for a normative account of privacy in terms of contextual integrity. [...] contexts are partly constituted by norms, which determine and govern key aspects such as roles, expectations, behaviours, and limits. There are numerous possible sources of contextual norms, including history, culture, law, convention, etc. Among the norms present in most contexts are ones that govern information, and, most relevant to our discussion, information about the people involved in the contexts. I posit two types of informational norms: norms of appropriateness, and norms of flow or distribution. Contextual integrity is maintained when both types of norms are upheld, and it is violated when either of the norms is violated.” Nissenbaum H (2004) Privacy as contextual integrity *Washington Law Review* **79(1)**: 119-58, at page 119.

<sup>159</sup> See, for example, the House of Commons Home Affairs Committee (2008) HC 58-I *A surveillance society?* (fifth report of session 2007–08), available at <http://www.publications.parliament.uk/pa/cm200708/cmselect/cmhaff/58/58i.pdf>. See paragraph 4.6.

- 3.9 An important class of privacy norms is embodied in the principles and practice of confidentiality. Whereas privacy may be about access to a number of different things (such as access to one's body, one's home or one's possessions) confidentiality is exclusively about information. However, confidentiality is not simply synonymous with informational privacy.

### Box 3.1: 'Privacy' and 'confidentiality'

The terms 'privacy' and 'confidentiality' are sometimes used imprecisely. They are often used in conjunction (as in 'privacy and confidentiality issues') which may contribute to an elision of the distinct concepts, and in casual discussion they are occasionally used interchangeably. It is therefore worthwhile clarifying how we understand their distinct meanings.

- **Privacy** concerns the interest people have in others' access to themselves, their homes and property, or to information about them. What counts as 'private' can change depending on social norms, the specific context, and the relationship between the person concerned and those who might enjoy access. Informational privacy is maintained by selectively withholding or allowing access or through establishing limits on acceptable behaviour by others (e.g. proscribing voyeurism).
- **Confidentiality** concerns the assurance that information provided by a person (or by another body) will not be further disclosed without their permission (except in accordance with certain established laws, norms or expectations about when confidentiality obligations may be set aside). Duties of confidence are created by well-established expectations that attach to certain relationships (for example, between a doctor and a patient or between a lawyer and a client) or may be agreed between parties in a specific context (for example, parties to a commercial contract or contract of employment). They allow information to be made available for the purposes of that relationship (and perhaps also to others whose involvement is necessary to achieve those purposes), but for no other purpose. In short, confidentiality is one – but only one – of the tools used to achieve and maintain privacy.

- 3.10 Moral duties of confidence exist among individuals (friends sharing a secret, for example) but some duties of confidence are made enforceable through contractual and legal instruments or through the reasonable expectations that patients, for example, have of their doctors. Medical confidentiality exists because information that doctors might need in order to diagnose or treat a patient might be information that is non-obvious and of a type that the patient might not otherwise (other than for the purpose of obtaining diagnosis and treatment) want to disclose (including to the doctor concerned) or publish more widely. Similar considerations apply in the case of research. Medical confidentiality protects patients from harm in two ways: it both encourages them to disclose information essential to their treatment, so that they do not suffer the harm of untreated disease, and it provides assurance against any harm that may occur to them from a more general disclosure of the information. Over time, respecting confidence helps to foster trust.

- 3.11 Privacy norms may be modified informally by individuals simply through their behaviour (in the way that they may impart private information to others), particularly

where they trust the individual to understand and observe the appropriate norms and not to disclose the imparted information any further. Privacy norms may also be modified through formal mechanisms, such as giving consent, particularly where a formal structure exists to provide assurance that those norms will be complied with, such as obtains in the case of medical treatment or legal advice.

### Box 3.2: Consent

Consent sets aside norms and standards, such as the expectation of confidentiality, in specific ways for specific purposes.<sup>160</sup> Consent does not abolish the underlying norm but modifies its application by creating a specific exception. (We discuss the operation and limitations of consent procedures further in chapter 4.)

Valid consent is consent that is freely (autonomously) given: for it to count as valid it cannot be obtained by coercion or deception. Furthermore, the person consenting should be aware of the morally relevant implications of giving consent. This does not mean that the consenting person needs to be aware of every last detail and consequence of the use of the data (so-called 'broad' consent may count as valid consent) but they should be aware of those details about the proposed use and the reasonably foreseeable implications that are morally significant to them. There is clearly room for considerable debate about how much information and understanding is necessary for consent to be valid, when different forms of argument and encouragement may undermine freedom and when the limits of previously given consent (perhaps one given in very different circumstances) are reached.

- 3.12 It should be noted that, while observing the terms of consent respects the interests of the person giving it in a limited way, the fact that information is only disclosed in accordance with the terms of the consent does not in itself protect the person from any harm resulting from the use of the information. Thus, consent should not be thought of as shifting the liability for any privacy infringements from the user of data to the 'consenting' person, and simply obtaining consent does not exhaust the moral 'duty of care' owed by the user of the data. This is consistent with the structure of consent, which implies permission to use the data but no obligation to do so, particularly where doing so would infringe the subject's interests. The fact that someone's consent must be sought is not, however, necessarily or straightforwardly empowering for the person giving it, particularly where the options available to them are highly constrained.<sup>161</sup> Consent is often, in fact, a rather blunt tool, allowing only a binary 'yes' or 'no' response. Genuine respect for the autonomy of individuals as 'world forming' is likely to be better realised through a richer involvement in the formation of norms and options than simply accepting or refusing options presented by others.
- 3.13 Consent is neither always necessary (since not all norms would otherwise prohibit data access and disclosure) nor sufficient (since it does not set aside the moral duty of the user of data with respect to others) for ethical use of data. However, where there is a

<sup>160</sup> The normative function of consent in creating a conditional waiver of pre-existing rights is discussed in Manson N and O'Neill O (2007) *Rethinking Informed Consent* (Cambridge: Cambridge University Press).

<sup>161</sup> This is the case, for example, where use of social networking software requires that the user accept the terms of an agreement that allows the provider to extract their use data and mine it for their own purposes or release it for others to use.

reasonable expectation that disclosure of information may infringe a well-grounded entitlement to privacy, consent may play an important role in enabling that disclosure.

## Community and solidarity

- 3.14 Conventional forms of Western morality treat the person – usually a living human individual – as the fundamental unit of moral agency and value. Nevertheless, the assumption that privacy relates only – or primarily – to personal forms of identity is not universal, or not necessarily applicable to all forms of information. There may be different indices for privacy norms, some relating, for example, to the family group, tribe or community, even when the information in question pertains most obviously to a single individual among them. These norms may differ significantly between distinct cultures or contexts.<sup>162</sup>
- 3.15 In some recent bioethical writing on data access, a concept of solidarity has been promoted as a reaction to what many bioethicists see as the over-privileging of individual autonomy at the expense of wider public interest. The concept of solidarity describes social cohesion as a result of the homogeneity or interdependence of individuals making up a community.<sup>163</sup> The concept has been applied particularly in relation to genetic and genomic information (our ‘shared genetic heritage’), but also in relation to biobanks and biomedical research more generally.<sup>164</sup> This concept of solidarity may be embodied and formalised in institutions.<sup>165</sup>
- 3.16 The arguments for solidarity as a moral basis for extending data access in relevant cases have, generally, been cautious rather than revolutionary. In the literature, solidarity tends to be proposed as a default social norm from which individuals retain the entitlement to withdraw, rather than as a moral obligation from which they may be released only exceptionally. While they change the emphasis, in ways that may bear on decisions about appropriate forms of governance (we discuss concrete examples in chapters 6 and 7), the arguments for solidarity rarely seek to overturn the primacy of individual autonomy. Implicitly, the shift in disposition comes about as the result of increased opportunities available to derive public benefit from personal data where the privacy risks to individuals are well managed, as well as the increasing practical difficulties of maintaining individual level controls in complex data flows.<sup>166</sup> In practice it amounts to little more than a justification for ‘broad’ models of consent: for example, the replacement of specific individual consent for research uses of data (to the extent

<sup>162</sup> For a specific case, see guidance on ethics in relation to the Canadian First Nations, Inuit and Metis communities: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>.

<sup>163</sup> See the distinction between ‘mechanical’ and ‘organic’ solidarity in Durkheim É (1984 [1893]) *The division of labour in society* (Basingstoke: Macmillan), book I, chapter II and III. The concept is also important in ethics and political philosophy: for a discussion of the recent emergence of the concept in bioethics see Prainsack B and Buyx A (2011) *Solidarity: reflections on an emerging concept in bioethics*, available at: <http://nuffieldbioethics.org/project/solidarity/>.

<sup>164</sup> See the concept of ‘genetic solidarity’ in: Human Genetics Commission (2002) *Inside information: balancing interests in the use of personal genetic data* (London: HMSO), available at [http://webarchive.nationalarchives.gov.uk/20061023110946/http://www.hgc.gov.uk/UploadDocs/DocPub/Document/insideinformation\\_summary.pdf](http://webarchive.nationalarchives.gov.uk/20061023110946/http://www.hgc.gov.uk/UploadDocs/DocPub/Document/insideinformation_summary.pdf). In relation to biobanks, see, for example, Stjernschantz Forsberg J, Hansson MG and Eriksson S (2009) Changing perspectives in biobank research: from individual rights to concerns about public health regarding the return of results *European Journal of Human Genetics* **17**(12): 1544-9; Buyx A and Prainsack B (2013) A solidarity-based approach to the governance of research biobanks *Medical Law Review* **21**(1): 71-91.

<sup>165</sup> See the ‘third tier’ solidarity in Prainsack B and Buyx A (2011) *Solidarity: reflections on an emerging concept in bioethics*, available at: <http://nuffieldbioethics.org/project/solidarity/>.

<sup>166</sup> See Stjernschantz Forsberg J, Hansson MG and Eriksson S (2009) Changing perspectives in biobank research: from individual rights to concerns about public health regarding the return of results *European Journal of Human Genetics* **17**(12): 1544-9.



that they should be re-contacted to consent to novel uses) with general ‘participation agreements’.<sup>167</sup>

- 3.17 It is relevant to observe, moreover, that just as the (re)emergence of the concept of solidarity can be seen as a reaction to the constraints of autonomy and individualism, the assertion of autonomy in bioethics was itself partly a reaction to extreme derogation of human rights that took place in Europe in the middle of the 20<sup>th</sup> Century and continued in totalitarian regimes during the latter part of that century.<sup>168</sup> Partly, also, it was an expression of growing resistance to institutionalised paternalism in fields such as medicine.<sup>169</sup> Although these political conditions may have been largely extinguished in Europe, it is easy to conceive that the pendulum may swing back towards autonomy as a consequence of large-scale privacy intrusions by states, for example, though the activities of state organisations such as the US National Security Agency (see chapter 2).

## Public interest

- 3.18 The ‘public interest’ is not the opposite of private interests although it is sometimes contrasted with them. The ‘public interest’ can be thought of as securing objectives that are valued by society.<sup>170</sup> There are two questions that we must address when we consider the relationship between the public and private interests. The first question is about the *content* of the public interest (i.e. its objects) and how this relates to the aims and interests of individuals. This leads us to questions about legitimate procedures for making collective decisions. The second question is about the *force* that should be given to the public interest, most importantly where it is in tension with private interests. This takes us to juridical questions about when it is legitimate to limit or even override private interests in the name of the public interest. Clearly, these questions are interconnected: the nature of the objects of the public interest and the value assigned to them will relate to the force that public interest claims have.

### The objects of the public interest

- 3.19 Identifying the proper objects of the public interest is not straightforward and political philosophers have argued about the merits of different approaches. A general distinction can be drawn between those that rely on abstract reasoning from premises (such as propositions about the moral nature of human beings) and those that employ empirical methods to discover actual preferences (such as, voting or deliberative decision making).

<sup>167</sup> Prainsack B and Buyx A (2013) A solidarity-based approach to the governance of research biobanks *Medical Law Review* **21(1)**: 71-91.

<sup>168</sup> Chadwick R and Berg K (2001) Solidarity and equity: new ethical frameworks for genetic databases *Nature Reviews Genetics* **2(4)**: 318-21.

<sup>169</sup> See Katz J (1984) *The silent world of doctor and patient* (New York: Free Press).

<sup>170</sup> We use the terms ‘community’ and ‘society’ to indicate, respectively, associations in which there is a unity of values and a common will among the members, and associations in which their shared project represents a compromise for the sake of self interest. The distinction was made by sociologist Ferdinand Tönnies (using the terms *Gemeinschaft* and *Gesellschaft*, respectively, to denote these forms of association). Tönnies F (2001 [1887]) *Community and civil society* (Cambridge: Cambridge University Press), book I. A community founded on kinship ties is the example of the first, whereas a trading group is an example of the second. All social groups are, in reality, a mixture of the two so the terms are used to emphasise the nature of a given association rather than to describe it. Feintuck uses definition of public interest within the field of regulation: “[...] the concept of public interest as a justification for regulatory intervention into private activity, limiting the exercise of private power, in pursuit of objectives valued by the community.” Feintuck M (2004) ‘*The public interest*’ in *regulation* (Oxford: Oxford University Press), at page 6.

- 3.20 The ‘common good’ theories of medieval Christianity take up Aristotle’s understanding of the relation between particular goods and the good of all as being the good of human beings in view of their nature. In supposedly pious societies the object of the common good was implicitly common to all (or ought to be so, once people were enabled to understand the vanity of their temporal concerns and carnal appetites).<sup>171</sup> The identification of the public good as the set of goods that all people share is appealing, but it offers a much poorer prospect of guiding policy or action in diverse societies where there may be disagreements over priorities and where individuals have strongly developed and diverse private interests. In these circumstances the objectives common to all are likely to be rather abstract: things like ‘security’, ‘health’ and ‘prosperity’.
- 3.21 As the exclusive pursuit of conflicting private interests is likely to be destructive (or, at least, sub-optimal), a way of limiting conflict and securing cooperation and the provision of public goods is desirable.<sup>172</sup> One way of doing this is to envisage the terms of an implicit contract that specifies what limitations to the free pursuit of their interests people ought to accept and, in return, what the legitimate role of the state will be in securing public goods. The idea of a ‘social contract’ of this kind was formulated by thinkers of the European Enlightenment (Locke, Hume, Rousseau) and had an influence on the founding fathers of the United States of America (Jefferson, Madison).<sup>173</sup>
- 3.22 An alternative approach that attempts to draw out the public interest by aggregating individual private preferences is offered by utilitarianism, as formulated in the 18<sup>th</sup> Century by, for example, Jeremy Bentham.<sup>174</sup> Utilitarianism assumes that if members of the community ‘vote’ to maximise their own happiness or ‘utility’ the aggregation of their interests will indicate the outcome that will maximise absolute utility. This both recognises and accepts that people may have different ideas about their preferred outcome but aims to find a resolution that they should all accept if they agree in advance that the voting procedure is a fair way of resolving them.
- 3.23 Any approach to determining where the public interest lies will have advantages and disadvantages. Any approach that derives rules of action from abstract principles must make assumptions about what it is people *should* value, notwithstanding what their actual subjective preferences may be. It will then have to account for how this can be consistent with respect for individuals as free moral agents. Aggregative approaches have the virtues of clarity and simplicity but, pursued mechanically, they can lead to perverse outcomes (for example, in a three voter system where two voters vote to kill the third and appropriate her property). There are many historical examples of

<sup>171</sup> Aquinas T, *Summa contra gentiles*, III.17.6, available at: <http://dhsprpriory.org/thomas/ContraGentiles.htm>.

<sup>172</sup> The concept of “public goods” is used loosely here to mean goods that are provided for public benefit: in economics, public goods are those that are non-rivalrous (my use of it does not deprive you of the opportunity to use it) or non-excludable (it cannot be made available to me without also making it available to you), or both. For those reasons public goods are typically provided by the state rather than by the market, since it is difficult to make commercial profit and public goods are vulnerable to ‘free riding’ (people consuming the goods without paying for them). Examples include policing and street lighting, and public health initiatives.

<sup>173</sup> The idea of the social contract predates the Enlightenment as it is usually described (i.e. beginning in the late 17<sup>th</sup> Century and lasting until the rise of romanticism in the late 18<sup>th</sup>). An important precursor was Thomas Hobbes’s *Leviathan* (1651) written during the English Civil War. The social contract tradition endures in the US notably in the work of John Rawls. See Rawls J (1999) *A theory of justice* (Cambridge, MA: Belknap Press of Harvard University Press).

<sup>174</sup> See Bentham J (1789) *An introduction to the principles of morals and legislation*, available at: <http://www.earlymoderntexts.com/pdfs/bentham1780.pdf>. Classical utilitarianism identifies the public interest with the preponderance of interests within a political community, which is arrived at simply by aggregating the interests of individual members. The chief appeal of an approach of this kind is its procedural fairness: “everybody to count for one, nobody for more than one.” This dictum was attributed to Bentham by John Stuart Mill in *Utilitarianism* (1861), available at: <http://www.earlymoderntexts.com/pdfs/mill1863.pdf>, at page 44.

individual interests being disregarded in the name of the common good. For this reason, where utility calculations are used as the basis of public decision making (e.g. in the form of cost-benefit analysis), the outcomes are usually qualified by some distributive principle (to ensure fairness) or other limiting factor (such as rights to non-interference) in order to prevent the interests of some being sacrificed for the good of others.

- 3.24 The best approach may well lie in some combination of both principle (to foreclose intuitively unacceptable outcomes) and practical reasoning (to allow expression to a plurality of legitimate interests). The approaches discussed above are not the only ones available and we will return to this discussion when we tackle the question of finding ethically appropriate forms of governance for specific data initiatives in chapter 5.

### The force of the public interest

- 3.25 In relation to the data initiatives with which we are concerned, the public interest will be an important legal and regulatory concept. This is particularly so where these initiatives are public initiatives, carried out with the involvement of the public sector or with public funding, or are otherwise aimed at delivering public goods. The claim that the object of any data initiative is an important public good may offer a justification for modifying the usual privacy norms (as, for example, some contagious disease reporting has been made mandatory to avert epidemics). However, it is not only the state that can appeal to public interest as a justification for normative action. Private actors may appeal to public interest as a justification for interfering with others' privacy, as when newspapers publish 'private' information about public figures. Individuals may claim a breach of confidentiality norms is justified by the public interest, for example when 'whistleblowers' make public interest disclosures.
- 3.26 Whereas public interest plays an important regulatory function in keeping private interests in check, or may justify overriding them in certain circumstances, there is a concern that it might be used to justify unacceptable levels of paternalism or state intrusion into private affairs. A significant bulwark against the intrusion of the state into the lives of its citizens, and of individuals into each others', is provided by human rights instruments.<sup>175</sup> (We will discuss human rights law in the next chapter.) Human rights law guarantees the protection of private life against interference except where this is necessary for an overriding public interest. A key concept in determining when a particular interference is justifiable, developed in the jurisprudence, is that of 'proportionality'. In other words, the interference, which must be necessary in order to achieve a legitimate aim, must be proportionate (sufficient but not excessive) to the achievement of that aim. Furthermore, it must be knowable, in a way that informs individuals' expectations and allows them to modify their actions accordingly. Thus, uses of data that might, at face value, interfere with privacy interests can be justified so long as these conditions are met. However, for the time being we are not concerned with situations in which rights come into conflict, but with interests and preferences, and the production of moral norms.

<sup>175</sup> "The European Court of Human Rights (ECtHR) makes important contributions to how the UK should conceptualise the notion of privacy and concomitantly protect against prospective violations of individuals' Article 8 rights, outwith the more narrow confines of the Data Protection Act 1998." Laurie G, Jones K, Stevens L, and Dobbs C (2014) *A review of evidence relating to harm resulting from uses of health and biomedical data*, at page 11 available at: [www.nuffieldbioethics.org/project/biological-health-data/evidence-gathering/](http://www.nuffieldbioethics.org/project/biological-health-data/evidence-gathering/).

## The mutual implication of public and private interests

- 3.27 Individuals are embedded in communities in complex ways: each has a private interest in protecting their privacy but also in contributing to the public good because, as a member of the public, they and those they care about benefit from the good that they bring about through cooperation with others in society. Likewise each knows that there is a public interest in respecting their privacy because the good of the community depends on their willingness to enter into voluntary cooperation with others under conditions in which they must share private information with confidence.
- 3.28 Consequently, our problem is not finding a 'balance' between privacy and public interest for a data initiative, but resolving a double articulation, between the private interest in protecting privacy and promoting the public good, and the public interest in protecting privacy and promoting the public good.<sup>176</sup> We all have interests on both sides, private and public, as individuals, members of families, groups, communities and nations. Navigating among these different relationships with other individuals, professionals and institutions requires a subtle negotiation of many different norms of information access and disclosure, of when and how they may be modified and where hard and fast limits should be drawn.

### Proposition 13

A fundamental question to be addressed in relation to the ethical design and conduct of data initiatives is:

**How may we define a set of morally reasonable expectations about how data will be used in a data initiative, giving proper attention to the morally relevant interests at stake?**

- 3.29 The question proposed above (proposition 13) is the one that we will be mainly concerned with answering, along with examining how data initiatives have addressed it, explicitly or implicitly. Formulating the question in this way recognises that people's interests may be mutually limiting or mutually reinforcing. What it is morally 'reasonable' to expect depends upon an assessment of the moral claims of those interests. When we consider whose interests are relevant it is important to remember that these include the expectations not only of those to whom data relate, but of those making use of the data, and those who have an interest in the aims or outcomes of a data initiative. It is also important to acknowledge that those whose privacy interests are engaged may also have interests in securing the individual and public benefits of data use. Three sorts of consideration will be relevant in formulating an answer to this question:
- the identification of the norms of privacy and disclosure that are applicable in relation to a specific data initiative. (Some, but not all of these, may be encoded in laws and professional rules of conduct.)
  - how respect is shown to persons, especially where their individual preferences do not coincide with these norms. (This may often be for good reason, e.g. because their

<sup>176</sup> In *X v. Y* [1988] 2 All E.R. 648, for example, the law was understood as requiring a balance of two public interests (in maintaining confidentiality and in disclosing information of public interest).

contextual vulnerabilities, or even arbitrary preferences, may deserve to be respected.)

- the form of governance (for example, the regulation of professional conduct) that will give acceptable assurance that the expectations will be met.

## Conclusion

3.30 In this chapter, we have examined the kinds of interests that are at stake in data initiatives and why these are morally relevant, and arrived at the formulation of a key moral question that faces data initiatives. Different approaches to resolving complex sets of interests may have advantages and disadvantages but it is likely that an appropriate approach will involve a mixture of ethical principles and empirical methods. This will be the subject of chapter 5. First, however, we will consider the problems with which conventional governance approaches are faced as a result of the developments in data science, information technology and data policy that we discussed in the previous two chapters.