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How Democracy Can Inform Consent: Cases of the Internet and Bioethics¹

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ABSTRACT Traditional conceptions of informed consent seem difficult or even impossible to apply to new technologies like biobanks, big data, or GMOs, where vast numbers of people are potentially affected, and where consequences and risks are indeterminate or even unforeseeable. Likewise, the principle has come under strain with the appropriation and monetisation of personal information on digital platforms. Over time, it has largely been reduced to bare assent to formalistic legal agreements. To address the current ineffectiveness of the norm of informed consent, I suggest that we need a notion of structural injustice (on a distinctive interpretation, elaborated here, which takes account of unequal power and property relations). I then argue that in order to protect and enhance people's freedom, we have to go beyond traditional applied ethics and introduce perspectives from democratic theory and social philosophy. I attempt to show how applications of the 'all-affected principle', together with new forms of democratic participation, deliberation, and representation can helpfully frame the narrower principle of informed consent. There is an important role for what we could call collective consent, and informed consent can only succeed in increasing individual agency if it is situated within enhanced forms of democratic decision-making.

Introduction

The idea of informed consent has been a pillar of applied ethics since the field's establishment as a distinct branch of philosophy in the 1960s and 1970s. As is well known, it emerged initially in medical ethics, coming out of a tradition of concern regarding surgical interventions by physicians that necessarily intrude on a person's bodily integrity.² The requirement for informed consent was also extended rather early on to the new field of research ethics, as a recognition that human subjects have rights to be informed about, and to consent to, experiments conducted upon them. With the emergence of computer networking, through the efforts of applied ethicists – myself included – it was suggested that informed consent could play a role in safeguarding some degree of informational privacy, and that principle eventually took root there as well. My own early version of the requirement for informed consent was formulated as a principle for networking ethics and articulated in my 1989 edited book, *The Information Web: Ethical and Social Implications of Computer Networking*.³ I proposed that the emerging uses of the Internet should be guided by a principle of maximally free and

open access to information and communication consistent with the norm of privacy, as indicated by informed consent.⁴

Over time, it has become evident that the requirement of informed consent is under strain, however valuable it may be in safeguarding some degree of individual freedom and privacy, whether in regard to one's body or to information about oneself. Taken alone, at least on current interpretations, it seems inadequate to meet its intended purposes. This is most evident in regard to the impacts of the new biotechnologies for research, e.g. genomics and biobanks and big data more generally, and it applies as well to recent attempts to extend the principle to cases affecting public health. In addition, we see informed consent reach its limits in regard to the extensive and intensive forms of surveillance carried out by both governments and corporations through Internet and web technologies and notably on social media. And even in its original home of medical ethics, the force of the requirement for informed consent has been eroded by the tendency to reduce it to merely legal and formalistic protections, often without adequate information being provided, and eliciting only perfunctory forms of consent.

In this article, I will analyse some of the limitations in the notion of informed consent in relation to the various social and technological contexts in which it is embedded. I will suggest that we need to bring in a notion of structural injustice (on a certain interpretation) in order to properly understand the contemporary challenges that delimit the effectiveness of this requirement. I will then argue that in order to protect and enhance people's freedom in the present situation, we need to go beyond traditional applied ethics and bring in perspectives from democratic theory and social philosophy. I will focus on some cases drawn from bioethics and from informational privacy online and try to show how applications of the all-affected principle, together with new forms of democratic participation and deliberation can helpfully frame the narrower principle of informed consent. It will be seen that there is a role for what we could call collective consent, as well as for democratic representation in various policy-making contexts, which can help with the hard questions we presently face. My approach here is primarily conceptual and will touch only lightly on some policy implications. But I hope to at least suggest how the reach of applied ethics needs to be expanded in more democratic and social directions.

On the Notion of Informed Consent and Some of its Contexts

As noted, the origins of the principle of informed consent lie in medicine, emerging from concerns to prevent assaults on the body such as are involved in surgical interventions, with separate roots as well in notions of negligence and the law surrounding it.⁵ For the most part, theorists have generally come to see the normative core of the requirement of informed consent as consisting in the need to protect a person's autonomy and dignity, in the understanding that people should be regarded as having rights of self-determination in regard to prospective interventions or, in the research context, in regard to being made subjects of experimental study. The principle is thought to encompass a requirement for full disclosure of procedures, costs, benefits, risks, and alternatives, some assurance that these are comprehended, and the voluntary granting of permission for the relevant intervention or research. Some critics have observed that the requirement has been almost entirely been narrowed down to disclosure alone,

with a focus only on the information conveyed, disregarding other communicative features of the situation,⁶ and in any case, that it is primarily concerned with matters of liability for harms, and specifically legal liability.

In contrast with dominant interpretations of informed consent, Onora O'Neill and Neil Manson argue that autonomy is not in fact a key concern. Instead, the key element is the waiver of the applicability of other moral requirements, where the relevant requirements and the waiver involved depend to a considerable extent on context.⁷ While maintaining that informed consent still has some relevance and importance, O'Neill has argued that it should be understood to apply primarily to medical ethics, and to research ethics, but that it does not extend to the domain of public health ethics.⁸ Yet, despite O'Neill's claim that informed consent cannot apply to entire populations, some public health researchers do in fact attempt to adhere to that desideratum (as we will see), or at least to apply requirements for nonexploitation of these populations, on related grounds of respecting their autonomy and dignity.

It has also been helpfully observed that informed consent is difficult or even impossible when evaluating the impacts of new interventions in public health, e.g. with GMOs, which have unforeseen impacts beyond the range of a given locale or population, since seeds, for example, can be disseminated by insects that travel widely, or by the wind. As Carolyn Neuhaus has recently discussed, trials involving the release of genetically modified organisms such as insects or animals pose special difficulties here, since they tend to move beyond a given community, raising issues of who should be informed and how consent could be elicited.⁹ Some ethicists have in fact proposed the use of mass consent forms in field trials.¹⁰ But given the evident impracticality of securing such consent, what alternative procedures could respect the autonomy and dignity of people in such cases?

Likewise, in regard to our other case of informational privacy, we can see that the idea of informed consent does indeed have some utility. Yet, its application there differs from the medical ethics case in important respects. With specific surgical or other interventions, the risks and benefits can usually be well articulated (at least at a given point of time). In the privacy case, although the specific intended uses of personal information for, say, advertising, can be specified, because of the large and often permanent accumulation of data on the Internet, the number of different collectors of information, and the surveillance that can be carried out online, the potential future uses of information about ourselves are largely unforeseeable. As a result, any consent cannot be entirely specific.

This brings the Internet case close to recent developments in bioethics itself, where increasingly theorists are proposing what has been called broad (or wide or general) consent, which is supposed to cover new research that does not significantly deviate from what was originally agreed to or, as it is sometimes put, involves consent to a framework for future research of a specific type. This would presumably be needed for biobanks, which collect extensive genomic data about individuals.¹¹ These broader forms of consent would seem to be essential to prepare the way for future scientific research or other uses, which cannot be precisely demarcated at present in any detail. Yet, the accumulation and subsequent agglomeration of the data, in the form of 'big data', can give rise to re-identification of the individuals from whom bits of DNA were initially taken, with unforeseeable consequences and potential harm to them. Given these indeterminable uses and their associated risks, the only consent possible would

have to be of this broad or general, rather than specific, sort. However, it is not entirely clear what such general consent amounts to (how general and to what?) and how much protection it can realistically provide for individuals' freedom and privacy.

Likewise, the argument in regard to informational privacy to date has been that because the developing Internet opened new possibilities for wide sharing of information and new networked forms of communication, there needed to be a way to protect individuals' privacy in regard to information about themselves. In fact, in the early days of the emergence of the Internet from ARPANET and NSFnet, I argued that given the storage possibilities and the emergence of large databanks, it would be important to supplement the (desirable) free and open communication online with protections for individuals' privacy as shown by their informed consent to the uses of their personal information. Subsequently, the legal gathering of so-called informed consent, via privacy policies to which people are asked to assent as a condition for almost any communicating and accessing of information online, has indeed developed into an entire industry.

Aside from this issue of specific and broad or general consent, we can ask whether informed consent is adequate as a way to deal with privacy online. Clearly, personal information has increasingly become commodified, in being highly valuable to advertisers. Further, the largest providers of online information and communication are private commercial entities, with the exception of Wikipedia,¹² which is hosted by Wikimedia, a nonprofit organisation.¹³ Increasingly, these large companies are dependent on advertising revenue and the sale of information about users for targeted advertising, which is their main source of profitability. Indeed, companies like Facebook and Snapchat have been described in the business press as advertising companies.¹⁴ This poses a structural problem of unequal power (in addition to unequal wealth), with users supplying much of the main information content online but having little say over what is done with their information. Likewise, participants in social media networks have sometimes been subject to forms of surveillance by various companies, in a phenomenon that has been dubbed surveillance capitalism.¹⁵ This development supplements government surveillance online, about which people also have little or no say.¹⁶ Both private and public variants make extensive use of data analytics in ways that are most certainly not transparent to the individuals who initially provide the data.

It seems clear that the requirement for informed consent, taken alone, is powerless to deal with these developments (especially in the United States). Since people want and need to communicate and gain relevant information – and, I would suggest, have rights to do so – they have to subscribe to the unfair – and some might even say, coercive – bargain they are offered. Often the consent forms are long and difficult to understand, even after they have been updated to accord with European Union requirements for easy-to-understand consent forms and even if the default is changed to opting in rather than opting out (to the degree those changes are actually implemented). Moreover, there are so many entities seeking access to personal information and the uses of this information are so obscure, that just checking boxes to agree to these uses becomes an empty gesture. Clearly, it does not adequately protect people's privacy or freedom, on nearly any interpretation of those concepts.

I certainly think there continues to be a role for informed consent, here and in bioethics. Nonetheless, it is clear that more is required, both to deal with the

structural injustice and the dominance of commercial interests, and in order to make informed consent effective.

Some Normative Considerations

Some theorists have already noted the problems that arise from relying exclusively on the individualistic principle of informed consent, even in the medical and research cases, and all the more so in regard to public health policy and the Internet. There are bioethicists who have begun to argue that we need to consider solidarity and other prosocial motivations if we are to deal with people's willingness to agree to contribute their DNA to biobanks, or to consent to organ donations, for example.¹⁷ Others focus on the norms of autonomy and of privacy and criticise interpretations of them as pertaining exclusively to individuals. In the Internet case, a narrow emphasis on individual decision-making alone supports current policies of relinquishing personal information, as though it is a matter simply of one's property.¹⁸ The commodification of personal information in turn undergirds commercialisation online, by regarding the information as something that can legitimately be traded away in exchange for participation in social networks or in online commerce.

Other theorists have argued for the superiority of the European approach to privacy, which appeals to the norm of dignity, and which proceeds with more social accounts of the norm of privacy, emphasising the role of privacy in ensuring recognition and of saving face. In these accounts, privacy becomes less a protection of a certain intimate space or of personal property, and more a matter of individuals' self-presentation to the world or a determination of appropriate boundaries of engagement with different groups of people in different contexts. But if informational privacy is framed simply in terms of saving face, it would still remain a rather negative justification for privacy, although distinct from the negative freedom notion ingredient in many US understandings, where it is understood in terms of freedom from interference.¹⁹

In contrast, I have operated with a notion of positive or effective freedom, which presupposes but goes beyond negative freedom to require access to various conditions for people's self-developing or self-transformative activity. I have argued that people in fact have *prima facie* equal rights of access to these conditions, which gives rise to what I characterise as a principle of equal positive freedom (as a principle of justice). Beyond requiring civil liberties and political rights, the conditions for self-transformation include freedom from domination and exploitation, as well as a range of enabling social and material conditions.²⁰ Moreover, the individuals involved are understood as individuals-in-relations, introducing a more relational ontology than existing liberal ones.²¹

I further argue that participation in co-determining the course of the common or collective activities in which these individuals may engage is one of the social conditions for their self-developing activity. This gives rise to a right to democratic participation or co-determination comparable to individual rights of self-determination (and in fact partly dependent on that right). However, co-determination by a group or community requires deliberation among the members followed by decision-making. It often also requires a system of democratic representation if the group involved is large. In this account, the scope for democratic decision-making (understood as more than

just voting and majority rule) is extensive, in that it pertains to institutional contexts organised around shared goals and is not limited only to the traditional political sphere.²²

In the next parts, I want to consider how informed consent can be supplemented and strengthened by reconceiving it through the lenses of social ontology and especially democratic theory (on a certain interpretation). To date, the main notions of democracy that have played a role in applied ethics come from deliberative democratic theory. Those applications have been illuminating, and there have been helpful proposals for citizen juries and minipublics, democratic forums, and other such modalities, particularly in public health contexts.²³ Deliberation has also been brought to bear as a way of expanding the Internet's communicative and informational functions to serve democratic ends.²⁴ Recently, others have begun thinking about the representation of patients on governance boards of biobanks.²⁵ In addition, using democratic theory, an important argument has been advanced for including study participants in the various transnational bodies that propose norms for determining the ethical status of scientific experiments and databanks.²⁶ It seems clear, however, that democratic theory and social ontology have not yet been fully mined for their applicability to applied ethics and specifically for our own concerns here, and I want to further explore their utility in what follows.

Strengthening Informed Consent: Domains of Bioethics

If we formulate the issue as one of making informed consent more effective or proposing relevant additions or alternatives that take it beyond its sometimes exclusively legalistic forms, we can begin by noting that even in the traditional context of medical interventions, there is an interesting proposal for enhancing the 'informed' part of this notion. Although most physicians are conscientious in explaining foreseeable risks and benefits of procedures to their patients, the current pressures on them (especially in the US context) may lead them to cut short the full discussion that is required and they may be disinclined to present alternative perspectives. Even remaining within the standard normative desiderata of avoiding any conflict of interest and providing complete information, one proposal for strengthening informed consent is to add a requirement for an independent physician or surgeon to participate in this process. This independent physician could present an alternative or contrasting perspective, if warranted, that would give the patient a fuller understanding of the risks, beyond that offered by the patient's own surgeon or physician. This task could be performed on a rotating basis by physicians in a hospital setting or by a physician member of the hospital ethics board.²⁷

In the public health case, although informed consent is not usually sought from affected populations, it has sometimes been proposed there, particularly in regard to field trials.²⁸ But as Neuhaus has observed, informed consent in any traditional sense would not work well, and an appeal to democratic modalities is required. As we will see, Neuhaus' proposal is for forms of what has been called community engagement.²⁹ We can ask whether there are additional directions from democratic theory for cases such as these, as well as for biobanks, and in regard to the troubling issue of informational privacy online.

In what follows, I want to focus on three aspects of democratic theory that I think can be helpful. The various applied cases, I will suggest, implicate 1) the all-affected principle in democratic theory, 2) the idea of co-determination concerning common activities (as I have called them³⁰) or, as it is more often conceived, concerning existing political communities or nation-states, and 3) the role of democratic representation. In addition, we will see how applying democratic theory is essential for dealing with the profound structural injustices that often frame the practices in question. For that purpose, it will be helpful to distinguish between two senses of structural injustice that have been blended in the existing literature.

The philosophical relevance of the idea of democracy for informed consent can be seen when it is appreciated that democratic decision-making can be understood as a matter of collective consent to – or, better, agreement to – policies or plans concerning collective or common activities. The rights to co-determine these joint activities is analogous to and partly derived from individuals' rights of self-determination regarding their own activity. Rights to democratic participation in decisions about common activities can also, and more deeply I think, be understood as a matter of joint control over the conditions of our activity, where the activity in question is collective and not individual. Because of the importance of such common activities to individuals' own self-transformative and self-developing activity over time, I argue that those who can be identified as members of the community or group in question should have equal rights of participation on the grounds of their equal agency.³¹ This need not mean that they personally need to (or even could) decide all issues that concern the collectivity, but that they have rights either to participate in those decisions or to authorise representatives to do so on their behalf, where the representatives are accountable to them.

The alternative social and political perspective advanced here also sees requirements like informed consent as embedded in a set of social practices, and not as freestanding processes, whether ethical or legal. Although in my view informed consent is rightly conceived as aimed at protecting the freedom of patients or of Internet participants, the practice of informed consent is in fact a historically emergent one and exists within a political economic and social institutional context that involves diverse and unequal power positions for those who operate within it. These institutions and practices are often characterised by what has been called systemic or structural forms of injustice. I will suggest that informed consent can only succeed in increasing individual control if it functions within an enhanced frame of democratic forms of decision-making that can address the structural forms of power that individuals face. In addition, we will see that deciding how to implement policies of informed consent, namely, who should consent and in what way, also depend on answering the central questions of democratic theory laid out above.

The applicability of both the all-affected principle and the rights of community members to participate in decision-making come out clearly in the public health case of field trials of genetically modified insects, which Carolyn Neuhaus has recently helpfully analysed. There the ethical import of the experimental release of genetically-modified insects and animals in a given locale cannot be adequately dealt with by seeking the informed consent of all members of the local community as some researchers have proposed, both because it would be impossible to gain unanimous agreement of the residents, and because some deliberation is needed as to the trial's impact on the community as a whole. Neuhaus instead argues that community

engagement is required in order to determine the acceptability of this release and the attendant risks. She proposes that this should involve opportunities for deliberation both among community members and between them and the experimenters, and she proposes community advisory boards as well.³²

But there are two limitations in the notion of community engagement here that come to mind. First, simply putting this in terms of engagement may not yet give the potentially affected members of the community and those beyond the community enough say in the actual decisions that are made, even granting the obvious importance of deliberation. If their future health and wellbeing are implicated, it would seem insufficient to give to the investigators the entire power of ultimate decision. Clearly, the community members and their political representatives would need to take some part in the actual decision-making. Although deliberative democratic techniques like minipublics and democratic forums are useful, they need to be accompanied by commitments to take the relevant input more seriously than at present, including in some cases taking it as binding.

The second limitation arises by reflecting on the implications of the all-affected principle. A notion of this sort may already be tacitly appealed to when evaluating the impacts of various public health policies on populations. But in the case of GMOs, especially insects that can move far from the place of release, the question of giving some say to all affected becomes particularly challenging. Given that their trajectory cannot be fully anticipated by any means, who should be consulted beyond the members of the immediate community and what forms of input should they have in the decision-making? This case calls for a role for broader publics, going beyond the locality involved, to contribute input to the decision. The scope of the impacts could also justify introducing framing regulations at broader levels, including national and regional levels, that could guide the implementation of these trials and similar research efforts.

While some democratic theorists, e.g., Robert Goodin, rely on this all-affected principle exclusively in determining who should have rights to take part in democratic decision-making,³³ I take it to apply primarily to the exogenous effects of decisions by primary collectivities, that is, their impact on outsiders. (Thus, the all-affected principle supplements the common activities principle, in my view.) I suggest that whenever a decision by a given community or its representatives has foreseeable important impacts on others beyond the community, including on distant others, it is important to gain some democratic input from these affected others (most often short of equal rights of participation). In order to make this principle workable, the notion of important impacts or effects needs to be delimited. What counts as important? My own proposal is that it should be understood as impact on the basic human rights of these outsiders and their ability to fulfil them (where human rights include also fundamental economic and social rights).³⁴ It is clear that using the all-affected principle in this way is especially helpful in dealing with the increasingly large number of policy effects that extend beyond a given locality (or nation-state). These widening impacts are highly characteristic of contemporary policy-making, which can have translocal, transnational, or global effects. Whereas the common activities principle requires equal participation by members or citizens, the all-affected principle can admit of differential degrees of input in proportion to the affectedness involved, which gives it an advantage in these contexts.

In some other domains of bioethics, introducing the all-affected principle could be useful as well. In regard to the ethical desiderata for handling genomic information – for biobanks, for example – the all-affected principle can help to frame informed consent requirements. While it might be decided that only those directly contributing genomic data would need to give formal consent, some of those affected beyond them should not only have their interests considered but also could even provide some input, either directly or by way of representatives or even trustees (in regard to distant others). Here, the all-affected principle can serve as a useful heuristic in the design of representation and also of who can participate in developing relevant regulations.

Given the broad conception of democratic participation and representation with which I operate, it is clear that the normative requirement for implementing these forms of decision-making extends beyond the usual contexts of government or the political sphere to apply to a range of economic and social institutions as well. This extension has implications when matters of governance are at stake in bioethics. Where it is a question of governing biobanks, or even healthcare institutions more generally, all those who can be regarded as taking part in it as members of the institutions in question should have some say in their governance. Moreover, the all-affected principle would support the inclusion of those participating in, say, healthcare data-banks, as having some rights to be represented on their governing boards as well as to have democratic input (short of equal rights of participation) regarding the policy making by the boards. These proposals are more demanding than mere appeals to board members to consider the interests of various stakeholders, or even to engage in amorphous forms of consultation. I have elsewhere proposed forms of input into the epistemic deliberations of these boards, deliberative mechanisms, and some new modes of representation that can have a place there.³⁵

Strengthening Informed Consent: Informational Privacy

We can now turn to the case of informational privacy and explore the utility of considering it from the standpoint of democratic theory. As I suggested in 1989 and reiterated above, there is indeed a role for informed consent to the uses of personal information.³⁶ But we need to look more deeply into the justifications for this form of privacy protection if we are to consider whether the existing bare forms of legal consent are adequate. We also need to ask what can be done about the troubling background conditions – the extensive use of personal information for surveillance and for commercial ends – and to figure out what more is needed to facilitate individuals' access to information and communication while safeguarding the confidentiality of their personal information. I can only sketch the outlines of an approach in this concluding section.

Informational privacy has most often been seen as a matter of control over information about oneself. In this regard, it is seen as a question of protecting negative liberty or freedom from interference by the state or, on some accounts, also corporations. As in the bioethics case, privacy, as the relevant norm to be protected, is most often construed in terms of autonomy or self-determination, where control over personal information is seen as a condition for autonomous choices. I discussed such a notion of control in my 1989 essay,³⁷ and I think that autonomy in a certain sense is implicated

here and should be protected. However, as I have argued elsewhere, autonomy is not a fully adequate interpretation of the sort of freedom that is characteristic of human action. Even when understood as relational autonomy, it does not do justice to the dynamism and biographical dimensions of freedom, which I have instead characterised in terms of notions of self-development or self-transformation. Although based in human choice and intentionality (as is autonomy), these alternative notions go beyond autonomy in being responsive to creativity and change over time, and by incorporating an integral relation to the conditions of activity that make choices effective. Without access to these conditions, choices remain empty and unrealised. The conditions include both the absence of constraint – including traditional interference, as well as freedom from oppression and domination – and the presence of enabling conditions, both natural and social, including recognition and care, along with basic material support for life activity. This therefore constitutes a conception of positive or effective freedom, but not in the sense criticised by Isaiah Berlin (as I discuss elsewhere³⁸). It is a conception that presupposes fundamental processes of choice and intentionality which themselves require respect and protection, as well as modes of self-transformation over time, including the development of capacities, the realisation of long-term projects, and the cultivation of relationships. The view is not perfectionist in nature, however, since forms of development remain open, with the main constraint being only the like freedom of others.³⁹

While the modes of self-transformative activity are open in this way, the conditions that enable them are widely shared. I have elsewhere argued that the conditions needed for human activity (in the sense of any activity whatever) can be specified in terms of a set of basic or primary human rights, while those conditions required for its fuller flourishing constitute a set of secondary, though still important, human rights. The notion of human rights here ranges over both civil and political and social and economic rights. These conditions themselves admit of varying interpretations over time, although those responsive to basic human needs, such as those for food or security of the person, have continuing core significances. Moreover, the social and political forms for realising these rights themselves tend to vary over time and across cultures.⁴⁰

How can this model of positive freedom and of social relations be extended to information and to its privacy? One problem with conceiving informational privacy as control over personal information is that is easily associated with the notion that this information is a commodity that can be bought and sold, in a way that conceives it as analogous to private property. This becomes problematic if one thinks of private information as belonging to advertisers, or to companies like Facebook or Google who sell it to advertisers, who can then do with it what they will.⁴¹ We have taken note of the extensive online surveillance engaged in by both corporations and by governments. But from a positive freedom perspective both access to information and privacy itself can be understood as among the fundamental conditions for freedom and ought to be included among the human rights. In fact, Article 19 of the Universal Declaration of Human Rights asserts the right to ‘to seek, receive and impart information and ideas through any media and regardless of frontiers’; and, in the US case, rights to privacy are recognised as implicated in several of the various protections included in the Bill of Rights.⁴² Beyond this, if informational privacy and personal information are understood in more social and relational ways than is customarily the case, they may well

yield some differences in how the norms involved should be understood and in how they should be respected and fulfilled. I will explore these differences in the remainder of this section.

As noted above, some legal theorists have recently tried to distinguish between the contemporary European and American understandings of informational privacy in terms of a contrast between control and dignity.⁴³ They suggest that the European understanding of the value of privacy appeals to the importance of social recognition, and people's concern with how they appear to others, whether they remain worthy of respect and whether their dignity is intact. There are some problems with this understanding as well, given its reliance on a rather old sense of dignity that is tied to dignified forms of treatment, with the sorts of recognition and respect that used to be given only to aristocratic dignitaries now extended more widely.⁴⁴ The notion of dignity has in fact recently been interpreted to have a deeper meaning and one less culturally relative than this.⁴⁵ Nonetheless, this so-called European perspective on privacy and personal data protection is important in casting light on the way personal information can function to establish our relation to particular others, rather than being significant as our possession. In this alternative view, privacy concerns how we wish to present ourselves to others in daily life (as much as, or more than our clothes do, for example), and to whom we wish to reveal ourselves in particular ways and in various contexts. This also brings in the notion of what boundaries we wish to set for our various relationships as well as for ourselves, that is, with whom we wish to share personal information.⁴⁶ A focus on relations also can implicate notions of differential power that are entailed by current legal and economic structures that enable extensive monitoring and surveillance.⁴⁷

In my view, the European protections recently introduced, with explicit requirements of informed consent to the uses of personal information, are significant whether privacy in informational contexts is understood as a matter of autonomy and control on the one hand, or of dignity and self-presentation on the other. But I suggest that this informed consent needs to go beyond existing legal forms of agreement if we are to deal effectively with the contemporary threats to informational privacy and if we are to make informed consent genuinely informed, and genuinely a product of consent, both individual and, in a certain sense, collective.

To gain further understanding of what is needed to make informed consent more meaningful in these contexts we need to reflect not only on the value of privacy of information but on the sociality of much information and its public value. In this connection, I want to develop a bit further the implications of the first part of my proposed early principle of network ethics. That part proposed maximally free and open access to information, supplemented in the second part with the idea that this access should be consistent with privacy rights as expressed through informed consent. How should we understand the information involved, as well as the required free and open access? Although efforts may be made to represent all information digitally in terms of 1's and 0's, much information is in fact context dependent as well as socially generated, and varies in its significance with the evolution of social practices, as well as with the development of new modes of understanding.⁴⁸ The social construction of information applies to much political and cultural information (and in some ways even to scientific information), as well as to personal information. It is obvious that such facts as social security numbers, dates of birth, and even our range of personal feelings and

political opinions, all presuppose background social practices and institutions, and have importance as expressions in interactive, social, and public contexts. Not only information itself, but also informational privacy, like the privacy of our homes and families, is important for enabling our own creative development as individuals and for enhancing our relations to other people, both those we know and those we do not. In my view, this does not make the value of privacy itself necessarily contextual (as Helen Nissenbaum holds⁴⁹), but clearly the information involved and the specific forms of privacy that we want to protect have important social and contextual dimensions.

The idea that access to information should be maximally free and open arises from the recognition that information serves as an important condition both for individuals' free development and for public purposes. Information can be viewed in historical perspective as a social creation, since it is difficult to entirely isolate individual contributions from the social background that enables them, however indispensable these manifold individual and joint contributions have been. This observation reveals how problematic are contemporary forms of corporate control over information. As noted, the largest information providers – which have become the gatekeepers of online information – are private companies, sometimes indeed possessing virtual monopoly power in their domains. But the creators of information and the masses of people who communicate on social media are providers of much of the content. Yet, they most often lack any real control over this information. They also have to agree to give up their personal information in exchange for access to information generally and for the basic right to communicate online. Their personal information is in turn treated as a commodity, sold for a profit to companies for the sake of targeted advertising. These purchasers of personal information have no obvious business incentive to safeguard it nor to be transparent about their uses of it. In this way, corporate (and government) users of personal information often violate the first part of the principle – requiring free and open access to information and communication – as much as they violate rights of privacy. Indeed, when people become aware of the commercial uses of their personal information, of the surveillance and the profiling involved, some studies have shown that they become much more wary and reluctant to give the required consent.⁵⁰ But it is also not surprising that most people continue to participate in the face of this reticence, since they very much need both access to the information and the opportunities that social media provide for communicating with their friends and associates.

If we are to make informed consent effective, then, I suggest that we need to look at ways not only to protect and enhance informational privacy but also to make information more freely and openly available. This again suggests a role for social philosophy and democratic theory in our applied ethics, if principles like informed consent are to be used to deal with contemporary social, political, and economic institutions.

One point of relevance of democratic theory is that democratic decision-making is most often needed in order to address the structural injustice that characterises the domain of information and its privacy. Currently, informed consent puts the onus on individual users to keep track of, and to respond to, the vast multiplicity of corporations, other institutions, and datamining sites that seek access to their information. And, as noted, although individuals provide much of the content of information, they lack power to control many of its uses, and must surrender personal information to powerful institutions simply in order to gain general access to information and to

communicate online. Inasmuch as information is in large part a social product and a public good, as well as an individual one, this suggests that we need to look to democratic framing and what I have called collective consent to supplement the existing weaknesses in individual informed consent. Moreover, if structural injustice is interfering with people's own control over their personal information, or its confidentiality, or is infringing on people's dignity or boundary-setting capacities, then individual action alone will not suffice to transform this situation. Rather, the transformations needed would require democratic decision-making to bring them about.

But before proceeding to some suggestions as to what this democratic framing might involve, we should clarify the meaning of the term structural injustice. In fact, I suggest that the term has two significances that, although related in various ways, have not been differentiated in the literature. The term has of late primarily been used in a sense elaborated by Iris Marion Young in her 'social connections model'.⁵¹ Although this first sense does indeed have some purchase, I believe it does not yet sufficiently capture the structural or systemic nature of the problems we face and that it needs to be supplemented by a second, more institutional, sense of the term that is adequate to contemporary political economy. The first meaning of structural injustice, as emphasised by Young, points to the way that people functioning within their everyday social life necessarily reproduce broader social practices and structures and thereby contribute to the reproduction of unjust forms of social life despite often having good intentions. Young further holds that although the specific contributions of people often cannot be measured in ways that make them legally liable for such processes, they have forward-looking responsibility to work to correct these injustices. Young recognises some differences in privilege and power within these structures, but eschews notions of blame, and holds that everyone has some responsibility for the practices by virtue of their everyday participation within them.

The importance of this first model of structural injustice, to my mind, is that it reflects the recognition that our social institutions and practices are in some sense social creations or constructions and hence are changeable. By participating within them and reproducing them through our actions, we can perpetuate them or else act to change them. However, I suggest that there is a second sense of structural injustice, with which I (along with some other theorists) have operated.⁵² This takes structure to apply more directly to the range of political and economic institutions within which we live, and which frame our choices. In recent contexts, this sense most often focuses on the critique of the structures of a capitalist economy, along with the institutions of nation-states and forms of government that tend to exert undue power over people's lives. In my view, these institutions too are human creations that have emerged historically and are maintained through social action, and are thus changeable, though often with great difficulty. However, the forms of injustice they embody are deeply structural in the sense of being embodied and codified in the functioning of institutions framed by law and administered through established power hierarchies and bureaucracies. They have a logic of their own and ways of functioning that are required by the very operation of the institutions in question, so that transforming them would require not only organised collective action or solidarity movements on a very large scale, but also fundamental changes in law enacted through democratic legislation, as well as transformations in the form of basic economic institutions. Even if every participant living within this systematic framework decided to orient themselves to justice and took

individual or socially organised action toward that end (however important that would be), this by itself would not yet suffice to produce the changes required. The specific systemic or structural demands need to be addressed not only collectively but also by way of law and politics. This suggests a role for democratic political action to change these background structural conditions.

From this perspective, we need to recognise that the structural injustices that limit the power of informed consent concerning online information and its privacy are related to underlying features of the capitalist system, namely, corporate private property rights and unlimited profit-seeking by large-scale institutional actors. While private companies like Google and Facebook do in some ways facilitate access to online information sources and to communications among friends and acquaintances, at the same time the functioning of capitalist corporations, exacerbated by increases in monopoly power and the concentration of wealth and income, have worked to constrain access and to limit the control that creators and providers of the information can exert over it. To the degree that there are structural injustices of this kind, they would need to be meliorated through regulations of a new sort, if they cannot be addressed through more fundamental changes in the existing political economic and legal framework. Indeed, specific proposals for regulation along these lines have been made that go beyond the European protections in place. They include bringing anti-trust law to bear on Internet monopolies, and also facilitating the creation of municipal broadband networks that would be community run, as well as providing extensive support for public service journalism.⁵³ From this vantage point, the protection of net neutrality, however vital, is only the beginning of what might be needed to enable full information access. Moreover, to the extent that further regulations are needed, they should (at least ideally) emerge by way of democratic processes that are more genuine and effective than those presently available, processes that would include the participation and deliberation of members of the public, as well as their representatives.

Another direction for dealing with the structural injustices that interfere with informational privacy would be the introduction of a new non-commercial web to add to or replace the existing one. This is in fact the current project of Tim Berners-Lee, who famously developed the original World Wide Web.⁵⁴ One could argue that ideally the web and the Internet itself should be transformed into public utilities, in view of the fact that information and communication are immensely important public goods, with many public and collective components. Although such transformations would seem to be far-fetched at present, there are in fact efforts underway to develop cooperatively and democratically-run platforms along these lines. These tend to model themselves on Wikipedia, but go beyond it, aiming at developing what has been called a true 'digital commons' (unlike the present proprietary use of that term⁵⁵). In a somewhat related way, the introduction of Creative Commons licenses attempts to establish a balance between individual rights and opportunities for sharing people's creative work more widely than under traditional copyright regimes (while still remaining within copyright law).⁵⁶ Needless to say, these small contemporary efforts tend to be dwarfed by the virtual monopoly status of companies like Google, which have enormous advantages in the provision of information, or Facebook, with similar advantages in regard to online communication.

Short of these innovative efforts at dramatic transformation, however, the importance of access to online information and communication for individuals and groups

suggests that framing regulations enabling such broad access are needed. Moreover, if we acknowledge that there should be more equal access to both information and communication (in view of the principle of equal agency and given the importance of those functions to this agency and its development), then societies would need to find ways to facilitate this access by means of democratically adopted policies. Although there has already been some progress in narrowing the so-called digital divide, yet even assuring everyone access to computers would be insufficient. In order to eliminate the distortions in the availability of information introduced by commercial use and gate-keeping, one can argue that access to information and communication would be more suitably provided on a nonprofit (if not fully public) basis. And if subscriptions to these alternative forms of information services were required to support their functioning, these subscriptions could be subsidised and made available at minimal cost or for free to those who cannot afford them. Indeed, some of the funds now going in abundance to surveillance activities, whether carried out by governments or corporations, could be re-purposed to provide new and more extensive forms of access and to support public or nonprofit sources of information.

Moving to less radical proposals, it is clear that more protections are needed in the short term for people's personal data, beyond those introduced with the recent European laws. The requirement for transparency regarding the various uses of personal information should be understood to go beyond legal disclosure and should include clear explanations of the range of surveillance and of targeting that is likely to be undertaken, whether by corporations or governments. Critical perspectives on these various uses should be made available as well, so that people could become aware of, and more accurately assess, the range of risks involved. In addition, limits can be placed on the type and range of personal information that need to be disclosed. In these and other ways, we would be framing informed consent by democratic decision-making about privacy and information access. I am suggesting, then, that we would need to introduce opportunities for more fully informed collective consent at the macro level of democratic politics and law. These new forms could in turn make it easier for individuals to protect their own information via traditional informed consent and to better manage their own self-presentation and boundary-setting in relating to others online.

So far, the various changes discussed pertain to the idea of co-determination of common activities, which was one of the three dimensions of democratic theory that I argued has relevance for strengthening informed consent in the present. Beyond the need for democratic legislation and regulation, it would be useful to introduce opportunities for deliberation, both online and offline, to help people become better informed about the conditions for consent and in order to assess the impact of any structural changes or new regulations on the political community. For example, as noted, the present risks attendant on widespread surveillance tend not to be well understood and need to be deliberated about publicly. Processes and practices such as minipublics and democratic fora can also be designed and implemented so as to provide important input for policy makers or representatives on the variety of ways in which it may be possible to better protect informational privacy, e.g. regarding the importance of anonymity,⁵⁷ or to assess forms of authentication for their acceptability to individuals.

We can finally turn to the implications of the other two dimensions of democratic theory that I proposed have relevance for our hard cases in both bioethics and informational privacy, namely, the all-affected principle and new forms of democratic representation and governance. Regarding the first of these, the Internet is obviously a key dimension of contemporary globalisation processes and is itself a fully global technology, perhaps the most notable one of all. I have proposed that the all-affected principle is particularly useful in demarcating who among those not part of a given collectivity should be able to provide democratic input into the decisions of the relevant collective or institution when those decisions have important impacts on outsiders. Attention to all those affected by current privacy policies is warranted as an application of this principle, especially inasmuch as decisions by national or regional bodies increasingly have wide effects that go beyond the boundaries of those political communities. Indeed, the all-affected principle can serve as a guide as to who should be asked to give individual informed consent, as well as whose input should be solicited when decisions about data protection are taken at these national or regional levels. Here, the notion of democratic input normally falls short of requiring full rights of democratic participation. The all-affected principle may also support moving from simple individual informed consent to collective forms of informed consent in cases where data collection can be expected to have effects on people beyond the individuals explicitly consenting on any given occasion, and especially on distant others. In such cases, representatives of distantly affected others should be asked to provide input into the relevant policies and regulations being contemplated.

We can already see how these considerations lead us to inquire into the need for agreements on data protection at fully international levels, going beyond the regional ones currently emerging, especially in Europe. They also raise issues of how to enhance transnational governance regarding Internet practices, an area still ripe for further development. Here, as in local and national democratic policy making, questions of democratic representation come squarely to the fore. Clearly, users of information and of online forms of communication should be represented on the various existing governing boards relevant to Internet activity. Beyond that, Internet governance would seem to present an arena for developing new forms of transnational deliberation and of representation comparable to those currently being implemented in regard to transnational environmental governance.⁵⁸

More generally, whether concerning existing restricted forms of internet governance or more visionary suggestions for the emergence of a democratic digital commons or cooperatively-run information platforms, there would need to be a role for democratic participation and/or representation for those who use the Internet and who are asked to consent to uses of their personal information. Deliberative forums and polling could be helpful as well, particularly to inform public policy making. In any case, we can propose that the goal of these new types of democratic participation and representation should be not only to protect the privacy needed for individual and social creative development, but also to find ways to open wider access to information and communication online. In this process, as I have suggested, efforts to enhance informational access and to establish informational privacy do not necessarily have to conflict with each other but can even be mutually enhancing and supportive of freedom, both online and off.

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NOTES

- 1 Originally presented as the 2018 Annual Lecture of the Society for Applied Philosophy, Kings College London, UK, October 26, 2018. I would like to thank the audience at that lecture for their helpful comments, and especially Neil Manson, Rowan Cruft, John Tasioulas, Leif Wenar, and Massimo Renzo. Thanks too to Joshua Keton, Laura Kane, and Michael Gould-Wartofsky for initial helpful discussions on the themes of this article.
- 2 See, for example, Ruth R. Faden & Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York and Oxford: Oxford University Press, 1986), pp. 53–113.
- 3 Carol C. Gould ed., *The Information Web: Ethical and Social Implications of Computer Networking* (Boulder, CO: Westview Press, 1989).
- 4 *Ibid.*, pp. 1–35.
- 5 On the development of the law concerning informed consent, see Faden & Beauchamp op. cit., pp. 114–150.
- 6 Neil C. Manson & Onora O’Neill, *Rethinking Informed Consent in Bioethics* (Cambridge: Cambridge University Press, 2007), pp. 48–49, 68–69.
- 7 *Ibid.*, pp. 68–96.
- 8 Onora O’Neill, ‘Informed consent and public health’, *Philosophical Transactions of the Royal Society B* 359, 1447 (July 2004): 1133–1136.
- 9 Carolyn P. Neuhaus, ‘Community engagement and field trials of genetically modified insects and animals’, *Hastings Center Report* 48,1 (2018): 25–36.
- 10 *Ibid.*, p. 28.
- 11 Kristin Solum Steinsbekk & Berge Solberg, ‘Biobanks – When is re-consent necessary?’ *Public Health Ethics* 4,3 (November 2011): 236–250.
- 12 Sebastian Seignani, ‘The commodification of privacy on the Internet’, *Science and Public Policy* 40 (2013): 733–739.
- 13 <https://wikimediafoundation.org/about/>
- 14 For example, in discussing Snapchat’s recent decline in users, the business analyst Brian Wieser expressed agreement with the company’s top executives that appealing to advertisers was more important than growth in users. ‘These are advertising businesses first and foremost’, he said. ‘Consumers are the product. Advertisers are the customer.’ <https://www.nytimes.com/2018/08/07/technology/snapchat-users.html>
- 15 Shoshana Zuboff, ‘Big other: Surveillance capitalism and the prospects of an information civilization’, *Journal of Information Technology* 30,1 (2015): 75–89.
- 16 For a discussion, see Neil M. Richards, ‘The dangers of surveillance’, *Harvard Law Review* 126,7 (May 2013): 1934–1965.
- 17 Ulrike Felt, Milena D. Bister, Michael Strassnig & Ursula Wagner, ‘Refusing the information paradigm: Informed consent, medical research, and patient participation’, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 13,1 (2009): 87–106; Barbara Prainsack & Alena Buyx, *Solidarity in Biomedicine and Beyond* (Cambridge: Cambridge University Press, 2017).
- 18 James Q. Whitman, ‘The two Western cultures of privacy: Dignity versus liberty’, *The Yale Law Journal* 113,6 (April 2004): 1151–1221; Seignani op. cit. It should be noted that it is controversial as to whether personal information can be viewed as a person’s property. It is sometimes argued that in the form of data, it arises in part through being collected, so data collectors may have some claim on it. (For a discussion, see <https://leidenlawblog.nl/articles/privacy-and-property-do-you-really-own-your-personal-data.>) Moreover, only intellectual property rights are currently recognised in law. Accordingly, while one’s photos can be subject to copyright, one may not in fact have ownership rights in many other sorts of information about oneself. Although Facebook in fact asserts that users own the content they create and post there, they also claim a license to use and distribute even one’s photos, specifically a ‘transferable, sub-

- licensable, royalty-free, and worldwide license to host, use, distribute, modify, run, copy, publicly perform or display, translate, and create derivative works of your content.' <https://www.facebook.com/terms>. While this license is subject to one's privacy and application settings, it can in fact prove difficult or even impossible to remove photos entirely from Facebook, if one has shared them with others.
- 19 Whitman op. cit.; Julie E. Cohen, 'What privacy is for', *Harvard Law Review* 126,7 (May 2013): 1904–1933.
 - 20 The original elaboration of this notion of positive freedom and the conditions for agency is in Carol C. Gould, *Rethinking Democracy: Freedom and Social Cooperation in Politics, Economy and Society* (Cambridge: Cambridge University Press, 1988), pp. 31–90; a recent statement is in C.C. Gould, *Interactive Democracy: The Social Roots of Global Justice* (Cambridge: Cambridge University Press, 2014), pp. 13–80.
 - 21 On this approach to social ontology, see Carol C. Gould, *Marx's Social Ontology: Individuality and Community in Marx's Theory of Social Reality* (Cambridge, MA: The MIT Press, 1978), pp. 30–39; Gould 1998 op. cit., pp. 91–113; and C.C. Gould, *Globalizing Democracy and Human Rights* (Cambridge: Cambridge University Press, 2004), pp. 33, 61–74, 97, 118–122.
 - 22 Gould 1988 op. cit., pp. 80–90, 247–261; Gould 2014 op. cit., pp. 81–96, 226–255.
 - 23 For example, see David, M. Secko, Nina Preto, Simon Niemeyer & Michael M. Burgess, 'Informed consent in biobank research: A deliberative approach to the debate', *Social Science & Medicine* 68 (2009): 781–789; John S. Dryzek, Robert E. Goodin, Aviezer Tucker & Bernard Reber, 'Promethean elites encounter precautionary publics: The case of GM foods', *Science, Technology, & Human Values* 34,3 (May 2009): 263–288; and Chris Degeling, Stacy M. Carter & Lucie Rychetnik, 'Which public and why deliberate? A scoping review of public deliberation in public health and health policy research', *Social Science & Medicine* 131 (2015) 114e121.
 - 24 See, for example, Todd Davies & Seeta Peña Gangadharan eds, *Online Deliberation: Design, Research, and Practice* (Stanford, CA: CSLI Publications/University of Chicago Press, November 2009).
 - 25 Prainsack & Buyx op. cit., especially pp. 114–119; and Carol C. Gould, 'Solidarity and the problem of structural injustice in healthcare', *Bioethics* 32,9 (November 2018): 541–552.
 - 26 Maxwell Smith & Daniel Weinstock, 'Political legitimacy and research ethics', *Bioethics* (2018): <https://doi.org/10.1111/bioe.12489>.
 - 27 I owe this suggestion to Dr. Yaron Harel, Associate Director of Pediatric Intensive Care at Valley Medical Services, Ridgewood, New Jersey, USA.
 - 28 See the discussion in David. B. Resnik, 'Ethical issues in field trials of genetically modified disease-resistant mosquitoes', *Developing World Bioethics* 14,1 (2014): 37–46 at p. 42.
 - 29 Neuhaus op. cit.
 - 30 Gould 1988 op. cit., pp. 71–80.
 - 31 Ibid., pp. 31–90.
 - 32 Neuhaus op. cit.
 - 33 Robert E. Goodin, 'Enfranchising all affected interests, and its alternatives', *Philosophy and Public Affairs* 35,1 (2007): 4–68.
 - 34 Gould 2004 op. cit., pp. 201–216; and Gould 2014 op. cit., pp. 81–96 and pp. 226–241.
 - 35 Gould 2014 op. cit., pp. 197–212 and pp. 235–241.
 - 36 Gould ed. 1989 op. cit., pp. 25–29.
 - 37 Ibid., pp. 21–25.
 - 38 Gould 2014 op. cit., pp. 58–80; and Carol C. Gould, 'Retrieving positive freedom and why it matters' in B. Baum & R. Nichols (eds) *Isaiah Berlin and the Politics of Freedom: 'Two Concepts of Liberty' 50 Years Later* (New York: Routledge, 2013), pp. 102–113.
 - 39 Gould 1988 op. cit., pp. 52–59; Gould 2004 op. cit., pp. 50–74; Gould 2014 op. cit., p. 65.
 - 40 For further discussion, see Gould 2014 op. cit., pp. 13–57.
 - 41 See the discussion in Sevignani op. cit., pp. 733–739.
 - 42 Needless to say, this is not to endorse either of these documents as ideal expressions of the set of human rights.
 - 43 See especially Paul M. Schwartz, 'The EU-U.S. privacy collision: A turn to institutions and procedures', *Harvard Law Review* 126,7 (May 2013): 1966–2009. See also Whitman op. cit.
 - 44 See, for example, Elizabeth Anderson, 'Human dignity as a concept for economy' in M. Duwell (ed.) *The Cambridge Handbook of Human Dignity* (Cambridge: Cambridge University Press, 2014), pp. 492–497.

- 45 I give one such interpretation in Carol C. Gould, 'Reconceiving Human Dignity as Relational and Embodied', unpublished manuscript.
- 46 See Cohen op. cit.
- 47 For a discussion, see Lisa M. Austin, 'Enough about me: Why privacy is about power, not consent (or harm)' in A. Sarat (ed.) *A World Without Privacy? What Can/Should Law Do* (Cambridge: Cambridge University Press, 2014). In fact, Austin goes on to argue against a focus on informed consent altogether. See also Lisa M. Austin, 'Is consent the foundation of fair information practices? Canada's experience under PIPEDA', *The University of Toronto Law Journal* 56,2 (spring, 2006): 181–215.
- 48 Marx W. Wartofsky, 'The digitalization of mind', (unpublished manuscript) and 'Epistemology historicized' in A. Shimony & D. Nails (eds) *Naturalistic Epistemology*, Boston Studies and the Philosophy of Science, Vol. 100 (Dordrecht and Boston: D. Reidel, 1987), pp. 357–377.
- 49 Helen Nissenbaum, *Privacy in Context: Technology, Policy, and the Integrity of Social Life* (Stanford, CA: Stanford University Press, 2010).
- 50 Seignani, op. cit., p. 736.
- 51 Iris Marion Young, 'Responsibility and global justice: A social connections model', *Social Philosophy and Policy* 23,1 (2006): 102–130, and *Responsibility for Justice* (New York: Oxford University Press, 2011).
- 52 Carol C. Gould, 'Varieties of global responsibility: Reflections on Iris Marion Young's last writings' in A. Ferguson & M. Nagel (eds) *Dancing with Iris: Between Phenomenology and the Body Politic in the Political Philosophy of Iris Marion Young* (Oxford: Oxford University Press, 2009), pp. 199–211; and Gould 2018 op. cit.
- 53 Victor Pickard, 'Toward a people's Internet: The fight for positive freedoms in an age of corporate libertarianism' in M. Edström, A.T. Kenyon & E-M. Svensson (eds) *NORDICOM*, Special issue on 'Blurring the Lines: Market-driven and Democracy-driven Freedom of Expression' (2016): 61–68.
- 54 <https://solid.mit.edu/>
- 55 <https://www.bepress.com/products/digital-commons/>
- 56 <https://creativecommons.org/about/>
- 57 For a discussion of this issue, see Karen Frost-Arnold, 'Trustworthiness and truth: The epistemic pitfalls of internet accountability', *Episteme* 11,1 (2014) 63–81; Gould 2014 op. cit., pp. 213–225; and John Francis & Leslie Francis, 'Identifying political participants on social media: conflicts of epistemic justice', paper presented at the annual conference of the American Section of the IVR, August 2018.
- 58 John S. Dryzek & Hayley Stevenson, 'Global democracy and earth system governance', *Ecological Economics* 70 (2011): 1865–1874.