

Biomedicalising genetic health, diseases and identities

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As the focus of the natural sciences shifted from cellular to molecular levels over the last half of the twentieth century, the question ‘What is life?’ has increasingly been raised. Rose (2007: 6–7) recently posited a parallel epistemic shift in biomedicine from the clinical gaze to the molecular gaze such that ‘we are inhabiting an emergent form of life’. Through biomedicine, molecularisation is transforming what Foucault called ‘the conditions of possibility’ for how life can and should be lived. The emergent biomedical molecular gaze offers possibilities of changing *bios* – ‘life itself’ – especially, but not only, through genetics and genomics. These new biomedical practices are increasingly transforming people’s bodies, identities and lives.

Historically, medicalisation has extended the legitimate jurisdiction of medicine into new areas of human life (Conrad 2000, 2007). Today biomedicalisation, relying more deeply on the biosciences, not only further extends but also reconstitutes biomedicine through technoscientific innovations often perceived as ‘imperative’ (Clarke *et al.* 2003, 2009). Genetics and genomics are increasingly major mechanisms of biomedicalisation. Consequently, biomedicalisation, next described in more detail, provides an exceptionally useful framework through which to read this Handbook.

Biomedicalisation theory: the new genetics and identities

At its most basic, biomedicalisation is about technoscientific transformations of health, illness and identities. It is an historical concept (e.g. Starr 1982; Clarke 2009a). In the US and UK, by the end of World War II, the professionalisation and institutionalisation of medicine had fully established scientific medicine as a legitimate, state-authorised politico-economic sector.¹ Over the next decades, medicalisation – the expansion of medical jurisdiction, authority and practices into new institutional and definitional realms – elaborated, constituting the medicalisation era. For example, alcoholism and drug abuse moved from the professional jurisdiction of the law to that of medicine and were (re)defined as diseases. State as well as private investment in medical research, health care service provision, pharmaceuticals and technologies also expanded, fuelling medicalisation.

Since c.1985, dramatic changes in both the organisation and practices of contemporary biomedicine, implemented largely through the integration of new technoscientific innovations (including applications of the biosciences, computer and information sciences and technologies) have been coalescing into *biomedicalisation* (Clarke *et al.* 2000, 2003, 2009; Clarke 2009a, 2009b). This third major era of scientific medicine is characterised by changes in how we can think about and live 'life itself'. The crux of biomedicalisation theory is that today medicine, broadly conceived, is being transformed from the 'inside out' through new socio-technical arrangements that implement biomedical sciences and technologies to intervene in health, illness, healing, the organisation of medical care and research, cultivating emergent forms of life.

Five main interactive and overlapping processes together constitute biomedicalisation. First is a new biopolitical economy of medicine, health, illness, living and dying. Here biomedical knowledges, technologies, services and biocapital are ever more co-constituted – mutually produced, maintained and transformed.² The centrality of biocapital (capital organised by and through *bios* – life in its many forms) and biolabour (the heterogeneous forms of labour that go into the production of biocapital) cannot be overemphasised (see Clarke *et al.* 2009). Expanding *bios*-centred economic sectors – agriculture, biofuels, biomedicine, health – demonstrate their growing importance.

The second key process of biomedicalisation is a new and intensifying focus on 'health', broadly conceived, in addition to traditional medical focus on illness, disease and injury. This includes expanding attention to and capacities for embodied enhancement by technoscientific means, nicely captured by Rose (2007) as 'optimisation'. Today we are expected to 'be all that we can be' and are increasingly deemed responsible for being so. The flip-side of the intensifying focus on health is its requisite elaboration of risk and surveillance at individual, niche group³ and population levels. These are accomplished by varied forms of monitoring, assessment, screening, check-ups, etc. The third key process is the technoscientisation of biomedical practices. Interventions for treatment, enhancement and optimisation are progressively more reliant on sciences and technologies, are conceived in those very terms, and are ever more promptly applied. 'Miracles of modern medicine' writ large – and frequently.

The fourth key element of biomedicalisation, somewhat less familiar, includes transformations of biomedical knowledge production, information management, distribution and consumption. To unpack this a bit, today the very ways in which new biomedical knowledge is being produced and managed by the sciences are different – deeply reliant on computer and information sciences. Classic examples here are the decoding of the human genome and the maintenance of complex databases. Distribution of and access to scientific knowledge have also changed dramatically – for scientists *and* for most everyone else. Use of the internet to seek diagnostic and treatment information and build communities is one major manifestation. Another is the dramatic growth in self-health books and articles. All this publicly accessible information is generally 'oriented to those whose bodies and identities are already implicated in the sciences in question, and ... offers ... the expression of agency of those involved in the technologies' (Thompson 2005: 265). Thus patients/consumers not only have greater access to knowledge but also greater responsibilities for using/applying it – and not only for ourselves but also for others. Using such new knowledge vis-à-vis genetic issues can be especially fraught, for example in preventive genetic counselling (e.g. Latimer 2007) and new direct-to-consumer (DTC) genetic testing (Nelson 2008a).

Fifth and last, biomedicalisation theory is also concerned with how biomedical transformations of bodies are producing new individual and collective (niche group or

population level) ‘technoscientific identities’.⁴ Such identities are *constructed through technoscientific means* via the application of sciences and technologies to our bodies directly, to our individual and collective histories, and/or to bodily products such as blood, DNA samples or images. These new identities are generating new ‘biosocialities’ – new modes of social relations deeply linked to living with such identities.

Thus the ‘bio’ in biomedicalisation does several kinds of work. It signals the increasing importance of *bios* vis-à-vis biocapital and biolabour. It highlights the salience of the biological sciences to biomedicine. It signals that Foucaultian questions of *biopower* and *biopolitics* are integral (Foucault 2008): power is ‘situated and exercised at the level of life’ – *bios* – and biopolitics today embraces ‘all the specific strategies and contestations over problematisations of collective human vitality, morbidity and mortality’ (Rabinow and Rose 2003/2006: 196–7). Last, emergent biosocialities – especially but not only genetic – link identities to action, for example through patient groups and health social movements (Rabinow 1992, 2008; Gibbon and Novas 2008). It is against this broader backdrop of social theorising about changes in ‘life itself’ that biomedicalisation needs to be understood.

Both the concepts of medicalisation and biomedicalisation are vital to understanding the increasing and widening impacts of genetics. Medicalisation continues unabated. Its practices (and the technosciences which inform them) typically emphasise exercising *control over* medical phenomena (Clarke *et al.* 2003). Medicalisation via genetics thus means that areas of life not previously framed through hereditary lenses now increasingly are, and enhanced control over such phenomena is commonly deemed desirable – for example, prenatal genetic diagnostics (Rapp 1999; Franklin and Roberts 2006).

In contrast, biomedicalisation practices (and the technosciences which inform them) emphasise *transformations of* these phenomena, largely through making high-tech biomedical interventions possible and available sooner rather than later, not only for treatment but increasingly also for prevention, optimisation and enhancement (Clarke *et al.* 2003, 2009). The potentialities of genetics and genomics⁵ today exemplify biomedicalisation – perhaps most vividly through the as yet unrealised promise of gene therapies, pharmacogenomics and ‘personalised’ medicine.

Within the broader epistemic shift from the clinical to the molecular gaze, then, medicalisation and biomedicalisation can be understood as the sociocultural infrastructures through which genetics, genomics, biotechnology and biomedicine emerge and on which they are built. Thus they are foundational to – set the conditions of possibility for – the development and applications of genetics and genomics. Significantly, medicalisation and biomedicalisation both legitimate and compel interventions that may produce transformations in individual, familial and other collective identities. The concept of ‘technoscientific identities’ serves as a useful generic term for risk-based, genomics-based, epidemiology-based and other technoscience-based identities (Clarke *et al.* 2003: 182–3). In this chapter, we elaborate upon current and emergent genetics-based technoscientific identities taken up individually, collectively and in terms of (sub)populations.

New technoscientific identities are frequently inscribed upon us regardless of our preferences. For example, individuals and families may unexpectedly learn they are genetic carriers of inherited diseases. New kinds of individual subjectivities arise through such biomedical governmentality as people negotiate the meanings of these identities in heterogeneous ways (e.g. Blackman *et al.* 2008). That is, attribution of a technoscientific identity does not equal acceptance of it (e.g. Novas and Rose 2000). Technoscientific identities are negotiated – selectively refused, ignored, accepted, and/or managed – because of their stigmatising capacities.⁶

Technoscientific subjectivities such as these have been conceptualised as ‘biomedical identities’ (Dumit 2003), ‘biological citizenship’ (Novas and Rose 2000; Rose 2007), ‘genetic citizenship’ (Heath *et al.* 2004; Gibbon 2007), and ‘biopolitical citizenship’ (Epstein 2007a: 11, 21). Across these, ‘citizenship’ is concerned with potentials for state-based recognition and inclusion of marked individuals and/or groups through the articulation of civil rights and responsibilities with health concerns.

In this chapter, we use the analytic frame of biomedicalisation to elucidate three dimensions of the new genetics: (1) health, disease, risk and the optimisation or enhancement of individual bodies, life chances and futures; (2) individual and collective identities and advocacy through health social movements engendered by biomedicalisation vis-à-vis genetics; and (3) individual and collective identities rooted in the genetics of race, geographic ancestry and aspects of human behaviours. We demonstrate how biomedicalisation theory helps illuminate the conditions of possibility for both current applications and future translations of new genetic knowledge from bench to bedside.

Biomedicalising genetic health, disease, risk and enhancement

In the biomedicalisation era, the biosciences (including the new genomics) and the will to know and transform oneself, one’s body and one’s future are mutually constituted and co-produced, creating new conditions of possibility. This section reviews the main perspectives on such possibilities that have emerged, raising questions about how genetics research produces knowledge about human bodies in the present and in the future – and how these questions connect to biomedicalisation.

Early genetic research tended to focus on simple, single gene disorders such as sickle cell anaemia (Pauling *et al.* 1949). Today, however, many if not most major diseases are not seen as monogenic, but instead as complex multifactorial conditions thought to involve multiple genes, as well as interactions between genes and environments (Rutter *et al.* 2006; Lock 2005; Shostak 2003; Hedgcock 2001; Perrin and Lee 2007). These are very challenging to assess (Turkheimer 2006). Consequently, most current research into the role of genetics in disease aetiology seeks to identify single nucleotide polymorphisms (SNPs) (or markers for as yet unidentified polymorphisms) that may indicate the likelihood that an individual with a specific marker will develop a particular disease. Notably, rather than diagnosing *actual* disease, the presence of genetic markers diagnoses individuals as more or less *susceptible* to specific conditions. Susceptibility testing is often the practice (Richards 2001) at the centre of complicated ‘sociotechnical networks’ of genetic counsellors, clinicians, disease registries, diagnostic technologies and advocacy groups (Hall 2005; Stemerding and Nelis 2006; Vailly 2006).⁷ The frame of ‘susceptibility’ (see Rose 2007: 18–20) resonates deeply with discourses of risk and the ethics of personal responsibility, an orientation to the future, and the possibilities for remaking oneself in order to optimise life itself that characterise the biomedicalisation era.

One central pillar of biomedicalisation theory is the intensified focus on health, risk and surveillance (in addition to illness, disease and trauma). Genetic susceptibility testing represents one powerful domain of the elaboration of surveillance through the identification of individuals and (sub)populations as ‘at risk’. Further, genetics may define individuals and/or specified (sub)populations as at differing degrees of risk, from ‘low’ to ‘moderate’ to ‘high’ in cases where the relationship of inherited or acquired genetic mutations to disease susceptibility is cumulative. Examples of currently available

susceptibility testing include genotyping for BRCA 1 and BRCA 2 genes (linked to 5–10 per cent of breast cancers) and APOE $\epsilon 4$ genes (thought to confer increased risk for late onset Alzheimer's disease) (Parthasarathy 2007; Lock 2005). These examples parallel other kinds of biomarker-based risk factor assessment, especially in their focus on the individual as the locus of risk and prevention, that are also proliferating (e.g. Shostak and Rehel 2007; Washburn 2009). The assumed benefit of testing for susceptibility markers is that more carefully calibrated levels of intervention (whether in the form of surveillance, prophylaxis or changes in 'lifestyle'), customised to the specific risks facing the tested individual (Novas and Rose 2000), could then be prescribed to reduce or manage that level of risk. However, as we elaborate later in this section, the ways in which the claims of genetic susceptibility testing are interpreted are extremely heterogeneous.

One reason for such heterogeneity is that genetic science invokes a kind of elasticity. It blurs distinctions between objectives previously differentiated by their time horizons, such as diagnosing and treating present disease, identifying future risk, preventing illness in the future, and maximising life and vitality (e.g. Hedgecoe 2004). As Rose (2007: 107) argues, the molecular gaze

creates an obligation to act in the present in relation to the potential futures that now come into view ... genetics takes its salience within a political and ethical field in which individuals are increasingly obligated to formulate life strategies ... and to act prudently in relation to themselves and to others.

Thus 'molecularisation' – the notion and set of practices that envisions life to be manipulable, recombinable, alterable at the molecular level – makes possible one project of 'optimisation'. Importantly, then, technical capacities – both potential and actual – can shape our notions of ethical practices and what it means to include an individual's duty to optimise his or her quality of life. Elliot (2003) calls this the mandate to be 'better than well'. The implication is that when risk is knowable then it must be known, and when it is believed to be mutable, it must be changed.

At the same time, the genetic biomedicalisation of health also underscores the probabilistic nature of genetic diagnosis and treatment and prevention. That is, the identification of susceptibility genes only yields often ill-defined probabilistic estimates of the risk of developing a disease – and usually without clear timelines. Consequently, attempts to reduce the susceptibilities allegedly posed by one's genotype (through behavioural changes, pharmacotherapy or even genetic modification, though still an unrealised potential) would at best decrease risk of disease, rather than eliminate it. They invoke notions of genetic responsibility – to 'know and manage the implications of one's own genome' (Rose and Novas 2005: 441).

Some social scientists have challenged the often tacit assumption that such interventions are an unmitigated 'good'. Instead, attempts to mitigate uncertainty through the detailing of risk may in fact exacerbate fear in individuals subjected to increasing screening and surveillance (Press *et al.* 2000; Crawford 2004). Social scientists are also concerned about the promulgation of what Foucault called 'technologies of the self' – ways in which we transform ourselves to be more congruent with normative discourses and expectations (Martin *et al.* 1988). In relation to genetics, pathways to the optimisation of life may be eugenic in their consequences, if not their intent (e.g. Duster 2003; Taussig *et al.* 2003). There are complex and elaborating biopolitical and economic incentives and imperatives for identifying persons and (sub)populations at risk. This is

because those at risk may themselves become objects of inquiry in the search for specific disease aetiologies (Fosket 2004), sources of basic research materials (Reardon 2004), and/or consumers of expensive, niche-marketed medical and pharmaceutical technologies (Kahn 2009). Biomedicalisation indeed!

The language and logics of risk and consequent practices of subjectification are not, of course, new: physiological and other risk factors (e.g. elevated glucose, high cholesterol, precancerous lesions, abnormal cognitive health measures, etc.) have long been widely seen as targets of intervention to reduce future risk (e.g. Shim 2009; Shostak 2003). But the powerful tools and discourses of the new genetics do 'sharpen' collective awareness (Atkinson and Glasner 2007: 3) and raise new and contentious possibilities of biomedicalisation. These include redesign and engineering – the use of technoscience at the molecular level to alter the body from the 'inside out' (Turney and Balmer 2003) – to transform life itself. Franklin (2000) sees these possibilities as instrumentalising nature. She argues that what is different and powerful about contemporary biotechnologies is the unmooring of genetic information from the conventional bounds of intergenerational reproduction – a respatialisation of genealogy (also Franklin and Roberts 2006).

At the same time, many scholars have pointed out that emergent relationships between public hopes and scientific expectations, between lay experience and technoscientific expertise are complicated, contested and at times surprising. For one, the notion of DNA as 'the book of life' (Kay 2000) and the seemingly limitless promissory potential of genomic science circulated in the public imagination and the media are not necessarily shared by genetic scientists themselves (Rapp 2003; Franklin and Roberts 2006). The very nature of 'genetic' is being debated *within* the sciences (e.g. Kelly 2007). Rose (2007: 130) uses the interesting distinction of an epistemology of *depths* versus *surfaces* in making this claim. Rather than genetics revealing a deep, inner, causal truth (a conventional historical assumption), contemporary genetics is instead beginning to conceptualise a 'flattened world' of complex, relayed, dynamic systems of networks of gene–gene interactions, gene–environment interactions, and highly individualised gene expression and regulation that together produce future bodily states (see also Fujimura 2005; Rapp 2003). This new and intrinsically modular conceptualisation both foregrounds the potential for manipulability and problematises deterministic assumptions.

Such 'flattened world' conceptualisations also potentially counter some claims about how 'deterministic' genetic and genomic information would detrimentally transform identities (e.g. Hedgecoe 2004, 2008). Initial fears of 'geneticisation' were linked to not unrealistic concerns about discrimination on the basis of genetic information by employers, insurers, educational and medical institutions and the state (Lippman 1991; Nelkin and Tancredi 1994). In the US, for example, a national anti-discrimination law now prohibits health insurance companies from using genetic data to set premiums or determine eligibility and protects against genetically based job discrimination (Feller 2008). Others have focused on not unrealistic fears of negative reactions to genetic information by families, potential mates, friends, etc. (Bharadwaj *et al.* 2007). These debates continue, with assertions that some scholars may have overestimated the power of biomedical discourse to determine the life course (e.g. Atkinson and Glasner 2007; Gibbon and Novas 2008; Hedgecoe and Martin 2007).

Another complication of genetic determinist arguments is that, as Novas and Rose (2000) argue, knowledge of genetic risk gives rise to new relations to expertise and to new conceptions of the self – the nature of which cannot be assumed in advance. At-risk individuals may or may not take up an image of the 'genetic body' (Turney and Balmer

2003) or see genetics as ‘miraculous knowledge’ (Franklin and Roberts 2006). Recent research demonstrates that many people understand the nuances of susceptibility and predictive uncertainty, and are therefore quite circumspect in their expectations of the personal and familial benefits afforded by genetic testing (Rapp 1999; Lock 2008; Lock *et al.* 2006; Mamo *et al.* n.d.; Thompson 2005). For example, Franklin and Roberts (2006) found that patients seeking pre-implantation genetic diagnosis to prevent the birth of children with inherited genetic conditions in fact appreciated experts’ explicit acknowledgment of the limits of genetic and technological manipulation. Their relief as patients lay not in the offer of (false) promises or (unfounded) optimism, but rather in experiences of ‘trust and transparency’ with medical professionals – in the opportunity to ‘manage their own uncertainty rather than have it be managed by others’ (Franklin and Roberts 2006: 222).

Interestingly, applications of genetics research have also begun to complicate the supposed one-to-one relationship between the genome and the self. To be sure, as Martin (2007: 205) has noted, ‘evidence from archives, interviews with cell scientists, and popular sources will show that, in a strange leap that has come to seem self-evident, journalists, lay people, and even scientists have come to equate genomes with selves.’ For example, in forensic science, DNA evidence typically stands in as proxy for one individual – one self. However, there is increasing use of ‘familial searching’ or ‘family forensic DNA’ techniques (Greely *et al.* 2006). In the BTK serial killer case in the US, a genetic sample from a suspect’s daughter was compared with crime scene evidence and led to her father’s – the murderer’s – apprehension, vividly demonstrating that DNA is indexical to not only to an individual but to kin as well.

In addition, human individuals may, if rarely, contain more than one genome – through fraternal twin embryo fusion, transplantation, blood exchange during development, and twinning (Martin 2007: 206). Gene therapies will likely make such genomic multiplicity – known as chimeras – more common and raise questions about how such multiplicity should be handled. Frieze’s (in review) work on nonhuman chimeras has demonstrated that the ‘nature’ of such beings is already highly contested in species conservation worlds, likely presaging parallel debates about human chimeras in the lab, the clinic, the courts and beyond. DNA is genealogical – always implicating the family, the community and/or the group – with or without its consent (Davis 2004; Nelson 2008a). As Finkler and colleagues (2003) asserted, genetics has medicalised kinship, further complicating familial identities and relations.

The biomedicalising potential for human inheritable genetic modification is also being hotly debated. Popular books such as *Babies by Design* (Green 2007) and *Enhancing Evolution* (Harris 2007) extend concerns from individuals to familial design to species redesign. The ways in which ‘blood matters’ (Gessen 2008) are elaborating. And eugenic practices enter not only through the back door (Duster 2003) but also through the front (Agar 2004; Taussig *et al.* 2003).

Overall, then, more deterministic outlooks on the impact of genetics are giving way to analyses that emphasise the networked complexities characteristic of the causal models currently used by genetic researchers, such as systems biology (Fujimura 2005). The heterogeneous and decidedly ungeneticised perspectives taken up by lay people with regard to health, disease and risk are also becoming more complicated and situated (Taubes 2007). People therefore increasingly rely upon their own embodied emotional knowledge about cause and care, upon their experiences of tinkering and experimenting with care management, and upon autodidacticism as legitimate sources of expertise for

managing their conditions (Epstein 1996; Novas and Rose 2000; Rapp 2003; Shim 2005). As Beck and Niewöhner (2006: 219) have argued, it is likely that 'looping effects' will emerge along different pathways between medical diagnosis, selfhood, social practice, and the body itself. This reflects one of the larger arguments about biomedicalisation: it is punctuated by contradictions and complications of power, knowledge and social action. Thus the obligation to optimise 'life itself' that is also a hallmark of biomedicalisation theory in the genetics era scales up from individuals to collectivities and progresses from identity to action, as we explore next.

Genetics, health social movements and collective technoscientific identities

Developments in the biosciences are also producing transformations of collective and population-level technoscientific identities that increasingly lead to the formation of 'biosocialities' reflecting collective interests. Such transformations of identity may be a goal of social movements – collectively working towards the 'kind[s] of sel[ves] we want' (Polletta and Jasper 2001: 298). Rabinow's (1992, 2008; Gibbon and Novas 2008) concept of 'biosocialities' both highlighted and predicted this:

underlin[ing] ... the certain formation of new group and individual identities and practices arising out of these new [technoscientific] truths ... These [biosocial] groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene in and 'understand' their fate.

(Rabinow 1992: 241–2)

Today, patient-founded and -led organisations are becoming increasingly central in advocating, funding, adjudicating and directing and carrying out their own research, shaping conditions of possibility around their own diseases and, in turn, their identities and subjectivities (Epstein 2007b). As forms of biosociality, embodied health movements reflect how 'life itself' becomes the stakes and biomedicalisation the usual means of addressing them.

Considerable scholarship has been devoted to these movements which take aspects of the *soma* as an organising principle, variously called 'associations' (Callon and Rabeharisoa 2003), 'concerned groups' (Callon 2003), 'health social movements' (Brown and Zavestoski 2005), patient groups and patient advocacy groups. Patient groups may not only have different relationships to the state (Epstein 2007a, 2007b), but moreover, identity and 'patienthood' are produced distinctively and varyingly (e.g. Nelis *et al.* 2007). Some health social movements were provoked by over-medicalisation, such as women's health (Ruzek 1978) and disability rights (Davis 2006), and others by under-medicalisation, such as Black Power and some other community-based health movements (Nelson 2003). Yet others demanded further (bio)medicalisation, such as HIV/AIDS movements (Epstein 1996). Vis-à-vis genetics, technoscientific identities fuse with social action, and most genetics-oriented groups do seek (further) biomedicalisation.

An ambitious array of studies has focused on these genetics-based health social movements featuring one or another facet. First, new social movement forms are emerging. Rapp, Heath and Taussig (2001) found associations formed by family members rather than (or

in addition to) patients themselves, sites where hereditary abnormality, biomedical explanation and family responsibilities meet. Ganchoff (2004, 2007) examined stem cell research and politics. Instead of ‘patient activists’ sharing a single type of ‘embodiment’ or diagnosis, he found a hodgepodge coalition of ‘stem cell activists’, interestingly including ‘scientist-activists’, drawn together by the promise of regenerative treatments. Others have found emergent coalitions across genetic-disease based groups (Heath *et al.* 2004: 163–4).

Among the most cutting edge issues is the relationship between health social movements and the production of biocapital (Rajan 2006; Novas 2007, 2008). Because body parts and/or testing may be involved, intellectual property rights may be invoked by movement organisations. (This also occurs with racial and geographic collectivities rendered as research subjects, discussed below.) For example, PXE gene patient groups have been successful in claiming property rights in their genetic materials (Heath *et al.* 2004: 163–4). An autism organisation maintains extensive, proprietary databases available to researchers who commit to undertaking research on the condition,⁸ and Huntington’s disease groups produce genealogies that then become biomedical research data (Nukaga 2002).

Of course, biocapital is also imbricated by the interpenetration of health social movements with research endeavours (Epstein 2007b). Many patient groups have long contributed in various ways to research on their illnesses (Epstein 1996), most commonly by organising donations of both capital and tissue samples to be used for research purposes. Today we are seeing new forms of interpenetration such that at times the movement *becomes* the research organisation *per se*. For example, Rabeharisoa, Callon and colleagues have been studying the French muscular dystrophy association (AFM) which had an annual budget of close to 80 million euros and employed more than 500 workers – a ‘partnership model’ of patient organisation (Rabeharisoa 2003: 2130). Callon (2003) sees increasing involvement of ‘concerned groups’ in R&D policies. Such collaborations are shaping new social identities based in *both* science and activism and constituting new hybridities – at once scientising social movements and mobilising scientists in new ways (Callon and Rabeharisoa 2003; Epstein 1996; Hess 2004; Washburn 2009).

In seeking (bio)medicalisation, there are also new forms of interpenetration of health social movements with governmental agencies (e.g. Evans, Plows and Welsh 2007). Going beyond lobbying for congressional support to deeper collaborations (Brown and Zavestoski 2005; Epstein 1996, 2007b), Rapp recently noted that the Genetic Alliance (a super-group of 600 genetic disease advocacy groups) is deeply linked with segments of the NIH’s Office of Rare Diseases (in Epstein 2007b). Activism has also led to new policies requiring the inclusion of women and people of colour in the full spectrum of federally funded biomedical research in the US, including but not limited to genetics research, with a range of intended and unintended results (Epstein 2007a).

Many studies of genetic disease-based health social movements have focused on breast cancer advocacy as it increasingly encounters means of assessing the genetics of the disease in ways that have direct implications for both individual and familial decision-making. Fosket (2004) analysed how constructions of ‘high-risk’ women rely strongly on family trees. Parthasarathy (2007) compared the development of genetic medicine in Britain and the US in terms of generating very different toolkits for BRCA testing and how these were then used with and by women. Gibbon (2007) studied breast cancer genetics as gendered knowledge and how that knowledge was taken up in both clinics and activist research support settings. Klawiter (2008) and Brown and colleagues (2006) contrast movements that engage and refuse the issues of environmental influences on the genetics of breast cancer.

Social scientists have studied movements around other diseases believed to have genetic causation. These include autism (Silverman 2008; Singh *in prep.*), cystic fibrosis (Kerr 2005; Wailoo and Pemberton 2006), dementia and Alzheimer's disease (Lock 2006, 2008; Mamo *et al.* n.d.), epilepsy (e.g. Shostak and Ottman 2006), PXE (Heath *et al.* 2004: 163–4), sickle cell anaemia (Duster 2003; Nelson 2003; Fullwiley 2004; Wailoo and Pemberton 2006); and Tay Sachs (Wailoo and Pemberton 2006). Currently at the cutting edge are studies of how new forms of genetic information, such as molecular biomarkers of environmental exposure, transform ongoing organisations and biomedical controversies (Brown *et al.* 2006; Shostak 2004; Washburn 2009).

Identities rooted in the genetics of 'race', geographic ancestry and aspects of human behaviours

The decoding of the human genome in 2000 established that human beings are more than 99 per cent genetically alike. At the same time, however, the computer-aided statistical analysis of genetic data has also made possible the parsing of that less than 0.1 percent of human genetic variation. Recently, such analyses have attempted to explain myriad forms of variation across social groups, including health disparities, geographic ancestry and dimensions of human behaviour. This 'turn to between-group differences' (Duster 2005) is both predicated upon and productive of the biomedicalisation of identity through varied processes of 'alignment' (Epstein 2007a). Here, we consider biomedicalisation as both a condition of possibility for and a consequence of the technoscientific identities that result from such alignments by examining varied 'pathways of sub-jertification' (Rabinow and Rose 2003/2006) produced by research on the genetics of 'race', geographic ancestry and human behaviour. In fields as diverse as genetic epidemiology, genealogical testing and behavioural genetics, classifications of individuals and groups based upon biomarkers (including SNPs and haplotypes) are both imbricated and co-produced with other social categories (Epstein 2007a; Fullwiley 2007a, 2007b; Montoya 2007; Nelson 2008a; Reardon 2004).⁹

Genetics, race and biogeographic ancestry

Race and geographic ancestry are emerging as two principal categories through which contemporary biomedical genomics researchers seek to ascertain individuals' disease susceptibilities and risk. One goal is to develop tailored interventions, including individual drug metabolism profiles data for personalising pharmaceuticals (Burchard *et al.* 2003). While costs of sequencing and analysing individual genomes are quickly decreasing, it remains cost-prohibitive in many contexts. Until such *individual* DNA susceptibility profiles are both economically and technically feasible, many scientists argue that *social* categories, especially 'self-identified' race and ethnicity, can and should be employed as an imperfect yet biologically meaningful and therefore necessary interim strategy (Risch *et al.* 2002: 2). These researchers claim that such a strategy has a scientific basis, as evidenced by DNA analysis with clustering software that shows several distinct human populations mapping onto common understandings of race (Risch *et al.* 2002; Rosenberg *et al.* 2002). The US FDA's approval of the pharmaceutical BiDil in 2005 to treat 'self-identified' African Americans with heart disease provides an early example (Kahn 2004, 2009).

Critics of the use of social categories such as self-identified race or ethnicity in biomedical research contend that it produces a ‘tautology, both informed by, and reproducing racialised truths’ (Lee *et al.* 2001: 55) in which notions of human difference become a ‘feedback loop’ (Ossorio and Duster 2005), at once both input *and* output of genetics research (Reardon 2004). These critics position such uses of race and biogeographic ancestry as artefacts of researchers’ assumptions and techniques (Graves 2005; Duster 2005; Kahn 2004, 2009; Fullwiley 2007b). Further, they contend that such modes of knowledge production engender racialising health risks (Sankar *et al.* 2004) and biologising social categories (Abu El-Haj 2007). Moreover, and gravely, they argue that there is no evidence that the use of social categories in genomic research will in fact reduce health disparities or improve disease prevention (Braun 2002; Kahn 2009; Fausto-Sterling 2004), yet there are abundant possibilities that clinical assessment based on assumptions about racial identity may result in inaccurate diagnoses and inappropriate treatments (e.g. Braun *et al.* 2007).

In contrast, genetic testing is used also by individuals who see in it the potential to reveal their biogeographic ancestry (inferences about the continental origins of one’s ancestors rendered on haplotype groups designations or a composite of ancestry ‘admixture’) and to establish their personal affiliation with specific racial and ethnic groups (e.g. Tenenbaum and Davidman 2007; Nelson 2008a). Though not directly focused on health or disease risk, this form of direct-to-consumer genetic testing may be understood as a form of optimisation – individuals seeking a better life through enhanced knowledge of themselves and their kin. However, the same markers used to discern race, ethnicity and biogeographical ancestry also may be used in medical settings to determine risk in the future. As such, genetic genealogical testing reveals how technoscientific identities ‘in a quintessential Foucaultian sense, are no longer contained in the hospital, clinic, or even within the doctor–patient relationship’ (Clarke *et al.* 2003: 172), but bleed into everyday life.

Critics caution that such genetic genealogy testing is imprecise and may be based upon misleading assumptions because ‘there is no clear-cut connection between an individual’s DNA and his or her racial or ethnic affiliation’ (Bolnick *et al.* 2007: 400; also Ely *et al.* 2006). Other perils include the biological reification and geneticisation of race and ethnicity and the potential for these ideas to subsequently ‘naturalise’ and legitimate discrimination (Duster 2005; Abu El-Haj 2007); the displacement of traditional ways of rendering relatedness particularly among indigenous groups, with accompanying political and economic stakes (TallBear 2008); and the possibility that unexpected, deleterious impacts of this testing might cause consumers to form negative opinions about genetic screening and research more broadly (Bolnick *et al.* 2007). Yet users of genetic genealogy testing may find the practice personally meaningful. They are strategic and adept in their negotiation of the genetic information provided, aligning it with other sources of genealogical information (Rotimi 2003; Nelson 2008a). And these new racial or ethnic genetic technoscientific identities may spur the creation of new transnational or diasporic collectivities of ‘genetic kin’ (Nash 2007; Rotimi 2003; Nelson 2008b). Biosociality indeed!

Genetics and human behaviours

Behavioural genetics focuses on how genes may influence the behaviour of an organism. Traditionally, human behavioural geneticists used quantitative analytic techniques in twin, adoption or family studies (Schaffner 2006), ‘to determine how much influence genes have on a trait – in a particular population, in a particular environment, at a particular

time – in comparison to the environment’ (Press *et al.* 2006: xxi). Increasingly, however, behavioural geneticists turn to molecular genetic techniques to search for genes underlying the heritability of specific behaviours and to identify their mechanisms (Press *et al.* 2006). Behavioural geneticists claim a vast jurisdiction: intelligence (Craig and Plomin 2006), sexual orientation (Hamer *et al.* 1993), substance use (Heath *et al.* 2003), mental disorders (Caspi *et al.* 2003), behavioural disorders (Plomin and Crabbe 2000) and, more recently, political beliefs and behaviours (Alford *et al.* 2005) and religiosity (Koenig *et al.* 2005). The field is marked by persistent controversy (Fujimura *et al.* 2008; Ossorio and Duster 2005) about the relevance of behavioural genetics to understanding of human agency, free will and responsibility (Alper and Beckwith 1994; Parens *et al.* 2006).

Biomedicalisation and behavioural genetics are intertwined at several critical sites. First, behavioural genetics is predicated on identifying phenotypes defined in public discourse as non-normative behaviours and/or as social problems (Duster 2006a). As the social and health sciences extend their foci from the definition and *control* of illness to identification of intermediary phenotypes (e.g. biomarkers) and *prevention* (Lock 2006), the range of phenotypes deemed appropriate for such biomedicalisation expands. This has profound implications for the stigmatisation of persons with traits, markers for traits, or relatives who are affected (Phelan 2005). Second, and related, as genetic information is used to identify individuals ‘at risk’ of disease, and such persons are asked to know and manage their genetic inheritance, such ‘health-related behaviours’ then become attractive subjects for behavioural genetic research. For example, ‘as medical evidence of the harmful effects of smoking became irrefutable, cigarette smoking as a behaviour became reified, pathologised, and medicalised, and the genetic underpinnings of addictions to nicotine and to the addictive behaviour of smoking are sought’ (Press 2006: 143).

Behavioural genetics traditionally focused on *within*-group differences. However, what Duster (2006a: 15) characterises as ‘the turn to between-group differences,’ may promote behavioural geneticists’ endeavours to correlate markers of genetic ancestry with socially devalued behaviours (e.g. violence, impulsivity, and addiction). Such correlations could ‘naturalise’ (Lee *et al.* 2001: 55) health and social inequalities, lending scientific legitimacy to invidious racial and ethnic stereotypes (Duster 2005). Another goal of behavioural genetics is the identification of molecular targets for pharmaceuticals to prevent and treat illness (Petryna *et al.* 2006; Press 2006: 143). This research agenda promotes medicalisation and biomedicalisation of a wide array of human behaviours and identities in the name of health.

In sum, the creation of new genetic categories of identity, whether based on disease risks, geographic ancestry or predispositions to specific behaviours, provides the basis for novel categories of personhood (Wailoo 2003; Wailoo and Pemberton 2006; Dumit 2003). Such identities may be imposed upon individuals through medicalisation and biomedicalisation. These identifications and subjectifications produce negotiations among scientists, the state and lay actors (individual, collective and possibly scientised) who all have stakes in the ‘politics of difference’ and biomedicalisation (Epstein 2007a; Venkatesan 2007).

Conclusions: genetics and the biomedicalisation of health, disease and identity

In sum, a new generation of scholarship is now coalescing around the shared assertion that the very grounds of ‘life itself’ are changing. Biomedicalisation is one key set of processes through which such changes are enacted – transforming bodies, identities and lives

through technoscientific interventions focused not only on amelioration and cure, but also on optimisation and enhancement. The new genetics and genomics offer powerful biomedicalising techniques manifesting the shift from the clinical to the molecular gaze (Rose 2007).

The biomedicalising approaches associated with attempts to identify, test for and intervene in genetic risk offer a new 'style of thought' (Fleck [1935] 1979; Rose 2007), a new imaginary (Franklin 2000) and emerging practices central to biomedicalised 'healthscapes' (Clarke 2009a). They are consonant with contemporary neoliberal emphases on individual responsibility, self-governance and a prudential approach to controlling and transforming one's future. At this moment, genetic and genomic interventions are still largely in the realm of potentialities (Conrad 2007). As Rapp (2003: 142–3) notes, because 'laboratory life cycles' are decades long, 'genomic knowledge has produced little that is life-extending, whereas the old-fashioned clinical gaze has produced quite a lot'. But this situation is changing rapidly. If not yet gene therapies, biomarkers are important new developments for the assessment of susceptibility identities, prevention of disease and the promotion of well-being.

Given how genetics/genomics seem to explode or at least tamper with prior assumptions about temporality and predictability, especially through discourses of risk, the old clinical distinction between diagnosis and treatment seems increasingly fragile and tenuous. The anticipations and demands of *technoscientific possibilities* intervene in how we think of our identities, bodies and lives – individually and collectively – and long before they can be implemented (Adams *et al.* 2009). The conditions of possibility opened up by genetic biomedicalisation allow – indeed promote – the imagination of possible new lives through the molecular gaze.

But, with Rabinow (2003: 14), we do not see these changes as 'indicating an epochal shift with a totalizing coherence but rather as fragmented ... changes that pose problems'. Moreover, the plethora of possible genetic futures also engenders resistances and counter-movements to biomedical (e.g. stem cell research) as to agricultural (e.g. genetically modified foods) innovations (Clarke *et al.* 2009). Contingency is rife, negotiations are ongoing. Biomedicalisation theory is useful for understanding the myriad ways that genetics *and* its social and organisational infrastructures and cultural imaginaries are co-constitutive of the genomics revolution – constraining yet also transforming, enabling and enhancing it. Biomedicalisation thus serves as useful a framework for the chapters that follow.

Notes

- 1 We focus on what today is best termed biomedicine. On the problematics of such definitions, see Clarke (2009b).
- 2 On biocapital, see Thompson (2005), Rajan (2006) and Novas (2007, 2008).
- 3 Epstein (2007a) discusses the shift in NIH-funded research and treatment protocols since the early 1990s from assuming a 'standard human' to 'niche standardisation' based on race, gender and other markings of 'difference'.
- 4 The term 'technoscience' indicates that science and technology should be regarded as co-constituted and hybrid (Latour 1987).
- 5 We have tried to distinguish genetics (genes, their function, roles, testing for, etc.) from genomics (the study, identification, analysis of the entire genome and/or its response to environmental factors/gene expression, etc.). However, such distinctions can be challenging and the terms are often used interchangeably, if wrongly so. The term 'genomics' was coined by McKusick and Ruddle (1987) to launch a new field and journal, emphasising 'a marriage of molecular biology and cell biology with classical genetics ... fostered by computational science'. See also Hauskeller (2004) and <http://publications.nigms.nih.gov/thenewgenetics/>

- 6 Strauss (1959) and Goffman (1963) pioneered the study of negotiated and stigmatised identities.
- 7 'Sociotechnical networks' or webs refers to how technologies and the people producing and using them are inextricably enmeshed, inseparable and often indistinguishable – hybrid (Bijker *et al.* 1987).
- 8 The advocacy group Cure Autism Now initiated and funded the Autism Genetic Resource Exchange (AGRE), a DNA repository and family registry, housing a database of genotypic and phenotypic information of over 900 families available to eligible autism researchers worldwide. See www.agre.org/program/intro.cfm?do=program
- 9 See the American Anthropological Association's online exhibition on race: www.aaanet.org/resources/A-Public-Education-Program.cfm

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