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NHS Genomic Medicine Service's Test Directory: shaping a new knowledge-control regime of genetic and genomic testing services

Abstract

To understand how infrastructures govern and shape social order, the way infrastructures itself are shaped and built upon other infrastructures needs to be considered too. The infrastructure of NHS England's Genomic Medicine Service (GMS) is a good example of this. The GMS introduces whole-genome sequencing in NHS England and has resulted in a reorganisation of their genetic and genomic testing services and a new knowledge-control regime of genetic and genomic testing. This regime has a more centralised governing structure, introduces new actors and collaborations, and redefines the boundaries between research and care in the NHS genetics and genomics services. Key to enacting this regime is the Test Directory that is central to its infrastructure. The TD regulates what genetic and genomic tests can be done by the NHS, what technology will be used, what genes will be looked at for potentially pathological variants and consequently determines what data will be produced by and in the GMS. In this paper, I discuss how the Test Directory shapes the new knowledge-control regime and how this is shaped as well by the wider history of genetic testing in the UK and the specific and evolving institutional settings in which the GMS developed. To do this, I outline 1) how the Test Directory has been constructed and builds upon and is different from the pre-existing directory of the UK Genetic Testing Network; 2) how it is shaping and has shaped the GMS, 3) I will highlight how the ambition of stimulating a genomics industry helps understand the particular form the test directory and the knowledge-control regime take.

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