Editorial

BioSocieties (2012) **7**, 221–223. doi:10.1057/biosoc.2012.13

The gap between the promises of contemporary biomedicine to radically transform clinical practice and the more mundane realities has been widely noted. The current emphasis on ‘translational medicine’ is born as much out of disappointment as it is out of hope. The much postponed ‘genomic revolution’ in clinical medicine is a key element here. One solution has been to place hopes in data – specifically in the development of evidence-based ‘data rich medicine’. In this context, we are seeing the collection of larger and larger electronic data sets, incorporating not merely genomic data but also other data – from epigenetic sequences to data on individual clinical histories derived from electronic patient records, to lifestyle information – in the ever proliferating and increasingly interlinked biobanks. In his extensively researched article on US biobanking strategies, Robert Mitchell examines the tensions between two distinct approaches to this issue of data collection. The first approach places emphasis on active recruitment of donors who agree to supply information to the biobank. The second approach avoids altruistic donation, and the ideals of citizenship which that entails; instead, it seeks to extract information unobtrusively from existing health-care records, although the individual may have only given routine and broad consent, and is not actively enrolled in the research enterprise. Mitchell terms this ‘biomedical immaterial labour’ and explores some of the implications, notably in relation to policies of open and closed access to biobank data, and their rival social and economic imaginaries.

Alongside hopes for genomic medicine stand those invested in molecular neurobiology, now often coupled with beliefs in the power of brain scans to reveal the intimate mental activities of individuals to our gaze in real time. The images of brain scans, and the belief that they render visible the mind in the brain, have migrated far beyond the lab and the clinic and into popular science and the mass media. There have been many criticisms from both the social sciences and the neurosciences, particularly from those concerned with the rhetorical power of such images, and their illusion of objectivity. Although many have suggested an uncritical reception of such images by the popular media, Louise Whiteley shows, through an analysis of media reports of functional neuroimaging research, that the process is more complicated. She describes the many challenges to the expertise of the fMRI scanner that can be found in media reports, ranging from explicit polemic to assertions of lay expertise. Whiteley cautions us to take a more nuanced view of the power of neuroimages in popular culture – a plea for further empirical research into this important question for science communication and public engagement.

Bringing questions of neuroscience and genomics together, and linking them to the lives of individuals and their families, Felicity Callard, Diana Rose, Emma-Louise Hanif, Jody Quigley, Kathryn Greenwood and Til Wykes examine ‘gene talk’ in family members’ accounts of schizophrenia aetiology. Drawing on original empirical research, they argue that ‘gene talk’ in the families of those diagnosed with schizophrenia serves to re-allocate blame

and guilt, and to reshape narratives of family history. Although some have suggested that an appeal to the biological and genetic origins of mental disorders will serve to reduce feelings of guilt and culpability among relatives, this research reveals complex and heterogeneous patterns of blame allocation in those families. Gene talk, it seems, displaces but does not efface the blame that is placed on family members, notably mothers, for the psychiatric diagnosis of their relatives.

In her study of the use of electronic pharmacies, especially those offering alternative or herbal remedies primarily to those in the Indian sub-continent, Bianca Brijnath explores how globalisation, the rise of diasporic communities, increased use of technologies, changing notions of citizenship and risk, and the commodification of health have contributed to the rise of both legal and illegal e-pharmacies. She examines the relationship between e-pharmacies, risk and the state, and the extent to which 'pharmaceutical citizenship' prevails over national citizenship in this context, notably in relation to the question of risk. She draws attention to the peculiarities of a situation in which customers appear to prefer the unknown risks of buying drugs online over the known risks of an inadequate health-care service provided by the state. Brijnath also points to the paradoxes of marketing 'exotic' pharmaceuticals with the rhetoric of scientific knowledge. Her article begins to chart the dynamics of a new 'pharmaceuticalization' in which the Internet increasingly bypasses the intermediary expertise of the doctor, and enables the marketing and purchasing of pharmaceuticals to escape the regulatory grasp of national jurisdictions.

In this issue, we introduce a new *BioSocieties* series of essays on *Thinking on the Edge*. The purpose of this format is to invite scholars to submit work that is not yet in the form of a fully developed article, but nevertheless makes provocative, challenging and well-grounded arguments that can inspire others to consider fresh concepts, theories, methods or research ideas. Essays submitted to *Thinking on the Edge* will be reviewed by the editorial team for suitability; if considered appropriate, they will be peer reviewed with a view to helping the author clarify their arguments.

In this *Edge* essay, Ilna Singh explores the ways in which social science may contribute to building a better understanding of relations between 'nature' and 'nurture' in human development. Focusing on post-genomic programmes of early intervention – programmes that draw on emerging arguments about plasticity and malleability – she argues that these raise significant social and ethical concerns. Yet, as she makes clear, these programmes challenge social scientists to move beyond their familiar postures of critique and invite them to play their part in developing new models of development that are not riven by debates over nature and nurture – perhaps beginning to construct a new conceptual architecture for thinking beyond the nature–nurture debate.

Our Books Forum in this issue focuses on autism, discussing three books that elucidate how autism, a century after the concept was proposed, is now so frequently diagnosed – affecting more than 1 child in 90 according to recent estimates in the United States. Ian Hacking, who has himself made significant contributions to this debate, discusses Adam Feinstein's *A History of Autism* and Chloe Silverman's *Understanding Autism*, and also considers the role that the Internet is playing in enabling autists to speak out and solicit support. Three reviewers – Steven Epstein, Stefan Timmerman and Andrew Lakoff – consider *The Autism Matrix* written by Gil Eyal, Brendan Hart, Ermine Onculer, Neto Oren and Natasha Rossi. Our discussants welcome this challenging intervention in the debate over

the rise of autism, but they take very different views of the book's methodological approach and its analytical framework, as well as its conclusions. Gil Eyal concludes our Books Forum with a spirited defence of his views, and in particular of his assessment of the role of the *DSM* in the creation of the contemporary reality of autism. This debate will undoubtedly continue, and these lively contributions should play an important role in stimulating future lines of argument.

Adele E. Clarke
Nikolas Rose
Ilina Singh