

## Research



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# The dynamics of big data and human rights: the case of scientific research

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In this paper, we address the complex relationship between big data and human rights. Because this is a vast terrain, we restrict our focus in two main ways. First, we concentrate on big data applications in scientific research, mostly health-related research. And, second, we concentrate on two human rights: the familiar right to privacy and the less well-known right to science. Our contention is that human rights interact in potentially complex ways with big data, not only constraining it, but also enabling it in various ways; and that such rights are dynamic in character, rather than fixed once and for all, changing in their implications over time in line with changes in the context we inhabit, and also as they interact among themselves in jointly responding to the opportunities and risks thrown up by a changing world. Understanding this dynamic interaction of human rights is crucial for formulating an ethic tailored to the realities—the new capabilities and risks—of the rapidly evolving digital environment.

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Today it is increasingly assumed that the past and present of all of us—virtually every aspect of our lives—must be an open book; and that all such information about us can be not only put in files but merchandised freely. Business empires are being built on this merchandising of information about people's

private lives. The expectation that one has a right to be let alone—the whole idea that privacy is a right worth cherishing—seems to be evaporating among large segments of our population.

—Vance Packard, *The naked society*, 1964 [1]

## 1. Ubiquitous data, ubiquitous ethics

Digitization is rapidly transforming our lives, our social relations and even our understanding of our own humanity. The Internet, mobile devices, massive data collections and the analytics applied to them are propelling a digital revolution. Information technology is ubiquitous, and our engagement with it has risen to such a level of intensity that we now inhabit what has been termed the *infosphere* [2]. The World Economic Forum suggested that we are undergoing the fourth *industrial revolution*, its effects apparent in all aspects of our lives, and not only in the way knowledge is generated. Such is the ‘velocity, scope and systems impact’ of digitization and global connectivity that the current phase of our history is sharply distinct from previous ones [3]. The seductive power of this revolution has generated hopes and expectations about its potential benefits for all facets of our lives: from personal well-being and health, to sustainable development, the global economy, the environment and even governance.

There are many inter-related dimensions to this revolution, but at the heart of it lie the increased capabilities to amass and store data and the analytical models applied to them for yielding knowledge. This, in short, is the big data phenomenon. Although it is notoriously hard to define big data with any tolerable degree of precision, it is certainly a powerful and seemingly inescapable phenomenon [4]. One manifestation of its dominance is the speed with which digital technologies are adopted. For example, it took only 10 years for smart phones to penetrate 40% of US households compared with landline phones that needed 30 years to reach a mere 10% of US households [5]. Yet the apparently inexorable rise of big data has prompted a broad gamut of mixed and conflicting responses. At one end of the spectrum, we find unbridled enthusiasm about the proliferating opportunities to improve our lives; at the other end, there is increasing alarm at the pressures and distortions to which big data applications subject valued patterns of life. For every opportunity that big data presents, there seems to be a corresponding anxiety. That is not unusual in the history of technology, particularly in the history of transformative technologies such as computers. Already in the 1960s Vance Packard and others warned about the risks that computers along with other technologies pose to privacy [1,6]. There is, however, something rather unprecedented going on here. The ubiquity, the pace of development and the very fact that big data has already become an unavoidable part of human life set the scene for an intense and potentially destabilizing encounter between big data and ethical norms. For many, this is far beyond an encounter; rather it is a brutal head-on collision, for example, between big data applications and the norms protecting individual privacy [7].

The Snowden revelations about government surveillance confirmed growing fears about how certain uses of big data can undermine not just privacy, but ultimately trust, democracy and liberty [8]. The disturbing stream of reports about hacked databases, data kidnapping and other cybercrime stoked fears of a new vulnerability in the digital world. Can we harness the potential of big data while keeping faith with our values? Do such values need to be ‘translated’ for the new digital environment? If the way we live our lives is undergoing such transformations, are our existing ethical values still relevant? Many have claimed that privacy, for example, is obsolete in today’s world, partly because it is impossible to achieve and partly because it does not fit with modern culture [7]. Do we have to choose between big data and the ethical outlook that values such as privacy represent? Or should we turn to new values for guidance? Ultimately, the central question is this: if big data is here to stay, in some sense, what kind of big data society do we want to have and how can we best achieve it?

On the popular way of understanding the situation, we are often thrown into a moral battleground. Typically, the appeal to ethics is cast as a conservative gesture, one hostile to

scientific progress. However, it is profoundly misleading to think of ethics as simply a series of ‘constraints’ on the pursuit of scientific knowledge. For example, the pursuit of health research through big data, insofar as it is justified, is justified primarily in ethical terms. We see this when we adopt a sufficiently expansive understanding of ‘ethics’. ‘Ethics’, on this view, includes goods that we have reason, and sometimes even an obligation, to pursue, such as the good of knowledge that can be used to bring about significant improvements in health. On this understanding, health research is an ethical enterprise from the very outset, being geared towards public goods such as knowledge and health. Ethics is not simply a series of ‘roadblocks’ on the path to scientific knowledge, but part of the ultimate *raison d’être* of the journey itself. After all, it would be deeply uncharitable to regard scientists engaged with big data as merely pursuing their narrow self-interest, whether defined in terms of monetary enrichment, satisfaction of curiosity or career advancement. Instead, they are seeking public goods, goods that benefit all, such as scientific knowledge, which is both intrinsically valuable and also instrumentally valuable as a means of realizing goods such as health, education, enjoyment, friendship and so on, by virtue of its technical applications. It is in itself an *ethical* imperative to foster these goods. But there are, of course, ethical considerations bearing on *how* we may properly pursue these goods; in particular, constraints embodied in a variety of norms, including human rights.

In this paper, we seek to address the complex relationship between big data and human rights. As this is a vast terrain, we restrict our focus in two ways. First, we concentrate on big data applications in scientific research, mostly health-related research. And, second, we concentrate on two human rights: the familiar right to privacy and the less well-known right to science. Our contention is that human rights *interact* in potentially complex ways with big data applications, not only constraining them, but also enabling them in various ways; moreover, that they are *dynamic* in character, rather than fixed once and for all, changing in their implications over time in line with changes in the context we inhabit, including the dangers and opportunities that confront us, and the knowledge and technological capacities at our disposal for meeting them. To this interactive dynamic between big data and human rights, we must add another such relationship between human rights themselves. At this second level, we explore how big data developments stimulate interactions between the rights to science and privacy that themselves affect both the content of these rights and the ways in which they may be productively exercised.

## 2. Right to privacy, right to science

To get an initial fix on the rights to privacy and science, we can take as a starting point the formulations given to them in some leading international instruments. These formulations, either as treaty provisions or as declarations subsequently incorporated into customary international law, have the force of binding international law.

### *Universal Declaration of Human Rights (1948)*

Article 12:

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks [9].

### *International Covenant on Civil and Political Rights (1966)*

Article 17:

1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.
2. Everyone has the right to the protection of the law against such interference or attacks [10].

The human right to privacy is a familiar one, even if, as with many other human rights, there are controversies surrounding its normative content and how it may be ‘traded off’ against competing values, including potentially competing rights such as the right to security. Leaving

these debates to one side, we shall proceed on the basis that the human right to privacy exists, and that one of the central interests it protects is the ability of individuals to develop their personality and to exert reasonable control over how they present themselves to others [11,12]. Our focus is on ways in which big data developments bear on such privacy interests and the extent to which they necessitate modifications in the requirements of the right to privacy.

### *Universal Declaration of Human Rights (1948)*

Article 27:

- (1) Everyone has the right to participate freely in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
- (2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author [9].

### *International Covenant on Economic, Social and Cultural Rights (1966)*

Article 15: 1. The States Parties to the present Covenant recognize the right of everyone:

- (a) To take part in cultural life;
- (b) To enjoy the benefits of scientific progress and its applications;
- (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author [13].

Unlike the right to privacy, the ‘right to science’ is an unfamiliar but potentially far-reaching right, one that has received comparatively little sustained attention from human rights scholars [14]. Our focus here is on the first component of this right: both the idea that everyone has a right to benefit from scientific advances, and the idea that people have a right actively to *participate* in scientific inquiry, rather than just to be passive beneficiaries of advances made by professional scientists. The participatory aspect of the right to science is liable to be overlooked, but it emerges most clearly in the formulation provided by the Universal Declaration of Human Rights, especially if we treat ‘the cultural life of the community’ as comprising as elements both ‘the arts’ and also ‘science’, as the second half of Article 27(1) suggests that we should. The participatory dimension of the right to science has been recognized by a large number of interpreters and official bodies, and perhaps most strikingly and presciently in a UNESCO report of 1952 [36] in which it is stated:

The first question of all to be considered in relation to the present state of scientific knowledge, is: in what ways can the non-specialist take an active part in scientific advancement (experiments, observation of nature, sociological observations, etc.)? How may active participation of this sort benefit the individual and science? *How can it be encouraged and promoted?*

More recently, the notion of participation was highlighted in the report by the UN’s Special Rapporteur in the Field of Cultural Rights, Farida Shaheed [14]. In a 2012 report, exploring the normative content of the right to science, she argued that participating in science should be understood as participation ‘in the whole of science’, not merely its products, and went on to state explicitly that the right includes ‘opportunities for all to contribute to the scientific enterprise [...]’.

It is precisely the ‘participatory’ dimension of the right to science that constitutes its main ‘value added’ in relation to other, more familiar, economic, social and cultural rights. It explains why the right to benefit from scientific advance is not already subsumed within the right to an adequate standard of living, including food, housing, etc. (Article 25 of the Universal Declaration of Human Rights and Article 11 of the International Covenant on Economic, Social and Cultural Rights). The right to science underlines a particular kind of benefit to ordinary individuals that might otherwise be neglected: not simply passively to receive the benefit of the fruits of scientific investigation, but to play a part in securing them by engaging in such investigation, even if one is not a professional scientist.

Thus, although a right of popular participation is a familiar idea in the realm of democratic politics, the right to science extends it significantly further, with the result that participation infuses and potentially radically transforms our modes of scientific practice. Information and communication technologies have enabled increasing numbers of people to exercise their right to participation, sometimes as part of the phenomenon dubbed ‘citizen science’ [15]. More specifically, in the area of health research, devices that collect and transmit data about individuals are offering means that facilitate the exercise of the right.

Both the human rights to science and to privacy that are discussed in this paper are to be found in formal human rights instruments, and are binding norms of international law, as well as being embodied in diverse ways in the laws of regional and domestic jurisdictions. Behind these legal manifestations, however, lies human rights conceived first and foremost as moral rights possessed by all human beings, simply by virtue of their humanity. It is these background norms of human rights morality that control the proper interpretation of the rights to privacy and science in human rights law [16].

### 3. Understanding human rights

The language of human rights is popular across cultural boundaries and carries considerable rhetorical power. Drawing on this language can help mobilize the force of public opinion in bringing about change and, to the extent that human rights are enshrined as justiciable entitlements, whether in treaties, constitutions or ordinary laws, they can be secured through litigation in the courts. Ethical and policy debates around big data and health research and practice often draw on contested ideas about human rights [17]. But although popular in this way, both the meaning of human rights claims, and the way in which they are grounded, often remain stubbornly unclear. This lack of clarity encourages a trend to enlist the language of human rights for any cause thought to be worthwhile, with the consequent unruly proliferation of human rights claims and the debasement of the currency of human rights. Clarity about what human rights *are* and what role they can play remains crucial for preserving their normative power and enabling them to be effective policy guides. In the name of clarity, we offer the following four observations about human rights conceived, in the first instance, as moral rights possessed by all human beings simply by virtue of their humanity.

#### (a) Grounding

The first concerns the *grounding of human rights*; or, put differently, the considerations to which we need to appeal in order to justify belief in the existence of a human right. A widely endorsed candidate for the grounding value is human dignity [9]. But this notion is often appealed to as little more than a place holder, its content left hopelessly vague. In this vein, the European Data Protection Supervisor has asserted recently that human dignity should be the foundational element of a big data ethics framework, on the basis that human dignity is the foundation of human rights: ‘the dignity of the human person is not only a fundamental right in itself but also is a foundation for subsequent freedoms and rights, including the rights to privacy and to the protection of personal data’ [18]. But even in this concrete example, the Opinion shied away from explaining what human dignity is and how it grounds human rights.

In seeking greater clarity, it is useful to distinguish at least two things that might be meant by human dignity. The first is the inherent value that attaches to being a member of the human species [19,20] irrespective of whether one is in a position to actualize the characteristic capacities of human beings. On this view, a newly born baby, a normally functioning adult and someone in a permanent vegetative state, all possess the value of human dignity, and do so in equal measure. Although this is an important value, it is evidently too limited to generate anything approaching the extensive lists of human rights we find in leading human rights instruments. Hence, some have appealed to a second interpretation of ‘dignity’, understood now as the value

of being a 'normative agent': one who has the capacity freely to choose and pursue their life-defining projects [11]. On this view, crucial to the grounding of human rights is the value of personhood (the ability to make autonomous choices, liberty to pursue choices made). But once we have admitted this universal human interest, it seems artificial to draw the line at personhood. A human right—like the right to privacy—appears to protect not only personhood, but also other interests, such as our interest in not being humiliated, in forming and maintaining intimate relationships, and so on. Moreover, we can readily imagine human beings who are not normative agents, such as those who are suffering from the advanced stages of senile dementia, having their right to privacy violated, e.g. by publishing intimate photographs, or detailed medical histories, on the Internet. Hence, our view is that human rights are standardly grounded in a multiplicity of considerations—dignity in the inherent value and personhood senses, to be sure, but potentially an open-ended series of additional universal interests, such as freedom from pain, knowledge, health, accomplishment, friendship, play and so on [21].

What we have said here about the right to privacy applies equally to the right to science. The latter also finds its basis in a multiplicity of interests that it serves. These include the interest in acquiring knowledge of the world, the interest in achievement (where this knowledge is acquired through one's own successful efforts), the interest in community with others (participation in science typically involves cooperation with other co-workers towards the shared goal of generalizable scientific knowledge). In both cases, we believe that a pluralistic grounding of human rights, rather than one narrowly focused on human dignity (in either or both senses distinguished above), offers the most satisfying justification of these human rights.

## (b) Content

Our second observation relates to the *content of human rights*—what they require of us, and how this can change over time. A moral right always involves one or more counterpart duties (or obligations, we use these terms interchangeably), which is the normative content of the right. The duty specifies what the duty bearer must do or refrain from doing in order to comply with the right. On this view, human rights are not to be identified simply with the interests that ground them (e.g. health, autonomy and knowledge); instead, they concern the duties generated by these underlying interests. The process of going from interests to the duties they ground is a complex one, but it is clearly highly sensitive to constraints of feasibility. 'Ought' implies 'can', with the result that a person can only be under a duty that it is feasible to impose on them. Minimally, it must be generally *possible* for duty bearers to do what they have a duty to do: there can be no duty to do the impossible. So, even if in theory certain security measures—such as foolproof anonymization of data—could enhance my interest in privacy, it makes no sense to say I have a right to them if there is no way to implement those measures given the current and foreseeable state of technological capacities. Moreover, even if it is possible, imposing a duty to take the measures must not be unduly *burdensome*. So, for example, my interest in privacy does not impose an obligation on the police not to require me to disclose my identity to them if they find me behaving suspiciously. Recognizing such a right would be unduly burdensome in relation to other important values, such as the detection and prevention of crime, which also bear on the protection of human rights. In order to determine whether I have a right to certain privacy protections, we need to ask whether it is unduly burdensome to impose a duty to provide them, given the costs they might involve. As this example reveals, the process of deriving human rights is *holistic* in character. Any given obligation corresponding to a human right must be specified in the light of other such obligations, to ensure that as a general matter they are all in principle jointly feasible. In this case, the right to privacy must be specified in a way that is generally consistent with a robust right to security, which may be in some circumstances permissibly upheld by requiring people to disclose their identity to police officers.

Now, a vital point here is that our assessments of what is possible and not unduly burdensome change over time in response to changed circumstances, e.g. the emergence of new forms of economic and social organization, technical and scientific innovation, etc. Hence, there may come



into being rights that did not exist before, e.g. a right to Internet access, as proposed by Frank La Rue, the Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression [22]. Existing rights also can change in shape, e.g. the right to health may encompass new forms of treatment as their cost declines over time, thereby rendering the duty to supply that treatment not unduly burdensome. So, although human rights are uniform in content at any given moment in time, i.e. they must be rights possessed in equal measure by all human beings, the schedule of rights and the content of any given right can change over time in response to changes in what it is feasible to deliver as a matter of right. Presumably, this is part of the explanation of why the Universal Declaration of Human Rights contains an ampler list of rights—including socio-economic rights—than many earlier rights documents. It was simply judged feasible, in the post-war era, to expand the demands of human rights in this way.

### (c) Duty bearers

The third observation concerns the bearers of the duties imposed by human rights. In addition to the task of specifying the content of the duties associated with human rights, it is necessary to allocate them fairly to agents who are capable of discharging them. Human rights law, especially international human rights law, treats the State as the exclusive, or at least the primary, duty bearer in relation to human rights. However, there is nothing in the underlying idea of a moral human right that restricts duty bearers to the State. Just as there is a plurality of considerations that ground human rights (from the ‘input’ side), there is also a diversity of potential duty bearers (the ‘output’ side). There is no reason in principle to restrict duty bearers of human rights exclusively or primarily to States. Some rights, such as the right to a fair trial, might be primarily targeted at the State. But non-State actors, ranging from individuals to transnational corporations, may also bear human rights obligations. It is a further question what sort of legal or other structure we should employ to give formal expression, and social efficacy, to these obligations. For example, the UN *Guiding principles on business and human rights* directly impose obligations to respect human rights on all corporations [23]. However, they are not legally enforceable obligations, but at best part of a ‘soft law’ that can help coordinate expectations and enhance compliance with human rights norms overall.

This latter issue is of special relevance to big data for several reasons. Corporations are engaged in massive data collection that stretches over many national jurisdictions; they possess powerful computational tools that are opaque to outsiders; given the accelerating pace of developments in big data, national laws designed in the analogue era may be inadequate in protecting rights affected by big data. Big data companies have responsibilities to respect privacy rights even when law does not explicitly demand such protections, as it might be when legislators are racing to fill gaps created by new technological capabilities. Corporations also have responsibilities to respect the right to science. For example, those with control over large scientific data repositories tend to have exclusive rights to their use. Even if they exploit the data for scientific purposes themselves, they may have obligations to make such datasets accessible to other researchers for science to advance. If obstacles to sharing impede scientific progress, they may also impede our right to share in, and enjoy, its benefits.

### (d) Not exhaustive

Our final observation is as important as it is neglected. Although human rights are weighty moral standards, they are not exhaustive of our ethical standards, not even of that subset of ethical standards that should guide and inform law and public policy. To begin with, there are obligations that are not associated with rights, such as obligations to oneself (e.g. to develop one’s cognitive capacities, or at least not wantonly to destroy them, or to refrain from making public disclosures of certain kinds of personal information). There are also obligations of charity and solidarity. The breach of these obligations constitutes a wrong, but no one’s rights are violated when this happens. In addition to the domain of obligations, law and public policy need to be responsive to

a whole range of ethical concerns, including the fulfilment of human needs, economic prosperity, the preservation of nature, the furtherance of the common good, even beyond the point at which any of these concerns generate obligations, let alone rights-based obligations owed to some individual.

It is vital to underscore this point, because otherwise we lapse into the error of pressing human rights to do all the ethical work that needs to be done, which risks distorting them while simultaneously marginalizing non-rights-based consideration. The specific implication of this point for the present topic is that we should not expect a suitably comprehensive ethical framework for big data to be grounded exclusively in human rights considerations. On the contrary, other sorts of considerations will need to be included alongside human rights.

Consider, as an illustration of these points, the right to privacy. Many make the dual error of supposing that the ‘ethics of big data’ reduces to the ethical requirements concerned with privacy, and further that these ethical requirements of privacy all boil down to respect for the *right* to privacy. But much more than privacy matters, such as the positive ethical goals around health, knowledge, security, etc. that big data can serve. And, even when privacy matters, it matters in ways that go beyond the right to privacy. One example is the duty to preserve one’s own privacy, which, not being owed to another person but to oneself, is not a rights-based duty. (We take it to be a conceptual truth that we do not have rights against ourselves.) Yet, clearly, people have good reasons, often of self-interest, not to undermine their privacy interests, and sometimes these reasons rise to the level of moral duty that it would be morally wrong to contravene. Imagine a university student who seriously damages his prospects of future employment, or of playing a constructive role in society, by posting online all the minute details of his personal history, psychological states, romantic entanglements, medical history, etc. The student may have a right of freedom of speech to do all these things, yet we might feel uneasy about his doing them, even to the point of believing he is acting wrongfully. If he does have a duty to respect his own privacy in certain ways, third parties—e.g. Facebook—may bear a derivative duty not to encourage or facilitate his contravention of that duty, as well as a duty to help him minimize the impact of these indiscretions (one line of thought leading to the much-discussed, but rather limited, ‘right to be forgotten’) [24].

Another, related factor is that living in a society where privacy is respected is a common good. A common good is something—such as a shared language—that benefits everyone in a community, benefits them in the same way (e.g. by furnishing a means of communication), and which is non-rivalrous, in the sense that its benefiting some is not in competition with its benefiting others (e.g. my benefit from using the English language in no way competes with the benefit you get from using it). But a culture of privacy’s being a common good goes beyond merely securing people’s rights to privacy. In a culture that is solicitous of privacy, for example, people tend to avoid asking personal questions of people with whom they are not on close terms. There is no need to think that such ‘forward’ behaviour is a violation of the right to privacy in order to regard it as morally deficient. This suggests that there is a common good of living in a privacy-respecting society that goes beyond the good of living in a society where the right to privacy is widely respected. The same point can be made about a culture in which there is widespread participation by citizens in scientific research. Although this is a common good, the good does not simply consist in respecting each individual’s right to science. Even in a society where people’s right to science was fully respected, they might nonetheless choose not to exercise that right. The common good of a culture of scientific participation is only realized when large numbers of people regularly exercise their right to science by engaging in various forms of scientific research. But the *exercise* of that right is not itself something that can for the most part be demanded as of right, no more than we can demand that people exercise their right to free speech in order to produce works that help sustain the common good of a vibrant literary culture. So, in fostering a culture of citizen participation in science, we need to do more than securing people’s right to science.

Having set out this understanding of human rights, we proceed now to consider our chosen rights and how they bear on big data health research. We try to bring out, in particular, the



point that human rights are dynamic, changing in their implications over time, and that they are interactive, in the sense that what they require and how they are exercised depends on relations among rights.

## 4. Rights in action

The right to science and the right to privacy may appear to be on a collision course with each other. The right to science demands that opportunities be made available to participate in, and benefit from, scientific advances. In some areas of science, however, such progress can only be achieved through the use of data with personally identifiable information. Is the right to science in conflict with the right to privacy in such cases? Is there a duty to enable the use of identifiable data and at the same time a rival duty to protect the privacy of those who might be identified? If these duties are in conflict, what is to be done? It would be odd to suppose that one right can be generally secured only if another is systematically violated. Part of the point of anything being a right, imposing corresponding obligations on others, is that the latter are not regularly trumped by competing considerations. Accordingly, before embracing the drastic conclusion of systematic conflict between the two rights, we need to take a step back and explore other possibilities.

Specifying the duties imposed by human rights, as we saw above, is an inherently holistic process: it is a matter of solving a simultaneous equation with multiple variables. Human rights impose duties, and duties are stringent moral reasons that are not regularly or easily overridden by other considerations, including by other duties. To think of human rights as habitually, as opposed to exceptionally, subject to trade-offs is to misunderstand their nature as sources of duties. It follows that the duties associated with human rights must be generally jointly satisfiable, with conflicts arising only in exceptional, emergency-like, circumstances. So, apparent tensions like the one between the rights to privacy and to science, from which we began, are largely to be pre-empted at the stage of giving an adequate specification of the duties associated with each human right. Adopting such a holistic approach, we understand human rights as interacting with their environment (e.g. a social setting in which new capabilities are constantly emerging) and also with each other, in the process of specifying their content. We offer some examples here to illustrate the interaction and how it shapes the duties that human rights impose in a way that pre-empts systematic conflicts, even if it does not entirely do away with conflicts involving human rights.

The maintenance of electronic health records (EHRs) is increasingly becoming a standard practice in healthcare. The primary purpose of EHRs is to capture and store patient information that is used in the clinical care of the patient. But EHRs are also an invaluable source of data that can be readily mined for a variety of research purposes. EHR data from a large number of patients can be pooled together, linked to other databases and queried with fertile scientific questions. To date, EHR data are under-used in health research and public health practice relative to the benefits that they are capable of generating. A variety of justifications have been offered for this [25], but a heavily cited one is privacy. Depending on the query that is put to the data, the answers may reveal patterns, behaviours, health risks, etc. about particular individuals or groups. Such revelations can potentially have adverse consequences for these individuals or groups (e.g. discrimination, stigma, etc.) Protecting privacy interests, by keeping their health information confidential, safeguards them from the risk of discrimination and other harms. However, making this information accessible to third parties is necessary for many scientific advances, and it can further people's interests to share in, and benefit from, such advances.

The usual way of easing some of the tension here is by asking individuals if they are willing to take a privacy risk in order to contribute to securing an advance in scientific knowledge. This is typically done by means of informed consent procedures authorizing access to one's health information for secondary uses. Another means of easing the tension is through anonymization of data, although in many cases health research may actually require identifiable data in order to succeed. In the current big data context, however, both of these approaches are of limited utility [26,27]. Individuals cannot fully control the exact direction of the information flow given

various practical reasons, such as the impracticability of seeking and giving authorization every time a research question emerges, or because broad consent for general data uses is not morally robust enough to cover quite unanticipated uses. Anonymization, on the other hand, may be undesirable depending on the research project, and in any case re-identification may eventually become possible as new capabilities or new computational methods emerge [28,29].

One way of engaging with this problem is as if it were a zero-sum game: going ahead with the proposed research, which may facilitate enjoyment of the right to science, requires us to justifiably override the demands of the right to privacy. But this way of looking at the matter imports the very problematic assumption that human rights systematically admit of trade-offs, including against each other [11,19]. But if a privacy right were truly being justifiably overridden in this case, would this not at least demand some compensation for the person who sustains the privacy harm? This is what happens, for example, when a person's property rights are justifiably overridden through compulsory acquisition by the State in time of public emergency, such as a war. But this will strike many as a counterintuitive analogy.

A more promising way of looking at the matter is to ask whether the right to privacy is to be specified in such a way that it actually poses significant obstacles to the right to science, or the other way around. There is a subtle, but crucial, distinction that needs to be noted here in thinking about how changed circumstances can bear on human rights compliance. Sometimes the changed circumstances leave the content of the right—the associated duties—unaffected, generating change only in the means available for fulfilling those duties. So, for example, the advent of the Internet provides a new means, among others, for the State to comply with its duty to publicize the laws that it enacts. But sometimes changing circumstances can have a more radical effect: they can change the content of a given right by altering assessments of possibility and burden that go to the specification of the duties associated with a right.

The content of the right to privacy, or of the right to science, is to be ascertained against the background of the advantages and limitations of the novel digital environment. If it is impossible for individuals to have absolute control over the information flow of their data within the healthcare system, is it possible to maintain that there is a duty on the part of data users to ensure that such a form of control exists? Or should the lack of such an option to control and authorize the information flow automatically eliminate the possibility of data access by researchers? The latter would surely be an obstacle to securing the right to science as it will diminish the possibility of scientific advance. Duties of privacy protection in the digital world need to be spelled out and may not entirely correspond with identical duties before the advent of digitization. UN Resolution 68/167 on *The right to privacy in the digital age* affirmed that 'the same rights that people have offline must also be protected online' [30]. The question, however, remains as to whether these 'same rights' change in their normative implications in this new context and, if so, in what way. Our suggestion is that the duties that correspond to the rights in the digital context are best seen as having undergone a change in content.

Furthermore, we also note here that the assumption that the online/offline contrast is binary is itself highly problematic. People seem to live in a continuum of on/offline, with the result that it is difficult to draw sharp and meaningful lines between the two. This must also affect the way we conceive of our rights and their protection. The blurred on/offline boundary has destabilizing repercussions for the private/public distinction. There is a growing body of literature exploring this phenomenon. People are thought to have become more open in the way they deal with personal information online. At the same time, empirical data show that people remain concerned about their privacy and want to be able to exercise their right to privacy. This phenomenon has been termed the 'privacy paradox', but the air of paradox can be readily dispelled [31]. One can be open and decide to share while still considering the right to have the option to use privacy protections to be an important one [32]. After all, it can be part of a right that one has the power to waive it, giving others, through one's free choice, access to personal information that would otherwise be out of bounds. For example, people choose to share certain information within certain online contexts, e.g. within a circle of friends, or with their physicians. Typically, many

would like the flow of information to stop there, and not to extend to the next circle involving algorithms hungry to combine them with other data in order to pursue some alien purpose.

Let us return now to the right to privacy in health research. The interests that it serves, for example, the interests in non-discrimination and non-stigmatization, do not necessarily have to be served through conferring on the right-holder exclusive control over the flow of data (assuming, indeed, that they can always be served by means of consent, which is far from obvious). Another way to protect such interests is by shifting the focus onto the conditions under which certain uses of data are permissible [33]. For example, data-driven research (like all other research) must be socially valuable and its benefits ought to be shared fairly among the community; data users should not subject data to queries that create certain risks, and if such risks arise, the information gleaned is not to be released to any parties that might use it to harm the person in question; data users commit to full transparency about data uses and related actions, and so on. Furthermore, one's interests in not being harmed through stigmatization, etc. may be better protected by means of laws that punish discriminatory treatment, or through other means that serve as deterrent to discrimination, including compensation mechanisms if discrimination does take place on the basis of the relevant information. The duties to protect privacy rights in the current context seem to be better placed downstream (at the data use stage) in the process, rather early on (data collection, use authorization) in pursuit of an impossible task.

This approach looks at privacy interests only insofar as they concern certain harms resulting from privacy loss. There is of course a further consideration here: even if there is no harm of stigmatization or discrimination resulting from privacy loss, does the person have an autonomy interest in no one under any circumstances accessing personal information about them without their authorization? And, is this the kind of interest that generates a duty to protect it? It would be erroneous to think this is always the case. This is because it is precisely 'circumstances' that strongly affect how we should balance various ethical considerations. Even if one has an interest in not having their personal information ever accessed without permission, the circumstances can potentially determine whether this is an interest that generates a duty to protect it. Imagine the scenario in which health data are accessed, linked and analysed in ways such that identification and the sort of harms associated with it are eliminated, or that there are sufficient mechanisms in place to remedy such harms should they occur. Imagine also that there is ground-breaking knowledge to be derived from such an analysis, for example, in genomic research. In this scenario, although the person whose data are accessed has an interest in not having his data accessed, yet it is plausible that no duty owed to him exists not to access the data if the conditions set out above are satisfied. The common good of health knowledge here is the type of 'circumstance' that can legitimately limit the right to privacy in this particular way. To clarify: the right to privacy is protected through protection of various underlying interests, but the duty to protect such interest can take a variety of forms. Moreover, some of those interests protected by privacy may not generate a duty of protection owed to the individual, given the circumstances.

Let us turn now to the right to science. As discussed above, this right engages everyone's interests in sharing in and benefiting from scientific progress, but it also engages their interests in participating in scientific research that may lead to such progress. When database controllers refuse to share data for health research, they defend their case not only on the grounds of privacy protections (which they think they owe to the individuals whose data are in the database) but also on the grounds of their own rights of intellectual property (IP). There is a long-standing debate as to whether data can actually be 'owned', and if so, who is the morally legitimate owner [34]. A greater degree of consensus exists, however, on the assignment of IP rights over the products created by means of the use of a dataset, e.g. copyright in a scientific research paper. The right to science has been mostly invoked in the latter sense and in defence of robust IP regimes. Such regimes, however, can severely impede the dissemination of, and access to, scientific knowledge and scientific advances on the part of the ordinary public. Limiting access to data or strictly controlling knowledge dissemination on IP grounds risks according disproportionate weight to one part of the right, thereby making the other part of it impossible or unduly burdensome to

exercise [35]. Granted that there might be several IP interests in data and their outcomes, the question is whether all of these interests nonetheless generate the duty to protect them, when in fact their protection will significantly impair our capacity to serve other interests or exercise other rights.

A less familiar aspect of the right to science is its reference to participation in the cultural life of the community, including ‘sharing in’ scientific advances. One interpretation of this aspect includes the right of everyone to have the opportunity to make a contribution to scientific advances through participation in scientific research. We have argued in other work that this interpretation offers a strong normative underpinning for the so-called citizen science movement [15]. People without formal scientific credentials have a right to engage in scientific inquiry, and there is a societal duty to enable them to do so. With the new capabilities that the Internet and big data analytics offer, one form of participation is through people collecting and sharing their own health data for the purpose of scientific discovery. There are numerous platforms (public, private or public–private) that provide such possibilities to willing individuals. New technologies enable people to exercise their right to science in novel ways. People are equipped to make contributions simply by virtue of possessing mobile devices that collect and transmit geolocation data, or because they can instantly connect with many other people online around a common interest.

However, in debates surrounding the ethics of this newly flourishing form of citizen science, concerns have been raised about protections that should be afforded to those who undertake such activity. A recurrent anxiety targets privacy protections. Sometimes citizen science projects may fail ethics review, because privacy protections are not deemed to be up to scratch. Often standards and procedures of ethics review, which were designed for scientific projects that did not involve big data or citizen science dimensions, are uncritically applied to these new models of research. Of course, people who are willing to exercise their right to participation in scientific discovery still have privacy interests. The capabilities of the new digital context create ample possibilities for technological solutions to both privacy and participation. Notably, these new capabilities can enable people to make privacy choices through tools that offer granular options of sharing and also enable them to determine their desired degree of contribution to a given scientific project. Offering people options finely attuned to their preferences, cultural identities and life circumstances can assist them in exercising their rights. The duty therefore here takes a positive form, requiring the provision of opportunities rather than simply demanding that we refrain from doing certain things. Moreover, an additional duty potentially arises here beyond making such options available. People should be given information about existing options and offered support in exploring them; for example, through tools and aids that help them grasp the contours of the new privacy environment and the capabilities that enable participation. In other words, for people to be able to exercise their rights of science and privacy in an informed way, they need to be informed and supported in doing so.

## 5. Conclusion

Big data, we are repeatedly told, has enormous untapped potential as an approach to scientific research. A serious challenge arises, however, in realizing this potential. It will require the development of an ethic tailored to the new realities—the new capabilities and risks—of the rapidly evolving digital environment. A wide range of ethical principles—central among them, the human rights we have discussed here—will need to inform the ethics of big data in scientific research. But these principles are not fixed and pre-existing templates that can be simply mechanically imposed on the new environment in a cookie-cutter fashion. Instead, the principles themselves are undergoing a dynamic process of evolution as they interact with the changing social and technological environment, and also as they interact among themselves in jointly responding to the opportunities and risks thrown up by a changing world. In this paper, we have offered a sketch of what it would mean to start taking the complex dynamics of big data and human rights seriously.

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