

Vulnerabilities and Power

The Political Side of Health Research

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9.1 INTRODUCTION

In this chapter, I will argue that there is a political dimension to research, and that accounts of health research regulation that ignore political relations between stakeholders are therefore incomplete. The concept of vulnerability – particularly vulnerability to exploitation – provides the grit around which the claims are built. This is because vulnerability is an inescapable part of human life; because research participation may magnify vulnerability, even while health research itself promises to mitigate certain vulnerabilities (most directly vulnerability to illness, but indirectly vulnerability to economic hardships that may follow therefrom); and because vulnerability is manifested in, exacerbated by, or mitigated through, inherently political relationships with others, the groups and communities of which we are a part, and in the context of which all research takes place. I shall not be making any normative claims about research regulation here, save for the suggestion that decision-makers ought to take account of latent political aspects in their deliberations. For the most part, I shall simply attempt to sketch out some of those political aspects.

9.2 SETTING THE SCENE

Certain key terms ought to be defined at the offset.

By *vulnerability*, I understand a susceptibility to harm or wrong arising from a physical or social contingency above and beyond that found in a recognisably decent human life.

By *the vulnerable*, I understand those who are at an elevated risk of harm or wrong arising from such contingencies.

By *power*, I understand the capacity to act, or to resist being acted upon.¹

By *power relations*, I understand the interplay of agents' relative power.

By *the political*, I understand the domain in which power relations are manifested.²

By *exploitation*, I understand the use of some thing or person to serve one's ends.

¹ This falls within a tradition that goes back at least as far as Hobbes: 'The POWER of a Man, (to take it Universally,) is his present means, to obtain some future apparent Good'. T. Hobbes, *Leviathan* (Cambridge University Press, 1999), p. 62. More recently, Miranda Fricker has defined 'social power' as 'a practically socially situated capacity to control others' actions'. M. Fricker, *Epistemic Injustice* (Oxford: Clarendon, 2007), p. 13; I take this to be related.

² H. Lasswell, *Politics: Who Gets What, When, How* (New York: McGraw-Hill, 1936), p. 3: 'The study of politics is the study of influence and the influential'. Combining this with Fricker's account above, gives us reason to think that social

Some elaboration is in order. At its most basic, vulnerability is any susceptibility to harms or wrongs; but such an understanding is generally unhelpful, because (*per* Rogers) ‘it obscures rather than enables the identification of the context-specific needs of particular groups’³ – plausibly, one may read this as ‘individuals and groups’ – and because (*per* Wrigley and Dawson) ‘if everyone is vulnerable, then no one is’.⁴ A more nuanced and useful conceptualisation of vulnerability would relate it to a susceptibility to harms or wrongs greater than is normally found in a recognisably decent human life. Correspondingly, in stating that ‘[s]ome groups and individuals are *particularly* vulnerable and may have an *increased likelihood* of being wronged or of incurring additional harm’,⁵ the Declaration of Helsinki is plainly referring to the ways in which persons may be *further* vulnerable above a universal baseline. That said, I will indicate below that, and how, the more basic understanding is not without utility.

Wendy Rogers provides an account of some of the difficulties of conceptualising vulnerability in this volume (see Chapter 1) and taxonomies of different kinds of vulnerability have been offered elsewhere.⁶ I will neither rehearse nor assess those accounts here, save to highlight the idea of *pathogenic vulnerability*, the sources of which include morally dysfunctional or abusive interpersonal and social relationships, and sociopolitical oppression or injustice,⁷ and which thereby illustrates plainly one of the political aspects of vulnerability. However, we conceptualise or parse it, though, vulnerability invites politically-informed responses. Wrigley and Dawson assert that vulnerability ‘implies an ethical duty to safeguard [the vulnerable person’s or group’s] well-being because the person or group is unable to do so adequately themselves’.⁸ For his part, ten Have claims that ‘[w]hat makes vulnerability problematic is the possibility of abuse and exploitation’; for him, vulnerability need not be eliminated, so long as it can be ‘compensated, diminished, and transformed’.⁹ Putative duties to safeguard the vulnerable, or to militate against abuse, could be discharged by individuals in some cases, and by the state in others. Venturing claims one way or the other implies a political position, because it speaks to decisions about how and by whom power may be exerted over, and on behalf of, another.

Exploitation, as defined above, implies the exercise of power over another: the exploiter is *in this context* more powerful than the exploited. As a manifestation of the power relations between agents, it is therefore a political phenomenon; and if exploitation violates a right of the exploited, it may be wrongful. Insofar as that vulnerability is susceptibility to certain harms or wrongs, it

power and politics are inseparable, that we therefore cannot talk about politics without talking about power, and that talking about power will at least often be talking about the political.

³ W. Rogers, ‘Vulnerability and Bioethics’ in C. Mackenzie et al. (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), p. 69.

⁴ A. Wrigley and A. Dawson, ‘Vulnerability and Marginalized Populations’ in D. Barrett et al. (eds), *Public Health Ethics: Cases Spanning the Globe* (Dordrecht: Springer, 2016), p. 204.

⁵ World Medical Association, ‘WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects’, (1964), §19, www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. Emphasis added.

⁶ C. Mckenzie et al., ‘Introduction: What Is Vulnerability, and Why does It Matter for Moral Theory?’ in C. Mckenzie et al. (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press, 2014), p. 7ff; F. Luna, ‘Elucidating the Concept of Vulnerability: Layers Not Labels’, (2009) *International Journal of Feminist Approaches to Bioethics*, 2(1), 121–139; F. Luna, ‘Identifying and Evaluating Layers of Vulnerability – A Way Forward’, (2019) *Developing World Bioethics*, 19(2), 86–95.

⁷ W. Rogers et al., ‘Why Bioethics Needs a Concept of Vulnerability’, (2012) *International Journal of Feminist Approaches to Bioethics*, 5(2), 25.

⁸ Wrigley and Dawson, ‘Vulnerability and Marginalized Populations’, p. 203.

⁹ Indeed, he goes so far as to entertain the (for my money, implausible) suggestion that ‘Love would be impossible if we [did] not make ourselves vulnerable to another person.’ H. ten Have, *Vulnerability: Challenging Bioethics* (Abingdon: Routledge, 2016), pp. 112–113.

includes susceptibility to wrongful exploitation; and since exploitation is a political phenomenon, vulnerability to wrongful exploitation will therefore also be political. The relevance of this will become clear as we proceed.

9.3 INDIVIDUALS' VULNERABILITY IN RESEARCH

It is in the nature of research that outcomes are uncertain; this means that healthy volunteers in medical trials might be susceptible to unexpected harms. If research concerns a treatment's effectiveness, it will often be necessary to recruit patients into a trial; but such a cohort will, by definition, be of people with medical needs, some of which may be otherwise unmet. The prospect of a health benefit, especially if there are few other extant or affordable treatment options, may mean that this somatic vulnerability is accompanied by vulnerability to exploitation: the patient may allow herself to be enrolled into a trial into which she would not have allowed herself to be enrolled otherwise. Moreover, participants' ability to control their exposure to risk may be limited: even without perfect knowledge, researchers are likely to have greater insight into the risks, and are able to control information in a way that participants, who rely on researchers for information, are not. This is a form of epistemic power held by researchers. Indeed, researchers may be *perceived* as having control over information even when they do not; and this perception may give them a 'credibility excess'¹⁰ that is itself a source of epistemic power, insofar as that it can influence the decisions that participants make, perhaps to the extent of inhibiting their making them at all. How researchers and research managers handle the power disparity between them and participants is a political problem writ small.

Even putting the political aspect of this relationship to one side, it would be reasonable to expect that researchers address questions about the broader political context of their programme and protocol. After all, if someone enrolls as a research subject because it is the only way they can access treatment, or because it is the only way they can afford it or other necessities, this tells us something about the characteristics of the state in which they live – notably, how just it is. Correspondingly, acknowledged political injustice may alter the likelihood that a person would act as a participant, how they behave as a participant, and whether their participation is voluntary. The political questions are clear. Does the political environment in which a person lives provide adequate protection against exploitation? What should be done if it does not?

At times, it may be that political circumstances make ethically acceptable research impossible. *In extremis*, this might be because certain people are forced to participate by an overweening government: prisoners, say, may be particularly vulnerable to this kind of pressure in some regimes. But participatory voluntariness may also be eroded by the lure of medical treatment that participants would not otherwise have, perhaps because it is not normally within the state's abilities to provide it. On the other hand, refusing to carry out research because the context in which it is proposed creates vulnerabilities or militates against their mitigation, may simply mean that would-be participants are deprived of benefits that they might have had – Ganguli-Mitra and Hunt touch on this problem when they consider the use of experimental interventions during the 2013–2016 Ebola outbreak in Chapter 32 of this volume – and that scientific opportunities are lost as well. A further problem is that some illnesses are illnesses of poverty; it may not be possible to carry out research on those illnesses without recruiting people who are socioeconomically vulnerable, because less socioeconomically vulnerable people would be less susceptible to the

¹⁰ Fricker, 'Epistemic Injustice', p. 17; I. Kidd and H. Carel, 'Epistemic Injustice and Illness', (2017) *Journal of Applied Philosophy*, 34(2), 172–173.

illness in question. (That said, one may wonder whether prioritising poverty alleviation would dilute any imperative to research the illnesses that it causes.)¹¹

There is unlikely to be an easy way to determine whether a given political situation is conducive to ethically sound research. Possibly the best that could be said is that good research practice may require an awareness of, and sensitivity to, the prevailing political dispensation as it applies to certain individuals.

9.4 INDIVIDUALS AND GROUPS

How well do these considerations translate to groups?

For the moment, I shall assume that groups are aggregates of individuals, and that groups' vulnerabilities are aggregates of individuals' vulnerabilities. Admittedly, this is a simplification: something might be good or bad for the group as a whole without being good or bad for each and every member thereof; a group's integrity, say, may be vulnerable in a way irreducible to its members' vulnerabilities. But, for the time being, and given space constraints, I think that the simplification is not gross.

Granted that groups are aggregates of individuals, discriminatory or otherwise unjust political arrangements may exacerbate or even generate vulnerabilities in those individuals *qua* group-members. Most obviously, individuals may be at increased susceptibility to harm or wrong if they lack legal or political representation, education, and so on, because of their membership of a particular group. This kind of powerlessness to resist injustice is a political product generating a pathogenic vulnerability – and a state in which injustice is not addressed is itself unjust, or vicious in some other way.¹² Further, the legacy of historic injustices may linger even if the unjust policies were ditched long ago.

But even having been identified as a member of a group at all may generate vulnerabilities in individuals, irrespective of the political circumstances. To give a simple example, a public health research programme may require population-level data-gathering. Any given individual may feature in such research by dint of having been identified as belonging to a target group – but they might not be aware that the research is taking place. Already, then, we will be confronted with the possible wrong of individuals not being treated as ends in themselves. This wrong has a political dimension in that the power of research subjects is a consideration: one is powerless to withdraw from a study in which one does not know that one is a subject.¹³ We might say that researchers who think their work is worth the effort ought to approach those persons who may be captured by it – something that is in principle in their power to do – to give them a chance to opt out, and that research without this opt-out would be impermissible. This would restore to individuals some power. Yet giving people the chance to opt out of a large cohort study would be very difficult in practice, and – perhaps more importantly – would risk undermining the study's scientific integrity, which is itself a criterion of its moral permissibility. There is no clear solution to this sort of problem, though awareness of it is an important precursor to formulating best practice.

¹¹ I have nodded towards this point elsewhere, though without making it explicitly: see I. Brassington, 'John Harris' Argument for a Duty to Research', (2007), *Bioethics*, 21(3), 160–168, esp. at 165. Again, it is hard to see how there is *not* a political aspect to such arguments.

¹² Here, I follow John Rawls's opening gambit: 'Justice is the first virtue of social institutions'. J. Rawls, *A Theory of Justice (Revised edition)* (Oxford University Press, 1999), p. 3.

¹³ I use 'subjects' rather than 'participants' here, since to say that one might *participate* in research about which one is unaware is oxymoronic.

Even if that problem is solved, others present themselves. A group might be characterised by an elevated occurrence of certain characteristics. Imagine that members of group A typically have an unusually high susceptibility to a given disease, and that members of B typically have an elevated inherited resistance to it. Facts like this would generate legitimate questions that would be worth investigating: by learning about how it is that some human bodies are more resilient or susceptible to an illness than others, we could glean insight that would help us prevent it or treat it when it occurs. Yet both groups would also be vulnerable to injustice and exploitation. Thinking about the distribution of the eventual benefits of the research will help show how.

Clearly, medical research contributes to the development of new treatments, at least some of which provide profits for the manufacturers; and the profit motive may drive socially-desirable research. However, the line between just profit and profiteering, which is by definition unjust, is crossed if the benefits of the research are not fairly distributed between researchers – and their backers – and participants. Thus, for example, if any drugs arising from research dependent on the participation of members of A are profitmaking, and those participants derive no benefit – perhaps because socioeconomic deprivation makes the drugs unaffordable – that would be a paradigmatic example of injustice. Even if A is a reasonably well-represented and educated group, it or its members might be exploited in other ways, perhaps by being targeted specifically for expensive medical interventions. B would be less vulnerable on these fronts, since its members' need for any drugs is, by stipulation, reduced. However, again, if members of B received no benefit at all from research into which their contribution was crucial, they might still have been exploited. After all, exploitation does not always imply harm – but to have contributed to something that benefits others is to have been exploited; and if this was without recompense, or at least without the opportunity to waive recompense, it is arguably to have been treated wholly as a means to their end, and therefore to have been wronged.

That groups can be exploited or treated unjustly – such as in the ways illustrated by A and B – is sufficient to show that there is a power differential in play; and because the political domain is that in which power relations are manifested, it is also straightforward to point out that this has a political dimension. As such, a full assessment of the ethics of a given piece of research, and a convincing regulatory policy, would take into account the political situation, both locally and globally.

On the local scale, it would be important to keep in mind questions such as whether the group's vulnerability to exploitation is exacerbated by things like systemic discrimination or economic disadvantage, which may make it difficult for members of a community to assert moral rights that themselves may not be fully reflected in law. The better protected a group is in law, the better able it and its members will be to avoid or resist exploitation in other contexts.

Globally, if research is carried out on people from low-income countries, and the benefits of that research flow overwhelmingly towards high-income countries, what we see is, in effect, a transfer of benefits from the least-wealthy to the most. In this context, the Swiss NGO Public Eye estimates that

[a]lthough most clinical trials are conducted in the United States and Europe, over the last 20 years there has been a strong tendency towards offshoring to developing and emergent countries. The proportion of testing in emerging markets increased from 10 percent to 40 percent. This continued to increase between 2006 and 2010, while the proportion of clinical trials conducted in Western Europe and the United States fell from 55 percent to 38 percent.¹⁴

¹⁴ Public Eye, 'Ethical Violation', www.publiceye.ch/en/topics/medicines/ethical-violation.

Such a transfer is facilitated and guaranteed by a system of domestic and international laws through the framing of which power becomes visible; and keeping those laws in place, or altering them to reduce the chance of exploitation, is correspondingly a matter of the political will of the powerful. And though individual researchers are powerless to do much about laws that facilitate unjust exploitation derived from research, they are able to do something about the design of individual research programmes, and whether or not they go ahead to begin with.

Yet this is not the most difficult problem in the way of handling group vulnerabilities in health research: that concerns how researchers and regulators should respond when the interests, wishes, and vulnerabilities of different members of a group are in tension. It is this problem to which I turn my attention now.

9.5 GROUP MEMBERSHIP AND GROUP VULNERABILITIES

Return to groups *A* and *B* from the example above. Suppose that researchers are particularly interested in a gene that is common in *A* but not in *B*; they hypothesise that this gene is relevant to understanding the medical condition they are studying. This presents a problem for consent: because genes are not confined to one member of the group, any individual's participation in the programme automatically recruits other members as what we might call 'indirect participants'. It might therefore be argued that every member of the group is vulnerable to having been wronged, even if the 'direct participant' – the person, say, whose blood is drawn – has given full consent. How might we take account of this vulnerability in other members of the group?

It is a commonplace that full, informed consent is at least a part of protecting the rights of research participants; from that we can infer that it would be part of mitigating their vulnerability. But obtaining the consent of each member of the group before beginning the research would be wildly impractical for any but the smallest groups in the most confined geographical areas. More, we would have to decide whether assent to participation must be unanimous: whether, that is, the permission of a person who would presumably not be a direct participant in the research should be a requirement to secure the participation of those who would be. Inasmuch as that this is a question about the relationship of individuals to each other, it is political.

Another layer of complication is added if we deny that a group's vulnerabilities are reducible to those of the aggregate of its members – and it seems as though this may sometimes be the case. Plausibly, there will be situations in which the vulnerabilities of individuals and of groups do not map onto each other particularly closely, if at all: groups can be vulnerable in their own right. For example, the size of a tribe of hunter-gatherers may fall as its members urbanise; we might therefore want to say that the group is increasingly vulnerable even as individual members, thanks to better access to things like health care and education, become less so. But if this is correct, then even addressing every individual's vulnerability may not address wholly the vulnerabilities of the group in the abstract, and so even unanimous consent may be insufficient to prevent impersonal harms or wrongs. Yet it does not seem plausible to say that a research programme should not go ahead because it is impossible to guarantee that the vulnerabilities of the group as a whole will not be exploited. Partly, this is because it seems to sacrifice the (probably admirable) willingness to participate of identifiable members of the community on the altar of concerns about everyone and no one in particular. And partly it is because, though the vulnerabilities of identifiable other members of the community and of the community itself may be important, they are not likely to be the only relevant moral consideration. After all: *everyone* who stands to benefit – directly or indirectly, tangibly or intangibly – from the research has an

interest in its going ahead. These are political problems: to echo Bernard Crick, ‘conflicts of interest, when public, create political activity’.¹⁵

Having a representative or representative body that can speak on behalf of the group broadly understood may be suggested as a way forward. For example, Charles Weijer argues that, although some groups and communities ‘do not possess a legitimate political authority empowered to make binding decisions on behalf of members’, which means that ‘it would be both impossible and inappropriate to seek community consent for research participation’, they ‘may nonetheless have representative groups, and researchers ought to engage these groups in a dialogue concerning study design, conduct, and research results’.¹⁶ Yet we may still wonder how we determine who represents the community and in what way, and what we should do if and when the views of members of the group or community broadly understood diverge from the views of its notional representatives. We should not forget the possibility that would-be research participants may be vulnerable to peer pressure, either to participate or not to, from the group of which they are a part. In this light, it is not obvious what should happen if one member of group A or B from the example above is willing to volunteer as a research participant when those representatives are opposed, or *vice versa*. Again: since these problems concern how individuals and groups interact, they are plainly political.

Neither should we forget that individuals may be members of several communities or groups simultaneously. As such, referring to membership of *a* community is likely to mask other problems. Accordingly, when, in the context of genetic research, Jones et al. state that, ‘depending on the research focus’,

a community may include a group sharing a common geographic location, ethnicity, disease, occupation, etc. as well as virtual communities linked regionally, nationally or internationally¹⁷

they leave open questions about whether one must specify just one of these, and which – if any – takes priority over the other. At some point, someone would have to stipulate that the ‘kind’ of community in question is *this* or *that*; but such stipulations would appear to be always disputable, and likely politicised to boot.

When considering research involving vulnerable groups then, the relative power of the researcher (and the researcher’s backers) and the participant is not the only consideration. Researchers’ power relative to that of the group as a whole would also be important to keep in mind; at the same time, so would the power of the group as a whole in relation to the individual participant. Finally, even if we think that the interests of the community are significant, there is a lingering question of where the boundaries of the community should be drawn: sufficiently cosmopolitan politics may deny that the boundaries of this or that group are significant.¹⁸ These questions are inescapably political given the understanding of the political as that domain in which power is manifested, but also political in a more everyday sense, because they speak to problems of how individuals relate to the groups and communities of which they are a part, and how we define group or community membership.

¹⁵ B. Crick, *In Defence of Politics* (London: Bloomsbury Academic, 2013), 10.

¹⁶ See, for example, C. Weijer, ‘Community Consent for Genetic Research’, (2006) *eLS*, 3.

¹⁷ D. Jones et al., ‘Beyond Consent: Respect for Community in Genetic Research’, (2014) *eLS*, 4.

¹⁸ I am conflating ‘group’ and ‘community’ here – but they may not be quite the same. We can arrange people or things into groups notwithstanding that they have no sense of community. A community is a *kind* of group: one that recognises, self-identifies as a community under the auspices of, and *endorses the importance of* some common feature. I do not think that this distinction makes much difference for the points I am making.

9.6 POLITICS AND PROTECTION

I noted earlier in this chapter Wrigley and Dawson's claim that there is an imperative to mitigate vulnerability. Allowing that there is such an imperative, it speaks to the obligations individuals have to each other, but also to the responsibilities of the community, as expressed through the state. Either way, there is a political dimension to it. More, it is reasonable to suppose that health research is one of the things that might be enlisted as a means of mitigating universally-shared human vulnerabilities, and it is likely that a functioning state of some sort is necessary to facilitate such research. Indeed, the idea that political existence is in one way or another crucial to human flourishing has been a touchstone of western philosophy since Aristotle.¹⁹

It should also be remembered that, as well as facilitating research, protecting research subjects from harms and wrongs more generally – notably, through regulation – falls within the state's demesne. It is in this light that we might consider moves such as the reforms to the Mexican General Health Law approved in 2008, which made 'the sampling of genetic material and its transport outside of Mexico without prior approval [...] illegal'.²⁰ The Genomic Sovereignty amendment states that Mexican-derived human genome data are the property of Mexico's government, and prohibits and penalises their collection and use in research without prior government approval.²¹ This may be seen as an attempt by the Mexican state to protect vulnerable groups within it from the depredations of large and wealthy biotech companies. Such moves may be seen as particularly called-for when, for example, the results of genetic research might be patentable. In such circumstances, a national government can shield minority groups that might not be able to resist unjust exploitation on their own, and can work to give them authority over what happens to data derived from their members.

This is not the only way to see things, though. Cooperation with commercial research institutions could provide vulnerable groups – think again of groups A and B above – with a way to capitalise on their own genetic resources, by entering into benefit-sharing agreements that guarantee them a portion of any proceeds. Such cooperation may also provide a way for research attention to be paid to conditions that may be more prevalent in that community than elsewhere. On this basis, legislative moves such as Mexico's may be seen as an appropriation, however well-meaning, of the rights of some of its people(s) to decide for themselves how to handle data derived from their genes. Alternatively, it may be national governments that are best able to persuade biotech companies to research certain conditions at all; and the state may be able to use its power not to prevent a group exploiting its genetic resources, or to coopt them, but to ensure that the group in question it is able to exploit them effectively, since only national governments have the heft to ensure that the exploitation is not of the objectionable sort.

9.7 CONCLUSION

Research promises us a way to address human vulnerabilities, but it may exacerbate others in the process. Ensuring informed consent from participants may be a means of mitigating some of these, but not others. Those that it might mitigate often have a political genesis; but the relationship between researcher and participant can only really be understood when its own

¹⁹ Aristotle, *The Politics* (London: Penguin, 1992).

²⁰ B. Séguin et al., 'Genomics, Public Health and Developing Countries: The Case of the Mexican National Institute of Genomic Medicine (INMEGEN)', (2008) *Nature Reviews Genetics*, 9(S1), S5–S9, S6. Slightly modified.

²¹ R. Benjamin, 'A Lab of Their Own: Genomic Sovereignty as Postcolonial Science Policy', (2009) *Policy and Society*, 28(4), 341–355.

inherent political dynamic is acknowledged, too. More, the complications of the political aspects of research are magnified when we are dealing with vulnerable groups and communities, and with their members.

It has not been the aim of this chapter to offer any normative suggestions; nevertheless, fully to account for individuals' vulnerability, and reliably to avoid exacerbating or exploiting it unjustly, researchers should probably take account not just of the familiar ethical norms of health research, such as informed consent, but also of the political context in which such norms are applied.