

Genetic Information, Discrimination, Philosophical Pluralism and Politics

In the paper 'Genetic Information, Insurance, and a Pluralistic Approach to Justice' Jonathan Pugh develops an argument from unresolved pluralism in our theories of justice, via the pluralism this occasions in relation to the specific question of the use of Genetic Test Results (GTRs) in insurance underwriting, to the conclusion that the UK regulatory approach in relation to the use of GTRs in insurance is broadly correct [1]. Pugh's argument is wide-ranging and I cannot provide a complete critique of it in this short comment, but I will gesture towards some strands of the argument that are potentially problematic.

The first potential problem in the argument is that Pugh bases his argument on a very extensive range of accounts of justice including pure maximising consequentialism (he calls it 'utilitarianism'), strict egalitarianism, and libertarianism among many others. If these are all accounts of justice, it is not strange that there is pluralism of conclusions in relation to a specific question of justice or discrimination, such as the use of GTRs in the underwriting of specific kinds of insurance contracts. Pugh's range, for instance includes accounts of justice that deny the direct importance of distributive concerns as well as accounts that see distributive concerns as crucial. These accounts not only disagree about the answer to Pugh's question, but also about whether taxation is theft, a legislated minimum wage can be justified and many other justice issues that are settled in modern welfare states. This matters because there is an unacknowledged slide in Pugh's use of the fact of pluralism in his arguments, e.g. when he writes;

'Of course, we can have strong reasons to endorse revisionary conclusions if they receive **strong pluralistic support**. However, in the final section, I shall suggest that although O'Neill's argument receives considerable pluralist support, **this support is not total**; ...' [1, my emphasis]

Here the requirement changes from 'strong pluralistic support' to total support, and we know in advance that if we make our range of accounts of justice wide enough we are never going to get total or unanimous, unqualified pluralistic support. A requirement of total support loads the dice against any social policy.

The second is the question of what is doing the work here, is it the philosophical analysis, or an analysis of what is politically possible in the UK. Pugh writes that:

'... there are ground for scepticism about the extent to [which] philosophical arguments will be sufficient to motivate this revisionary approach amongst policy-makers, especially given that there is room for reasonable disagreement about what justice may demand here.' [1]

But, as he himself points out in the introduction to his paper, many countries have chosen a different, more revisionary regulatory path than the UK. So, either their policy-makers must have been sufficiently motivated by the extant philosophical arguments at the time they made the decision and UK policy-makers could be similarly motivated if they took the arguments seriously, or the role of philosophical arguments in policy-making may not be particularly strong.

This brings us to the third problem, the characterisation of the UK situation and policy-making context. Pugh places some weight on a distinction between social insurance and mutual insurance and claims that the National Health Service (NHS) is an example of a social insurance scheme, where different conceptions of justice are appropriate than in a mutual insurance scheme. But, characterising the NHS as a social **insurance** scheme is problematic because it misrepresents the

rights of citizens and their relationship to the NHS. The NHS is a fully tax-based system without hypothecation, so there is no particular amount of money paid into the scheme by anyone; and citizens do not have any rights to receive specific services from the system either, with a few exceptions. It is thus not really an insurance scheme in any meaningful sense, and using it as the example of one is therefore problematic. The other issue about context is that there is no discussion of why someone in the UK might need to take out Life, Critical Illness, or Income Protection insurance. Among wealthy nations with some kind of commitment to a social security system, the UK has one of the stingiest systems, for those who have to rely on the state. Statutory sick pay is very low as are the amounts paid by the various schemes providing support for those without income [2]. This means that insurance becomes a basic social need for the self-employed or the, mostly lower-paid workers who do not have some kind of life insurance in their pension scheme or proper sick pay in their employment contract. If they want to protect themselves or their families from abject immiseration they have to buy insurance. This perhaps points towards a stronger reliance on Rawlsian accounts of justice in relation to basic needs, than on maximising consequentialism or libertarianism in analysing questions of justice for these kinds of insurance. However, to be fair we must note that this consideration strangely enough points towards these kinds of insurance being more important in the UK than in some of the countries that have prohibited the use of genetic test results for underwriting.

Finally, a slightly more pedantic point. Pugh claims in the introduction that the Council of Europe Oviedo Convention prohibits the use of GTRs for underwriting [3]. This is referenced to Nill et al [4], who do not argue for the claim themselves, but in turn references the claim to Otlowski et al [5]. However, it is not obvious that the claim is true despite Otlowski et al's arguments. Article 12 of the Convention prohibits predictive genetic testing that is not 'for health purposes or for scientific research linked to health purpose' and Article 11 states that 'Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.' It is clear that Article 11 is not prohibiting 'discrimination' in the neutral sense of treating differently, since it clearly allow situations where health care professionals discriminate between those with certain genes who need treatment or preventive interventions because they have those genes, and those without the genes. So, 'discrimination' has to be read as problematic discrimination to make sense of Article 11, and as Pugh amply demonstrates classifying the use of GTRs in insurance underwriting as **problematic discrimination** requires argument.

References:

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