

## Personalization in Healthcare and Medicine 31 May - 1 June 2012

### Symposium Report

This symposium took place over two days at Lancaster University, involving 19 participants from Great Britain, Netherlands, France and Norway. It was organized around three areas: i) diagnostics and clinical environments, ii) do-it-yourself (DIY) applications in health and self care, and iii) conceptual developments and orientations in relation to personalized medicine. The second day of the meeting concluded with a discussion of existing and upcoming funding opportunities and of ideas for future networking and collaborations.

In the first session, **Stuart Hogarth** (King's College London) talked about mapping the emergence of a socio-technical regime for personalized medicine in the bioeconomy of competition and regulatory states. Stuart sketched out the pivotal roles of *intellectual property right*, *corporatization* and *regulation* in facilitating the translation of post-genomics into the clinic in the shape of personalized or stratified medicine. **Michael Hopkins** (Sussex University) spoke of genomics-related diagnostic innovations in medicine, in particular, the move from genetic testing for rare diseases towards the testing for biomarkers associated with cancers and susceptibility to common diseases. Michael also highlighted the vexed issues of intellectual property rights and the way in which patents might 'cast a shadow' over ongoing research. **Adam Hedgecoe** (Cardiff University) focused on the clinical uptake of personalized medicine, arguing that uptake was not being driven by clinicians but by regulators, industry and government. He cautioned that a simplistic economic model to explain the uptake of pharmacogenomic testing was insufficient to explain the variation seen amongst different clinical specialities. Continuing the focus on the clinic, **Rebecca Dimond** (Cardiff University) asked how the patient experience and identities might be re-shaped under a regime of personalized medicine. Drawing on her research with orphan disease patient groups, she reflected on the kinds of patient mobilization that could be formed around pharmacogenomic biomarkers.

In the second session, **Kate Weiner** (Manchester University) spoke of common expectations surrounding DIY techniques and technologies for self care. She juxtaposed *Idealizations of the Consumer* as health-aware, informed and rationally instrumental with her empirical observations of people's attitudes, ranging from rational instrumentality to symbolic actions to non-agential accounts. Among key questions she raised is how these new markets are imagined and for whom DIY health technologies are useful and usable. **Larry Reynolds** (Lancaster University) performed a blood glucose test on himself and then proceeded to discuss user-driven innovation that shows the monitoring

device in a *Feral State*. An argument he made was that DIY monitoring for diabetes type 2 is more than about controlling glucose levels. It introduces the alternative to control metabolism by incorporating the device into everyday decisions about diet. A further study, he suggested, would explore the status of the self-experimenter as well as available data on self-experimentation. **Sharif Mowlabocus** (Sussex University) talked about his research into online gay communities and then discussed in more detail how different types of interfaces and modes of accessing information about sexual health, affect the ways in which the communication is figured. Communication has shifted from face-to-face engaging of context, to online settings and representations, to electronic *Decision-Support Protocols*. Examples he took of media and lifestyle-embedded applications deal with the diagnosing of conditions, of disease and risk, as well as ongoing measures of health statuses. **Maureen McNeil** (Lancaster University) drew connections between 'life-writing' - autobiographical accounts of disease or genetic risk - with ideas of personalization in health and medicine. She talked about her current work on cancer memoirs and reflected on how these autobiographies not only help to construct a certain self, i.e., one that is responsible and active in the face of uncertainty, but they also cultivate heroic depictions of scientists.

In the third session, **Paula Saukko** (Loughborough University) talked about the *Lifestylization of Medicine* which is evident in the development of direct-to-consumer (DTC) genetic testing as well as the controversy which DTC testing has sparked. Paula situated this development within the history of Western medicine over the past 200 years and argued that the emergence of 'lifestylized medicine' is seeing major changes in perception of risk and the authority of certain forms of knowledge and expertise. **Ingrid Geesink** (Rathenau Institute) explained the work at the Rathenau for the Dutch government—the policy relevance of their collaborations with academic and industrial research groups, public engagement efforts and science communication. She then proceeded to introduce the *Quantified Body*, a new project and concept aiming at better understanding the policy implications of self-monitoring, self-testing and electronic mediation / communication in personalized health and self care. **Catherine Will** (Sussex University) offered reflections on the DIY metaphor, including some taken-for-granted interpretations and what they might imply. For example, she talked about the ambiguities in assuming that people are on their own and/or makers of their lives, and the tensions in where responsibilities actually lie, who does what in care-taking of health-related conditions. She also spoke of the happenstance of available tools and techniques and of the *bricoleur* who represents another variation to DIY. **Kristrún Gunnarsdóttir** (Lancaster University) foregrounded the economic and political climate which encourages innovation in the private sector, in particular *eHealth solutions*, and the responsabilization of citizens to take greater initiative in managing their health and healthcare needs—ideally, to avoid or significantly delay the onset of common lifestyle and ageing-related conditions. A key task here, she suggested, would be to better understand the implications of redrawing the boundaries between the state, private enterprise and citizen responsibilities. **Richard Tutton** (Lancaster University) presented on his ongoing work, looking at ideas of personalized medicine over time and how these have been reshaped by genomic and information technologies in the past twenty years. Drawing on the work of Foucault, Rose and Clarke, Richard outlined how we might understand personalization in relation to contemporary biopolitics.

Over the course of these three sessions, five key areas of interest emerged:

1. Clinical uptake and the role and position of clinicians in personalized medicine; the role played by health care providers and healthcare payers in both the US and Europe with regard to the clinical uptake and use of personalized drugs and diagnostics.
2. The acquisition and use of medical devices outside of the clinical settings in various domesticated or *feral states*; how these can conflict with established health care provisions and the regulation of medical services; how these devices are implicated in the ways people form new bio-digital identities through new forms of media.
3. The lifestylization of medicine and lifestylization of technologies-in-use more generally; the push for a greater responsabilization of citizens; the shifting of responsibilities from public provisions to private enterprise to individual judgement, involving various idealizations of health consumers.
4. The emergence of new sociotechnical regimes in the context of broader political economy questions; the corporitization of medicine, changes in regulation in US and Europe; and questions of intellectual property rights.
5. The historical periodization and conceptual framing of personalization in relation to the history of western medicine and the challenges faced by analysts to find a suitable language in which to describe some recent developments

It was clear from the meeting that each of these areas could be the subject of future research and collaboration.

It was agreed at the end of the meeting that one outcome should be to establish an informal network of scholars interested in personalization in health and medicine, as broadly conceived.

The report of the meeting will be sent to both symposium participants and others who could not attend but with shared research interests. Everyone will be invited to signal their willingness to be part of this network.

It was also suggested that funding from other sources could be sought to facilitate future meetings of this network.

To that end we will be in contact in July about an opportunity to apply for ESRC funding to support International Partnerships and Networking.

To help facilitate the sharing of resources of interest to the network, we will soon circulate details of a dropbox.

This report was prepared by Krístrún Gunnarsdóttir and Richard Tutton at ESRC Cesagen. This symposium forms part of the research programme at ESRC Cesagen. The support of the ESRC is gratefully acknowledged.

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