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Infrastructures and knowledge-control regimes

In my presentation, I discussed how the infrastructure of NHS England's newly implemented Genomic Medicine Service (GMS) is key in shaping a new knowledge-control regime that changes the governance of genetic and genomic testing in the NHS. With the GMS, the UK government not only intends to increase the provision of genomic testing in England, but it also intends to create a new innovation system that should help leverage the NHS to support a genomics and life science industry (e.g. Davies, 2017; HM Government, 2012). As I discussed, the infrastructure, and especially the test directory, is key to this. The GMS infrastructure can, therefore, be seen as an example of what DeNardis and Musiani (2016, p. 5) describe as governance by infrastructure: the co-optation of infrastructures 'for purposes other than those for which they were initially designed'. However, in the case of the GMS, it is not a form of internet infrastructure but a knowledge infrastructure that is being used to drive changes. In the remainder of this position paper, I focus on outlining my conceptual approach to analysing how a knowledge infrastructure can shape the governance of genomic and genetic testing in the NHS. For my more empirical discussion of the GMS infrastructure, watch and listen to my presentation.

My understanding of infrastructures is based on the work done by Susan Leigh Star and others building upon that. Following this body of work, infrastructures are not understood as just material and technological elements. Instead, they should be understood as sociotechnical systems that make things work and consist of an ecology of various technological, social, cultural, and organisational elements (e.g. Bowker and Star, 2000; Edwards et al., 2009, 2013; Star and Ruhleder, 1996). Key aspects of infrastructures are that they are embedded in other structures and sociotechnical arrangements, they work across communities and sites, and are built upon existing structures. Additionally, they are relational because they only come into existence 'in relation to organized practices' (Star and Ruhleder, 1996, p. 113). They cannot be separated from their use and only get meaning in their use. What appears as an infrastructure is therefore not the same for everyone. This means as well that changing or developing infrastructures will affect different people and groups in different ways and this can cause tensions and resistance. For example, some work practices will be better aligned with a new infrastructure than others and some forms of knowledge will be preferred over others. This can bring changes to who has power and authority (Edwards et al., 2013). This indicates that infrastructures have the capability to change governance and affect social life significantly. However, it does not specify how infrastructures can shape governance and power. I try to offer some mechanisms for that in the remainder by discussing scales of infrastructure and introducing the concept of knowledge-control regimes.

Infrastructures operate on and are connected to multiple scales (Karasti and Blomberg, 2018; Star and Ruhleder, 1996). Ribes and Finholt (2009) discuss three scales of infrastructures, which can be used as sensitising concepts to analyse the different activities involved in the development of infrastructures and which I extend to analyse the organisational and governance effects of an infrastructure. These three scales are 1) enacting technology, 2) organising work, and 3) institutionalising. Enacting technology focuses on the work that needs to be done to create a stable technology and infrastructure for everyday and future use. Organising work focuses on the practical work, including maintenance, development, and management, and organisational arrangements involved in developing and using the infrastructure. Institutionalising brings attention to the long term goals and aims beyond the project itself that the infrastructure is intended to achieve. In my case of the GMS, that means looking at how the infrastructure is created, for example the creation of the test directory I discussed in my presentation. I also look at the organisation arrangements that are needed to keep the test directory working and focused on how the test directory may contribute to the wider goals set out for the GMS. Especially, by comparing the organisational arrangements with previous arrangements and by looking at the wider goals, using these scales can highlight how power and authority and subsequently governance shift as the result of the GMS infrastructure.

To help further understand the processes through which infrastructure can shape organisations and governance, the concept of knowledge-control regimes is useful. Introducing this concept to analyse changes brought forward by the Human Genome Project, Hilgartner (2017, p. 9) defines a knowledge-control regime as 'a sociotechnical arrangement that constitutes categories of agents, spaces, objects, and relationships among them in a manner that allocates entitlements and burdens pertaining to knowledge'. They regulate the access and use of knowledge, which in the GMS would be ultimately about the use of genomic data and knowledge. Knowledge-control regimes are produced through governing frames and the control of objects, jurisdictions, and relationships. Governing frames structure action and interpretations of the situation. They structure what actors can do and have access to, the relationships between actors, and what objects are involved. The control of objects is about the control, use, access, and creation of knowledge objects, which are objects 'that contain or constitute knowledge' (Hilgartner, 2017, p. 7). This can be data, people, techniques and many more things. The control of jurisdictions is about boundary work done to designate something as one or the other, for example classifying certain things or practices as research or care or who gets involved in decision-making or not. Lastly, the control of relationships is about shaping the relationships between different actors involved and how actors can interact with each other. For example, it may structure who can collaborate or who is accountable to each other. Looking at these three interconnected dimensions of knowledge-control regimes, allows me to study the governance and control of the GMS and specify changes between the genetic testing services before the GMS and now.

But how are infrastructures and knowledge-control regimes related? Both can structure actions, knowledge-control regimes more institutionally and infrastructures more materially. However, more relevant here is that I would argue that infrastructures can constitute or set the conditions for a knowledge-control regime, especially knowledge infrastructures. Infrastructures such as the GMS infrastructure influence who can access and use certain knowledge and how new genomic knowledge will be produced. In that way, infrastructures can be viewed as part of knowledge-control regimes. In the case of the GMS, where a separate infrastructure has been created to transform the previous existing genetic testing services, the infrastructure can be seen as constitutive of a new knowledge-control regime changing the control of access and use of genomic data and knowledge. It is important then to look at how an infrastructure shapes the control of objects, jurisdictions, and relationships as through them it is one way in which governance by infrastructures can happen. The concept of knowledge-control regimes is therefore a valuable conceptual tool in analysing and studying the role of infrastructures in governance.

References

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