Genetic information: making a just world strange

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Abstract In an article recently published in this journal, I raised a puzzle about the control of genetic information, suggesting a situation in which it might turn out that we have a duty to remain in ignorance about at least some aspects of our own genome. In this article, I propose a way that would make sense of how the puzzle arises, and offer a way to resolve it and similar puzzles in future: in essence, we would consider genetic information to be something the distribution of which may be more or less just. We would not know in advance what a just distribution would be, though, and in some cases there might still be a justice-based reason to deny a person genetic information about himself. However, others might also have justice-based claims to be able to access that information. This suggests that there is a possible world in which one person is entitled to at least some genetic information about another, while that other person—to whom the information refers—is not, and that this world would be just.

Keywords Genetic information · Privacy · Insurance · Justice

A puzzle about genetic information…

In an article recently published in this journal, I raised a puzzle about the control of genetic information [1]. It revolves around a pair of identical twins, Gerry and Terry, and whether one should be able to learn information about his genome, granted that doing so would violate his sibling’s privacy. What makes this a particularly thorny puzzle, I suggested, is that claims about rights to know information about oneself stem from a more basic claim about what we may term ‘informational privilege’; but claims about rights not to have that information propagated to others also stem from a claim about informational privilege, and to have one’s identical twin learn about his
genome is, in effect, to find oneself in a situation in which another person gets access to information about one without one’s say-so. In a nutshell, the kind of argument that might be generated in favour of a right to know is itself the twin of the kind of argument that might be generated in favour of a duty to remain in ignorance.

Nor are any of the most promising candidate methods to break the deadlock necessarily good at generating an intuitively satisfying conclusion, if indeed they can generate a conclusion at all. If one tries to understand the conflict between Gerry and Terry in non-consequentialist terms—say, as a matter of one rights-claim coming up against another—it is not obvious which would win out, given that both can be traced back to the same basic idea about informational privilege. However one tries to solve the puzzle, someone’s rights will be sacrificed on the altar of someone else’s; and to have to violate a right to informational privilege in the name of respecting what is essentially the same right to informational privilege is unsatisfactory.

To interpret it in consequentialist terms may at first glance appear to settle the matter in favour of Gerry’s right to have the test and learn about his own genome at the expense of Terry’s privacy: we do tend to think that knowing things, especially about oneself, is not only good, but also generates more benefits than having others not know them. The confounder here is that Gerry might not benefit all that much from such knowledge. If he is symptomatic, a genetic test will probably do nothing more than confirm medical suspicions; if he is not, we can still legitimately ask whether he would learn anything enormously important from his genome, since knowing he has the gene for a given condition C only tells him about the probability of C manifesting, granted all the other things that might kill him in the interim. As such, the value of genetic information has to have a discount applied to it, based on all the other things—lifestyle, time, epigenetics—that might make a gene less of a threat than it could appear; by contrast, the value of privacy appears to come with no such discount. If nothing useful is achieved by telling Gerry about his genome, the benefits of maintaining Terry’s privacy might turn out to be the most significant concern after all.

Finally, to attempt to interpret one twin’s claim in consequentialist terms and the other’s in non-consequentialist terms will obviously be philosophically incoherent, and so will not get anyone very far.

In short, Gerry’s interest in knowing, and the benefit that that will yield, could turn out to be trumped by Terry’s interest in maintaining privacy, and the benefit that that will yield. Exactly where the balance tips may be unclear a priori; but there is no reason in principle to think that it will always be in favour of Gerry’s right to know. Or, to put it another way, there might be situations in which there is a duty to remain in ignorance concerning one’s own genome. What I want to consider in the rest of the article is something that might appear to be a fairly straightforward response to the Gerry-and-Terry (henceforth, G&T) problem, but which throws up counterintuitive results of its own.

… and a possible solution

There might be a way to sidestep the G&T problem by characterising it as being based not in the need to protect all people’s rights, but in a requirement to ensure
justice and the just distribution of information. Deciding in favour of one or the other twin’s prima facie rights might be characterised as having reached a just outcome; but here, justice would be pressed into the service of more fundamental claims—the just outcome would be that which involved the least egregious violation of a right. What I have in mind is a reversal of that: a picture in which, if one is going to talk about rights at all, one does so only in the wake of having decided what a just outcome would be—one’s rights, and one’s duties for that matter, would simply be expressions of what justice allows and demands. To an extent, this echoes a Rawlsian claim that what rights there are must be assigned in accordance with the principles of justice [2, p. 9]. In this picture, one can talk about a just outcome without needing to invoke rights. The idea of informational privilege would not be a necessary feature in such a picture, and it might not appear at all if there are justice-based reasons to discard it.

There is an initial attraction to this approach inasmuch as that questions about genes are frequently questions that refer to more than one person at once: they are interpersonal—a fact that is central to the G&T problem. And it is precisely in the interpersonal realm that considerations of justice come into their own: justice, too, is an interpersonal phenomenon. Treating the G&T problem as a problem of justice offers the possibility of looking at Gerry and Terry’s competing claims through the prism of a question about how much information about himself or another a person ought to be able to have, rather than a question about whether he should have any at all. It might turn out that he should have none. But by ditching the assumption that information is privileged, we can move away from the idea that it is an all-or-nothing affair, and concentrate on more subtle questions.

Admittedly, it is necessary to be aware of a few potential problems before going down this route. Notably, we tend to think of justice problems in bioethics as being related to the distribution or allocation of a scarce commodity: for example, they have to do with who should get the available transplant organ, or how much money the state should allocate to healthcare, or whether the state can require that we pay a certain proportion of our income into a central health fund at all. In all these cases, the question is one of who should get what proportion of a limited supply of some good. Information is, at least on the face of it, different: my having more does not mean that you have less. Indeed, information might strike us as being singularly unlike other goods, in that the more it is shared, the greater the quantity there is; and one person having information does not in any way limit anyone else’s having it as well. The same applies when talking about access to information as when talking about information per se. Neither can we really turn things around and say that ignorance is the limited and diminishing commodity that has to be shared out, because there is no competition to maximise ignorance, any more than there is competition to have no peaches.

Nevertheless, treating the problem as being about the just allocation of information is not fundamentally threatened by the fact that the good at issue is neither scarce nor finite. There are other times when questions that we unproblematically take to be questions of justice are quite naturally capable of being framed in terms of the allocation of a non-finite good, and in which we say that justice demands restricting a person’s access to an unlimited good. Liberty might be one
such good: the total amount of liberty in the world is not finite, and Smith having more liberty does not mean that Jones has less. But there might still be situations in which justice demands restricting the liberty of one of them—as criminal punishment, for example. If Smith has committed a crime, then we may engage in all manner of debates about the justice of curtailing his liberty and the extent of that curtailment (and Jones may prefer a greater curtailment than we do); but the central notion that how much liberty a person should have is a matter of justice is utterly mundane. Questions of penal justice might well involve questions about who should retain or lose liberty, and how much they should retain or lose.

As for Smith and Jones, so for Gerry and Terry. One can proceed on the basis of the idea that, though information is not scarce, and one person’s holdings are not diminished by another’s having increased, it still makes sense to frame questions about information as questions about the just allocation of a resource. What is important is that information is treated as a good of which a person could have more or less, of which it would be reasonable to expect parties to want to maximise their holding, in respect of which one person might prefer that another’s holding not be maximised, and the morally best distribution of which can be discerned by looking through the prism of a given set of moral norms. Should this strategy provide a plausible means for solving the G&T problem, there will still be no guarantee that the solutions will be particularly intuitive—but the paradox by which one person’s claim to a piece of information rests on exactly the same grounds as another’s denial of that claim will at least have been avoided.

So, for example, one might decide that Gerry has an interest in having access to certain information, and that Terry’s acknowledged interest in his privacy being maintained is of secondary importance in this case. It is possible that the balance would be struck differently if Gerry sought different information, or even information about a different gene: there is no reason to think that one would always come down on the side of either brother’s claim. What counts is that one has some guiding principle that can be used to assess whether any given distribution of information is just. There is, of course, any number of rubrics that one could use to assess what justice requires: I have already nodded towards Rawls, and a tool like his veil of ignorance might provide a method for assessing the merits of a given distribution of information; but there might be rival theories of justice that could offer to do the job in other ways. My aim here is not to argue for any account of justice, Rawlsian or otherwise, in particular, so much as it is to say that by making use of a preferred theory of justice, one could hope to determine how information should be shared, and who has which rights to what.

**Information in insurance**

Given this, Gerry and Terry can be left to settle their dispute in peace for a while. Settling on some method of deciding the just allocation of information about genes might help us decide what to do in other situations in which two people might have competing interests in respect of the distribution of that information. I have in mind problems of deciding what, if any, information employers or private insurers ought
to have about our genes. The specific concern of this article is with insurers, though
the principle ought to translate well enough: for any two parties in dispute about
who should have access to a given piece of information, the problem can be treated
as one of deciding which distribution of that information has the most to commend
it in terms of some agreed framework of justice.

Many people have an intuitive resistance to the idea that insurers ought to have
any access at all to genetic information. As Jyri Liukko notes, this resistance flies in
the face of the intuitions of many about other kinds of information:

Traditionally it has been widely accepted that private insurers are legitimately
allowed to classify and discriminate between applicants according to specific
statistically relevant risk factors, particularly age, gender and health. However,
in the recent debate, genetic health information is often considered to have a
different moral status from that of the other classification variables. Importantly, discrimination according to all other kinds of relevant health
information is deemed fair, while genetic discrimination is not. This so-called
‘genetic exceptionalism’—according to which genetic information is unique
and needs special protection—has been institutionalized in many European
countries and in the United States through the enactment of genetic non-
discrimination legislation for life and health insurance. [3, p. 458]

In the US, the Genetic Non-Discrimination Act was enacted in 2008; in the UK,
resistance to the use of genetic information has been formally recognised by the
insurance industry itself: under some pressure from the government, it accepted a
moratorium on the use of predictive genetic testing in 2005 [4, §19]. This
moratorium was originally supposed to hold until 2011, but it was extended in that
year. A statement from the Association of British Insurers explained that ‘the results
of a predictive genetic test will not affect a consumer’s ability to take out any type
of insurance other than life insurance over £500,000. Above this amount, insurers
will not use adverse predictive genetic test results unless the test has been
specifically approved by the Government. Only around 3% of all policies sold are
above these limits. The only test that is approved is for Huntington’s Disease’ [5].

It is fairly unremarkable that some of us would prefer that institutions such as
insurance companies not have access to at least some genetic information. This is
because there is no need for them to have access to the information unless they plan
to make use of it, and we may fear that we would be disadvantaged by this use. For
example, if we carry a gene that is associated with a higher risk of, say, glaucoma,
which might be taken as an indication of risk while driving, our car insurance
premiums might rise. The problem is, though, that there are corresponding situations
in which institutions like insurance companies would prefer to have the information
in question. More, those situations in which we would prefer insurers not to have it
are reasonably likely to be precisely those in which they would contend that it is
especially important to have access: a person who (rationally enough) withholds
information about susceptibility to glaucoma on the grounds that it will increase his
premium might expect to be told that the premium is calculated according to risk,
and that that information is crucial in deciding how much of a risk he presents.
Conversely, we might sometimes prefer that insurers do have, and make use of, the
information, because it may work to our advantage if, for example, we could show that we definitely did not carry a gene associated with glaucoma. I will come back to this later.

I take it as axiomatic that—if a firm can be said to be the sort of thing that has interests at all—the insurer has an interest in knowing information like this. (As we will see later, even if the axiom is false, it does not follow that insures should not have it.) Its business model, not to say its survival, relies on being able accurately to assess risk and attach a price to it. This requires information, without which the firm would be more likely to fail. Of course, merely asserting an interest does not suffice to show that one has a claim to a good or commodity: if it did, then Terry would be forced to accept Gerry’s violation of his privacy, which is something I am prepared to deny. However, it is the starting point for an argument. In this case, the argument would be directed at working out how we should distribute access to the information and how policymakers in a hypothetical polity might go about deciding what, if anything, the law should do to regulate access to, and use of, genetic information.

We should note that the insurer’s claim does not stand or fall depending on its ability to identify an interest in the information. An insurance contract is, at the end of the day, just another contract; and so it is reasonable to assume that both parties to it should be able to access pertinent information, lest the contract be considered void. This assumption is quite explicit in law: as a general rule, insurance contracts are considered by the law to be uberrimae fidei—of the utmost good faith. This means that if relevant information is not disclosed, that may be enough for one party to treat the contract as though it never existed. Moreover, ‘the proposer’s opinion as to the materiality of non-disclosed facts is irrelevant even though they may well have acted in good faith. It is the law that a man may act in perfect good faith within the ordinary meaning of the phrase, yet still be held not to have acted in the utmost good faith in the legal sense’ [6, p. 6] (slightly modified).

Thus, if the potential client—call her Kerry—knows something that would be relevant to the person selling insurance—call her Perry—she may have a legal duty to reveal it. But she may also have a moral duty to disclose, for the sake of maintaining the freedom of all parties to make decisions for themselves. That is, I am assuming that Perry has an interest in making a decision to enter into a contract freely that is logically separable from her interest in whatever she may receive from the contract.

Moreover, the operation of a free insurance market relies on the idea that all parties can negotiate the price for a good or service based on perfect knowledge, or knowledge that is at the very least as good as possible. For sure, both parties will be trying to get the best deal for themselves—Kerry will want to minimise the cost of buying a policy, and the insurance agent Perry will want to minimise the costs potentially incurred if a claim is made. Kerry does therefore have an incentive to withhold information, and might have some kind of entitlement to do so; but potential sellers have a competing incentive to obtain it, and might have some kind of entitlement of their own. It would be unfair to Kerry if Perry added clauses to the contract without telling her, just because Kerry has—it is reasonable to assume—a right to information about her contract and the likelihood that it will pay out. But, pari passu, it is hard to see why roughly the same thing might not be said on behalf
of Perry: she has the right to know what risks Kerry faces, so that a fair price can be put on it, and the insurer will not be left out of pocket. Whether a free market for insurance is desirable is something to which I will return.

So there is a question to be answered: does Perry, who represents the insurer, have a claim to genetic information about Kerry that is sufficient to warrant infringing Kerry’s privacy? It ought to be fairly easy to see the parallel between what I have in mind here and what would apply in the Gerry and Terry case. To solve the G&T problem, we would work out what it would be just to let Gerry know—what kind of information he should have and how much—given that it will impinge on what we ordinarily consider to be Terry’s prima facie rights. We might decide that, in relation to a gene associated with a serious but easily-preventable condition, Gerry’s putative right to access the information trumps Terry’s putative right to privacy; we might not, too. In relation to a gene associated with something trivial, or for which there is no treatment on offer, we might decide that there is no real merit in violating privacy, and so shift the fulcrum of the scales of justice. In all cases, we would be weighing one claim against another. As for Gerry and Terry, so for Kerry and Perry.

The task would require that we take seriously both the insurer’s claim about a right to access the information and Kerry’s claim about a right to deny access. We can take a stab at resolving this question by making an appeal to justice. In this case, the question would not be one of who has what privileges over the information; rather, it is a question of how we should decide how to divvy it up, granted the hypothesis that no one has ab initio privileged access but more than one person may have an interest. And it is quite possible that we would discover that justice demands that the information be shared with insurers. Clearly, this discovery might well have implications for how policymakers in our hypothetical polity would regulate genetic information. Over the next few paragraphs, I will briefly outline the factors that could lead us to this conclusion.

Justice for insurers?

An important question that needs to be answered is whether it is true that companies have interests, or interests of the kind morally weighty enough to yield anything like at least a prima facie right to genetic information, to begin with. One might talk in terms of interests, but it is possible to think without incoherence that for an entity’s interests to be morally important, the entity has to be a person, or some kind of sentient being. Additionally, there is a much bigger question about the ontological status of a corporation: is it a thing in its own right, let alone the sort of thing that can have interests? If it turns out that corporations do not exist as anything except terms of art, or that if they do, they are not the kind of thing that can have morally important interests to defend, then Kerry’s interest in maintaining her genetic privacy may go through by default. But it is not unreasonable to think that firms might meaningfully be said to have, or at least to represent, morally important interests. This is for several reasons.
First, queries about the ontological status of the firm are misguided. In the example above, I treated Perry as the representative of a firm; but she does not have to be. Imagine instead that Kerry is reluctant to buy an insurance policy from a corporation, but that Perry is a wealthy friend who is, as it happens, well versed in statistics. Perry offers to cover Kerry’s liabilities in the event of misfortune. In return, Kerry will pay Perry a small amount, calculated according to the size of the liability and the chance that Perry will have to pay out during the period of the agreement. In this version of the story, Perry would appear to have a moral claim to relevant information; and there are times in which genetic information might be relevant. Perry is still, in effect, selling insurance to Kerry; but worries about the power differential between the lone individual and the large corporation can be set aside. What matters is the question of whether or not Perry has an entitlement to certain information—and she might well.

But if Kerry has an obligation to one rich friend, then why not the same obligation to two less-rich (but cumulatively rich-enough) friends? Or three? Or a few hundred? Why not, in short, a firm? Maybe what makes the difference is that Kerry can be friends with a certain number of specific people, but cannot be friends with a group of people arranged into a commercial organisation. Friendship is certainly morally important: I might have obligations to friends that I do not have to others. However, my obligation to be honest with friends about relevant information does not seem to me to be based on any appeal to the moral importance of friendship: rather, it has to do with honesty being recommended in its own right. Whatever obligations we have to friends that we do not have to others, it does not seem self-evident that honesty is one of them: we owe that to everyone.

Second, and perhaps more importantly, there is no reason to suppose that the moral difference between an individual and a firm is all that compelling to begin with. For while there is something intuitively odd about the idea that a company might have the same kind of moral footing as an individual, we do quite naturally tend to think of companies as the kinds of thing to which responsibilities can be assigned. This assignation can be either retrospective, as when we seek to assign sanction for companies’ having done things we would have preferred undone (perhaps, for the sake of argument, when they have made use of genetic data in a way we think they ought not), or prospective, as when we decide that they should behave in certain ways (as when we say that, henceforward, they should foreswear the use of genetic data when it comes to calculating insurance premiums). Corporations do, therefore, appear to have some moral substance; and if they are substantial enough to have responsibilities, it is not obvious why they cannot in principle be substantial enough to have something at least resembling rights.

But even if one rejects the notion of a corporate moral status comparable to that of persons, the point would still stand that a firm can be characterised as being nothing but the representation of a group of other stakeholders; and in the case of an insurance company, those stakeholders will be the owners or shareholders, and the other policyholders. Quite plausibly, agreements with companies are simply

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1 For a recent example of arguments along these lines, see Dempsey [7] and Dubbink and Smith [8], each of which supplements an intriguing argument with a good list of the voluminous literature on this topic.
agreements with the stakeholders in those companies at one remove; and, *qua*
stakeholders, there is a justice claim to be made here about access to information: they might well have a reasonable interest in having information accessible, even if the company that acts as a cipher does not have any rights or interests of its own. Among these lines, it would be plausible for shareholders to complain that they were being unfairly expected to carry the cost of agreements entered into on incomplete information: again, if Kerry were prevented from knowing some detail about the policy she was about to sign, we might well think that this situation would demand remedy, and it is hard to see why the same considerations would not apply in the other direction.

Is any of this modified by the fact that firms and their shareholders are motivated by profit? We might think that it is. After all, seen in this light, the process of negotiating a premium is effectively a game of strategy in which insurers are looking to maximise what they can charge and minimise what they pay out. This is not a game that invites much in the way of generosity from those firms—the ad-man’s insistence that insurance companies really care about their clients is reassuring, but it is a myth; and we might think that there is not all that much reason to make life easy for firms that, in the end, only have their own interests at heart. Disclosure, seen through this prism, may not seem all that attractive. However, there is an all-too-easy *tu quoque* response to this, since it is not only companies that will be looking to secure the best outcome for themselves: customers will also be looking to minimise what they are charged and maximise what they are paid. The reason why a person like Kerry would *not* want to share genetic information with an insurer is—presumably—so that she can ensure a favourable price for herself. The motivating attitude is the same for companies as it is for clients. And so if it is wrong for Perry and her colleagues to seek to maximise benefit and minimise outlay for themselves, then the same would seem to apply, at least on the face of things, to Kerry—by implication, she should disclose.

Maybe the profit objection is a little blunt, then. Maybe we should worry less about profit than about *profiteering*. By this, I mean that the worry might be not so much that firms are looking to make the outcome as good as possible for themselves, as that they are doing so from a point of unfair advantage. Insurance cover is a necessity for many quite everyday things; to some extent, Perry and her boardroom colleagues already have potential clients at a disadvantage. This is compounded by the fact that insurance companies have the actuarial muscle to name their price—few people, if any, would have the wherewithal to challenge the method by which a quotation is calculated. As such, the disclosure of information about a person’s genome might not be conducive to a fair price; rather, it might allow firms to squeeze clients until the pips squeak.

Would the disclosure of information allow profiteering, though? It might, but we should also note that the nature of the relationship between information and profit in a free market means that the charge of profiteering does not always stick. One of the features that characterises a free market is that both buyers and sellers have full information—which is to say, there is full disclosure and knowledge of risk profiles. But what is important to keep in mind is that, in a perfect market, profits would tend towards zero. This is because, if an insurer is making a profit from Kerry of £5 *per*
annum, a rival will know this, and be incentivised to enter the market and offer a similar policy at a lower price. This rival will make a smaller profit, for sure—say, £4 per annum—but since he gets the business, this does not matter: what matters is that he makes a profit at all, and ends up £4 better off than he would have been. This cycle can continue more-or-less indefinitely, on the Micawberish principle that all that matters is that some profit will be generated for there to be an incentive to enter the market. It is only when the expected profit reaches a level that is, to all intents and purposes, zero that there will be no further incentive for someone else to make a new bid for Kerry’s customers. In a perfect market, there is no room for profiteering—there is very nearly no room for profit.

And yet a perfect market is one in which information is shared. This is enough, I think, to show that sharing information will not necessarily lead to profiteering at the client’s expense. True, the real world is not one in which markets operate perfectly. But the point stands that it is market imperfection that makes profiteering possible; what matters at this stage of the argument is simply that Kerry’s genetic information being made available to Perry is not necessarily going to result in her being exploited. Indeed, if we believe that a perfect market minimises the chance of profiteering, we might be forced not only to accept, but to embrace, Kerry’s information being publicly available, inasmuch as it is a step towards perfecting the market. Denying this appears to commit us to the belief that all the steps from market imperfection to perfection need to be made in concert—that if any is made on its own, the situation will be worse. I confess that this might actually be true, but I cannot address that issue here. The gist of the argument remains sound, though: information-sharing in a perfect market militates against profiteering.

All the same, we might have precious little sympathy for the kind of people who own insurance companies, and lose no sleep over the idea that they might prefer that information be shared. But I shall put that to one side for a moment in order to concentrate on the policyholders, who are the source of a second argument against maintaining privacy.

It is not uncommon to hear that one of the problems facing the car insurance industry is that firms have to cover the cost of uninsured drivers; and this means higher premiums for the rest of us. If we are inclined to complain about those higher premiums—as well we might—it would be quite natural, and quite sensible, to frame that complaint in terms of the injustice of having to pay more because of others’ refusal to pay anything.

The situation that would arise if Kerry kept relevant information to herself is slightly different, but it is clearly related. As noted, she does have an incentive to keep to herself information that might be relevant to her risk profile. If clients are allowed to keep such information private, insurers will know that. They will not necessarily know that Kerry has an elevated risk profile; but they will be able to make an educated guess that at least some of their clients will generate higher risk, and to what degree. Being rational actors, they will therefore act on the assumption that the aggregate real risk to which they are trying to attach a price is at least slightly higher than the aggregate declared risk. In practice—assuming for the moment that insurers have no access to things like family history, which could serve some of the function of a genetic test—this means that they will increase premiums...
across the board to reflect not so much the elevated risk presented by one particular client as the risk that any given client might be the one with an elevated risk profile. The long and the short of it is that everyone could conceivably end up paying a little bit more than they otherwise might.

Now, other policyholders may complain that it is not fair that their premiums are set at a level to take account of the lack of information from Kerry. If this complaint is well-founded, it might be said that Kerry has a justice-based obligation to disclose not because of the respect that is due to Perry’s interests, but because of the respect that is due to the interests of other people in her position—people like Gerry and Terry and you and me. It is for this reason that I claimed a few paragraphs ago that it does not really matter if firms turn out not to have interests in accessing information in their own right. Once again, justice might be on Kerry’s side on this occasion; but there is no a priori reason to think that it would be, and the question we have to ask has to do, once again, with the just allocation of information.

Interestingly enough, a world in which people like Kerry know but are permitted not to share information about their genome might actually be worse for them. In this world, Kerry can assess the risk that she will suffer from, say, cancer. The lower her risk, the more rational it will be to avoid the cost of buying insurance against it. Correspondingly, those with the greatest incentive to insure will be those with an elevated risk. But this means that the whole market will be skewed, such that there will be an unrealistically high proportion of high-risk people buying. This will force up prices, effectively forcing those at high risk to pay more than they would have otherwise. As Andrew McGee notes,

widespread genetic testing has the potential to undermine the life assurance industry. At present the industry works on the basis that those who live long will by the premiums pay for those who die young, all parties taking a gamble on their life expectancy when the policy is taken out. If the element of gamble is significantly reduced, then it may be that those with a long life expectancy will be less inclined to insure, leaving only a pool of poorer risks, whose premiums will have to increase to a point where insurance may be too expensive for them. On this theory the industry would do well to discourage the practice of genetic testing. [9, p. 74]

As it happens, Hoy and Witt modelled what would happen if proposers were allowed to know their own genetic risk but keep that information from insurers:

the size of adverse selection costs generated by a regulation prohibiting insurers from using genetic test results for the BRCA1/2 genes would probably be very modest in most circumstances. Thus, equity and privacy arguments that favor such regulation would not pale in comparison. However, for some higher-risk family background types, if women in sufficient numbers obtain genetic tests, then adverse selection costs from such regulation could be substantial [emphasis added]. This points to the possibility that as genetic information in society grows, there may come a point when genetic privacy may not be desirable. [10, p. 525]
The claim that privacy would not be desirable rests on the finding that full candour would result in some people paying higher premiums, but that this effect would be in line with actuarial fairness \cite[p. 536]{10}. This suggests that the adverse-selection problem may not be as pervasive as often feared. But there are still possible situations in which allowing the proposer but not the insurer to know her genetic profile may be the worst arrangement in terms of fairness. The idea that sharing information will always work against those at high risk is not always true.

**The problem of discrimination**

Much of what I have argued up to this point revolves around claims about actuarial fairness and market efficiency. But while actuarial fairness and market efficiency are undoubtedly important when it comes to deciding what is just, it is implausible to think that they are the whole story.

One reason to think that the just distribution of access to genetic information would exclude insurers is based on a wider appeal to problems of discrimination: the idea that people would be excluded from access to a market like the insurance market for reasons over which they have no control. Just as it would be unjust and discriminatory to refuse a person insurance coverage on the basis of ethnicity, so it would be unjust and discriminatory to refuse her on the basis of any other fact about her constitution.

How compelling is this argument? Not very, as it turns out. The mere fact that an insurer discriminates ought not to be surprising, because that is how they work. Nor is the mere fact that someone discriminates sufficient to demonstrate injustice. For example, the leisure centre might discriminate according to sex, inasmuch as that there are some areas (changing rooms, toilets, and so on) to which members of one sex do not have access; and if this is acceptable, it ought to suffice to show that merely showing discrimination is not enough to show injustice. Having said that, of course, there are forms of discrimination that are unjust; the question to confront here is one of whether an insurer charging a higher premium to someone on the basis of her DNA is an example of unjust discrimination.

On this note, the analogy with ethnicity is misleading, because there’s no link between ethnicity and risk: Afro-Caribbean people are not worse drivers, Scandinavians are not unusually careless with power tools, and so on. To use ethnicity in decisions about insurance would, therefore, be arbitrary, and that is what makes it indefensible. Meanwhile, though there might be certain medical conditions that are more strongly associated with a particular ethnic group, it is having the condition, or the gene that is associated with it, that carries the weight here, rather than membership of the ethnic group per se. Admittedly, some insurers might use ethnicity in such cases as a rough guide to risk for such conditions; but this is something of a blunderbuss approach, and these insurers would quickly find themselves out-competed by others with a more precise algorithm who could therefore calculate premiums based on actual risk. Insurers ought therefore to recognise a commercial reason to avoid a pricing strategy based on ethnicity even if they happen to be indifferent to the moral one.
At least sometimes, genetic information is different: carrying a gene associated with glaucoma might be relevant to car insurers; a disposition towards a life-threatening illness is not irrelevant when it comes to life insurance. So the mere fact that there is discrimination would not debar an insurer from gaining access to information in many circumstances. Besides, as I have hinted, there might be people who would benefit from having their genetic information accessed, and they might be able to make a claim that they are being discriminated against if this is forbidden.

However, even here, worries about discrimination may reflect a tacit assumption that insurers are more stupid than they actually are. Suppose that Kerry really is at an elevated risk of some genetic illness. It would be very strange to think that she would be uninsurable: there would still be a market for her risk. (The real world reflects this: gay men found themselves uninsurable at the beginning of the 80s due to worries about AIDS, but it did not take long for new entrants to the insurance market to appear who were willing to take the chance; and once the market opened up, being gay began to assume its true actuarial relevance, which is almost nothing.) And because genes are only one factor in illness, it is not a given that she would be priced very much higher to begin with. Even in cases where a disease is caused by just one gene, no one can be absolutely certain that that gene will make a difference to Kerry’s life: lifestyle, or the counterbalancing effect of some other gene, may mean that whatever illness she is susceptible to will never materialise; and the fact that she lives next to a major bus route may, for the most mundane of reasons, mean that she does not live long enough for the gene to do its work anyway. (Remember that this was one of the considerations that counted against Gerry having access to genetic information that would violate Terry’s privacy: the information may not be nearly as useful or important as Gerry thinks.)

If Perry is a sensible insurer, she may ask that Kerry take certain health tests when her policy is up for renewal because of her genetic susceptibility—but the susceptibility in its own right need not be all that much of a worry. Neither is it implausible that Perry would make this request anyway. For example, if Perry is selling a policy against the risks of breast cancer, she might well want assurance that Kerry is displaying no irregularities in her breast tissue before agreeing a price; but this need have nothing to do with whether or not Kerry carries BRCA-1. It is the irregularities that will worry Perry; and if there is none at the time of policy renewal, she will likely as not happily insure Kerry irrespective of Kerry’s genetic profile: there is a profit to be made where there is a sellable policy.

Information, justice, and basic goods

What might be problematic is a slight extension of this, in which an insurer’s refusal to give coverage means that the would-be emptor is denied a basic good. Particularly, Perry would have a reason to increase Kerry’s premiums to an unaffordable level, or to refuse to sell insurance entirely, should any irregularity arise. This would leave Kerry stranded, unable to buy insurance at the point when she most needs it, because she needs the healthcare that it will buy.
However, the power of this argument obviously depends on the idea that healthcare is only going to be available by private means. This does not have to be the case. The affordability or otherwise of health insurance is only really morally important if one’s access to a basic good like healthcare depends on having it; but if we think that healthcare is a basic good, it is not implausible to think that the community should provide it anyway, without having to advert to the tender mercies of the open market. This being the case, debates about the affordability or otherwise of health insurance would evaporate. If there were still a market for it, it would be one that people could choose to enter as a means of supplementing what would be available as a matter of course. For sure, there might still be people unable to afford insurance for whatever reason—but this does not have to be any more problematic than their inability to afford expensive but unnecessary consumer goods.

Insurance is, of course, often necessary for other things. For example, it is illegal in the UK to drive without motor insurance, but such insurance might be more expensive for some people because of some quirk of their genome. But is it, in the grand scheme of things, a given that people need motor insurance? It is if they are going to drive; but the necessity of driving is influenced by considerations like the availability of decent public transport, town planning decisions that determine whether the distance between people’s houses and the shops is walkable, and so on. It is not beyond the realm of possibility that the “need” for private transport is illusory, and that, if we arranged the world differently, people would be able to get by perfectly well without it. City-dwellers often manage without a car already; if Kerry cannot afford motor insurance, it is possible that the root of her problem has less to do with her genes than with her being a suburbanite.

And the same considerations apply in other areas in which insurance is a necessity. Getting a mortgage might well depend on taking out an insurance policy so that payments are protected in the event of illness; and people with certain genes may be effectively priced out of the market. But, again, much of the worry here depends on taking it as read that it is important that people be the owners of property. This can be doubted. A world in which people do not own their homes—one in which they let homes from either a private landlord or from the state on behalf of the community—is not obviously any less just for that. The inability to get a mortgage might be a problem in a world in which we take private property ownership for granted and in which we tend to think of non-owners as potentially dispossessed; but we do not have to accept this world. The inability to get a mortgage may not matter in a world arranged slightly differently; and in this case, Kerry’s genome would not be economically important.

The point is that problems such as this may not be solved exclusively by refusing to share information; there might well be other ways. Having said that, a counterposition might be this: it is all very well to say that hypothetical policymakers drawing up laws for hypothetical polities from behind something like a Rawlsian veil would allow insurers access to information, but they would, presumably, also ensure that everyone is still reasonably-well catered for even without private insurance as part of the same process. But the justice of sharing information in the real world, where people are often not reasonably-well catered for by default, and may lose out on access to certain goods, is not nearly so clear. It
might be unjust to apply ideal-world reasoning such as that sketched above to a non-ideal world.

This is a powerful point. However, I am not proposing to throw open the medical records in practice: I am suggesting merely that we do not have to take informational privilege for granted when thinking about genetic data; and if we do not, we can deny that Gerry or Terry, or Kerry or Perry, has a fundamental right to control information. What rights there are will be assigned according to what is assessed to be just, given some agreed rubric to determine justice. It may turn out that justice requires denying Perry a right to the information in some, or even all, real-world situations; and to all intents and purposes, this would amount to Kerry having a right not to share it. But this right of Kerry’s would not be inalienable; if the circumstances change, so might the scope of her justifiable claims.

Solving a puzzle and creating an oddity

I am therefore left with the idea that there could in principle be a justice-based claim for insurers to have access to genetic information: the insurers themselves have an interest in accessing and using it, but other policyholders also have an interest in its being shared. It will not always go through without a comment; but there will be certain circumstances in which it will be possible for an insurer, or someone of the like, to make a case to have access to a person’s genetic data, and in which this case will be sufficiently strong to overwhelm that person’s prima facie claim to privacy. Even if this is not the world we would necessarily want to inhabit, it might be just: nowhere is it written that just outcomes must make everyone happy.

But this conclusion does itself suggest something distinctly odd. I have already mentioned that a just settlement to the G&T problem might sometimes be to let Gerry have the information, but that it might sometimes be the opposite: Gerry might at times have a justice-based duty to remain in ignorance. Now, suppose that the gene for which the test is performed is associated with an elevated susceptibility to an illness that could shorten his working life, and for which there is no prophylaxis. The absence of treatment might add power to the thought that there is really no need for Gerry to learn the details of his genome: if and when the illness manifests, he can still be treated in just the same way as he would be without the test. This thought would be accentuated if the increase in his risk were only small. In this sort of case, not a great deal of benefit would appear to derive from Gerry learning about his genome; the point is that there are certain possible permutations of events in which Terry’s claim to privacy would prevail against Gerry’s desire to know.

But now suppose that Gerry is a homeowner and has the associated insurance policy intended to protect his mortgage payments in the event that he should no longer be able to work. In this situation, Perry the insurer might plausibly have a claim that a just distribution of information would allow her access to information about Gerry’s genome so that she knows what price would be appropriate. For the sake of the argument, assume that in practice, Gerry’s premium would rise in cost by only a small amount, if at all: he would certainly not be excluded from affordable
cover. So there would seem to be a slightly strange, but possible, world in which Gerry might be less entitled to know genetic information about himself than Perry is, and that this would be just, even though it is Gerry’s genome that is at the centre of the debate. And that is quite interesting.

I admit that I have not wholly decided whether this is a defence of information-sharing with insurers or a reductio ad absurdum. My hunch is that the latter option is closer to the mark, and that arguments between Gerry and Terry, and Kerry and Perry point to rather deep problems about the concept of privacy vis-à-vis genetic information. But these are problems that will require further examination elsewhere.

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