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## Have we seen the geneticisation of society? Expectations and evidence

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**Abstract** Abby Lippman's geneticisation thesis, of the early 1990s, argued and anticipated that with the rise of genetics, increasing areas of social and health related activities would come to be understood and defined in genetic terms leading to major changes in society, medicine and health care. We review the considerable literature on geneticisation and consider how the concept stands both theoretically and empirically across scientific, clinical, popular and lay discourse and practice. Social science scholarship indicates that relatively little of the original claim of the geneticisation thesis has been realised, highlighting the development of more complex and dynamic accounts of disease in scientific discourse and the complexity of relationships between bioscientific, clinical and lay understandings. This scholarship represents a shift in social science understandings of the processes of sociotechnical change, which have moved from rather simplistic linear models to an appreciation of disease categories as multiply understood. Despite these shifts, we argue that a genetic imaginary persists, which plays a performative role in driving investments in new gene-based developments. Understanding the enduring power of this genetic imaginary and its consequences remains a key task for the social sciences, one which treats ongoing genetic expectations and predictions in a sceptical yet open way.

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### Introduction

Within the sociology of health and illness, the development and implications of contemporary genetics have been a major focus for both debate and research for the past 25 years (Conrad and Gabe 1999, Tutton and Hallowell 2009), and continue to be an important area of study. This had led to the creation of new research programmes, journals, conferences, and institutes and has also stimulated the development of a series of important concepts and theoretical frameworks. One of the most influential of these has been Abby Lippman's geneticisation thesis. Put simply, Lippman anticipated that, with the rise of genetics, increasing areas of social life and health-related activities would come to be understood and defined in genetic terms, leading to major changes in society, medicine and health care. Yet to date, the contribution of

genomics to transforming routine healthcare is relatively modest, especially when viewed against past expectations. What then are we to make of this situation and to what extent has society been geneticised?

In this review article we provide an overview of this important field and take stock of the now considerable literature on geneticisation. In particular, we consider where the concept now stands both empirically and theoretically, and reflect on the future of this topic. To achieve this, we present and analyse an in-depth review of the literature published since the early 1990s under a series of headings related to the main areas covered by the geneticisation thesis: scientific discourse and practice; clinical discourse and practice; popular culture and lay discourses and practices. We argue that relatively little of what Lippman anticipated has come to pass, and suggest that the past twenty five years have seen both shifts in scientific understandings of disease and in social scientific understandings of the processes of sociotechnical change, both of which have come to be characterised in more complex ways. We conclude that while the specific expectations embedded in the geneticisation thesis have not been realised, a powerful genetic imaginary persists. There is a place for continued scholarship on the origins and consequences of this genetic imaginary which remains open yet sceptical about the futures imagined.

### **Lippman's concept of geneticisation**

Abby Lippman first introduced the concept of geneticisation in two key papers (Lippman 1991, 1992). In several subsequent papers, Lippman reiterated and further developed her arguments about geneticisation (see for example Lippman 1993, 1998). Together, this body of work provided a wide-ranging critique of the role of genetics in health care and made a comprehensive set of claims about genetics and its uses. She defined geneticisation as:

An ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and psychological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health. Through this process, human biology is incorrectly equated with human genetics, implying that the latter acts alone to make us each the organism she or he is. (Lippman 1991: 19)

The central tenets of Lippman's thesis can be summarised as follows:

- 1 Genetics is becoming the dominant discourse – both professional and popular (mass media) discourses about health and disease are increasingly drawing on genetics. Indeed, this is becoming the dominant discourse about health and disease (Lippman 1991: 15).
- 2 Genetic discourses are reductionist and deterministic – they suggest that models of health and disease can be reduced to a set of (biological) components and that, in the end, genes determine health.
- 3 Society is becoming stratified along genetic lines – geneticisation redefines what are to be understood as significant differences between people, establishing hierarchies among people on the basis of differences in their DNA.
- 4 Geneticisation affects our healthcare practices and our values and attitudes – it conditions how health problems are defined, viewed and managed. It privatises and individualises health risks and responsibility and focuses attention on biological rather than social conditions, potentially increasing social inequalities and leading to victim blaming. It further leads to the increased use of genetic technologies in health care, displacing other ways of categorising and managing illness.

- 5 Genetic discourses suggest that genetic research is imperative for future health improvements – these discourses suggest that ‘increased understanding of disease and improvement in health will – and can only – be produced by mapping and studying genes’ (Lippman 1992: 1470).
- 6 Geneticisation reflects the power of geneticists to identify and classify health problems – it reflects the cultural assumptions of ‘clinical and research geneticists and their colleagues [who] are conditioning how we view, name and propose to manage a whole host of disorders and disabilities’ (Lippman 1991: 18).

Lippman’s critique combined a constructionist understanding of health and illness and a commitment to health activism. Her aim was both to highlight the social and cultural assumptions that underpin genetic ways of categorising and responding to health problems, and to prioritise alternative responses that foreground the social and structural determinants of health. In this way, the geneticisation thesis was part of a much wider debate about the construction and management of health and illness. In particular, Lippman’s reference to the individualising and privatising of health risks and responsibilities echoes critiques of the wider field of health prevention (Petersen and Lupton 1996), suggesting that her arguments have broader relevance beyond the specificities of genetics and genomics.

At the same time, Lippman’s original papers were partly intended to counteract the hyperbole surrounding the Human Genome Project (HGP) and in particular, her work contributed to a wider critique or unease about the growing prominence of genetic discourses and practices around this time. Subsequent theorising about bio/medicalisation (Clarke *et al.* 2010, Conrad, 2005) has continued to posit a dominant role for genetics/genomics, whilst rehearsing updated technoscientific visions of genomic enhancement and redesign.

### **Methodology and scope of the review**

In the years since the geneticisation thesis was first elaborated it has become an important concept and reference point in the burgeoning of social science work on the so-called new genetics and subsequently genomics. In addition, the concept has also travelled, been adopted and reinterpreted in the context of other disciplinary traditions, most notably philosophy. A key task of this review is therefore to map the development of the geneticisation concept and examine its multiple meanings.

As a starting point to identifying a corpus of relevant literature that was essentially concerned with the geneticisation concept we undertook an in depth search in ISI Web of Science, ASSIA and SCOPUS databases using the terms “geneticis/zation” in headings, abstracts and keyword fields. We also searched for references citing Lippman 1991 or 1992. The authors then went through all the results to identify references that employed the concept of geneticisation and to consider, in particular, those in which this provided a central analytic theme. Inclusion was derived through consensus following a collective process of reading and discussion. We supplemented these results with additional references, particularly books, drawing on both Google Scholar and our own knowledge in this field. Papers and books which only noted geneticisation in passing or had a primary focus elsewhere were excluded.

It should be noted that there is a wider body of social science literature about genetics/genomics that does not enrol the concept of geneticisation or cite Lippman’s papers, and instead uses alternative concepts, such as biomedicalisation or molecularisation. For purely practical reasons of scale and scope, we have not included these studies and have in general used the inclusion criteria outlined above. However, in a small number of cases where such papers are highly pertinent to the arguments they have been referenced.

So to be clear about the scope and limits of this review, we do not set out to undertake a comprehensive sociology of the new genetics, and our review excludes much interesting scholarship and further concepts in this field. Instead, its focus is on a circumscribed body of work that elaborates, analyses, and critiques Lippman's geneticisation thesis.

### **The debate about geneticisation after Lippman**

The geneticisation thesis has sparked a long-running and at times heated debate about its validity and interpretation both within the social sciences and between social scientists and other disciplines, most notably philosophers working in the field of bioethics. Geneticisation, as Lippman (1991) acknowledges, can be seen as being based on the idea of medicalisation, and discussions of geneticisation have followed a similar trajectory along two main lines. The first has contested the analytical and empirical basis of the concept and the second has broadened the range of actors implicated in the phenomenon of geneticisation. These debates set out an empirical agenda for the social sciences and help to circumscribe some key considerations, which have been taken up to differing degrees in the scholarship we consider in the rest of this paper.

#### *The analytical and empirical basis*

*A neutral and descriptive approach* One of the scholars most active in this debate has been Adam Hedgecoe. His critique of geneticisation (Hedgecoe, 1998, 1999) represents a call for empirical research rather than philosophically based bioethical analysis. He criticises the use of geneticisation in bioethical analyses, which, he argues, treat geneticisation as an inherently critical concept, where the implementation of genetic technologies can only be seen as negative. Hedgecoe (1998: 235; 1999) argues that, in parallel with earlier discussions of medicalisation, the inherently negative framing of geneticisation prevents 'a balanced discussion of the pros and cons and an accurate picture of how the process of geneticisation takes place' and calls for a more neutral approach and thorough empirical evidence.

*Limited empirical evidence* Having set out this agenda, Hedgecoe's own work looks at developments in the definitions and management of a number of conditions (schizophrenia, diabetes, cystic fibrosis, etc.), mainly through the analysis of published biomedical review papers. We note, however, Kerr's (2004) thoroughgoing critique of Hedgecoe's methods and analytical focus on geneticisation, which she argues erroneously foregrounds genetic reductionism at the expense of ambiguity and uncertainty.

*Going beyond empirical description* Hoedemaekers (2001) and ten Have (2000) have also taken issue with Hedgecoe. In contrast to the emphasis on geneticisation as an empirical phenomenon, they regard geneticisation, like medicalisation, as a heuristic tool that helps bring different moral perspectives into view. It can be considered as a 'philosophical interpretation of the self-understanding of today's human life and culture' (ten Have 2000: 298), which is not necessarily demonstrable through empirical research. Reflecting Lippman's own arguments, they suggest that the concept helps draw attention away from the dominant ethical debate at the level of individual decision-making to the wider socio-ethical issues.

#### *Range of actors implicated*

*The importance of lay agency* Novas and Rose (Novas and Rose 2000, 2004, Rose 2001) argue that geneticisation ultimately implies the subjection and control of (passive) individuals

and groups. They disagree, suggesting that patients at genetic risk ‘are increasingly demanding control over the practices linked to their own health, seeking multiple forms of expert and non-expert advice in devising their life strategies’ (Novas and Rose 2000: 489). Further, they argue that genetic information is both individualising, through the responsibility to manage oneself in the light of genetic risk information, but also collectivising, locating individuals in a network of relations ‘involving actual and potential kin, employers, partners and children’ (Rose 2001: 19). Furthermore, through increasing ‘biosociality’ (Rabinow 1992), people are joining into groups based on shared at-risk or biological identities and these groups are actively shaping biomedical research and practices. Clarke *et al.* (2010: 80) also refer to the emergence of ‘new genres of risk-based, genomics-based [...] and other technoscience-based identities’.

*Industry as drivers of geneticisation* Conrad’s (2005) appraisal of the ‘shifting engines’ of medicalisation foresees the introduction of a wide range of genetic tests, treatments and enhancements. While these expectations align with those of geneticisation, Conrad argues that these will be driven by the interests of biotechnology companies rather than clinicians, thereby introducing a further set of actors with a stake in geneticisation.

*Boundary work* Weiner and Martin (2008) have suggested that the notion of geneticisation may partly be seen as a form of boundary work (Gieryn 1983) undertaken by social scientists as a means to reinforce their own authority, expertise and resource claims in the area of health and illness. This view recognises that there may be a number of different professional groups with a stake in any particular field of medicine and sees boundary work as part of normal disciplinary practices.

### **Analysing different dimensions of geneticisation**

Given the breadth of the notion of geneticisation we organise our analysis around three overarching areas which have formed both the main topics of research and represent key areas of social life that might be transformed by new genetic knowledge:

- scientific discourse and practice;
- clinical discourse and practice; and
- popular culture and lay discourses and practices.

In adopting this approach we are not making a distinction between conceptual and empirical work, but focus instead on how the concept of geneticisation has been constructed in these different fields.

#### *Geneticisation in scientific discourse and practice*

Work in this category can be divided into three types: first, there are articles of a philosophical nature that focus on demonstrating that genetic models of disease are erroneous, and suggest that ethical and social analysts have reinforced these mistakes. Second, there are a number of papers with an empirical focus which explore the rhetorical and practical work of scientists when attributing genetic causes to diseases or characteristics. Finally, there are papers looking at the development of the genetic/genomic paradigm and shifts in expectations over time.

In the first group, the philosopher Gannett (1999) proposes that there are no wholly objective criteria for attributing cause and that the designation of a disease or susceptibility as

genetic always involves a pragmatic element. Echoing Lippman's constructivist view, she suggests that geneticisation is not the result of increased theoretical knowledge. Rather, genes are perceived as 'easier to manipulate, and thus more convenient "handles", than environmental factors' (Gannett 1999: 351) and this view stems from and corresponds with current scientific, clinical, economic and political modes of thought. Chaufan (2007) suggests that scholars engaged with geneticisation have focused on the degree of emphasis on genetic variation and the benefits and disbenefits of such information, but have largely failed to question the feasibility of identifying such variation in the first place, a view she undermines drawing on methodological arguments. Again echoing Lippman, Chaufan posits that the quest to illuminate differential vulnerability to common diseases may be at best redundant and at worst harmful in diverting resources from factors known to produce health irrespective of genome. She concludes that the failure to challenge the genetic paradigm 'on its own terms matters because it leaves beliefs about its "potential" (or its imagined dangers) alive' (Chaufan 2007: 1739).

A second group of scholars look at how such genetic models concerning a range of conditions are accomplished in practice. Hedgecoe (2001, 2002, 2003) provides empirical studies based on textual analyses of biomedical review papers to suggest different processes of geneticisation: schizophrenia is characterised by a discourse of 'enlightened geneticisation' whereby genetic explanations are prioritised, while environmental factors, although acknowledged, are underspecified and undermined; diabetes was subject to a process of 'geneticisation by stealth' in which the move from clinical to aetiological classification involved the early involvement of genetic explanations that only became apparent at a later stage; and the introduction of a genetic test for cystic fibrosis (CF) resulted in a possible extension of the category of CF, but also resulted in tensions between clinicians' diagnostic practices and researchers' definitions and uncertainties in the classification of the condition.

Subsequent studies based on ethnographies and textual analyses have found parallels with Hedgecoe's work, while tending to stress complexity. For example Hall (2005), and Weiner and Martin (2008) also find discourses of enlightened geneticisation, yet Hall (2005) reports in the case of hypertension the strategic enrolment by geneticists of essentialism and uncertainty at different points in the funding cycle. Arribas-Ayllon *et al.* (2010) also find coexisting narratives of complexity and reductionism in psychiatric genetics, allowing the field to present itself as cautious, flexible and responsible, and allowing past failures to be reconciled with future promises. They argue that the narrative of complexity contributes to the everyday work of managing uncertainty.

Weiner and Martin (2008: 380) focus on the heterogeneity of models of coronary heart disease in the biomedical literature, arguing that geneticisation is 'at odds with the diffuse and distributed nature of biomedical knowledge and practice'. Building on these ideas in the area of asthma, Bitsch and Stemmerding (2013: 1165) suggest that not only do different aetiological discourses about asthma co-exist, they also co-evolve over time, and argue that genomics has not resulted in geneticisation, but 'has become part of an "omics" based, complex, multi-level approach to asthma'. Navon and Eyal's (2014) work on genomics research into autism again finds complexity rather than reductionism. Here genetic mutations act as boundary objects that can accommodate different understandings of aetiology while facilitating cooperation and exchange. These studies, then, demonstrate the rhetorical role of complexity in the work of geneticists, as well as the continued complexity and heterogeneity of disease models across different fields of biomedical science.

One area of discussion about geneticisation unanticipated by Lippman concerns race. There has been a major debate about the extent to which notions of race are being reconstructed or reinscribed along genetic lines in scientific discourse through the increasing use of DNA technologies (Duster 2015, Skinner 2006). Although the human genome project was meant to

herald the end to any biological notions of race, geneticists and biologists have actually become greatly interested in race and racial differences, especially in the US (Kahn 2012, Pollock 2012). Studies of understandings of race in biomedical research (Epstein 2007, Smart *et al.* 2006) conclude that, while considerable effort has been made to establish a geneticised understanding of race, there is great confusion and uncertainty over the biological meaning of the categories, with no standardisation or stabilisation. Socio-political constructions of race and ethnicity remain dominant.

Finally, we consider work that more broadly explores shifting narratives and expectations within the field of genetics. Here we draw on both social science scholarship and scientific commentary, that, while not referencing geneticisation, proves illuminating. The dominant paradigm within genetics historically attributed inherited factors a major role in the aetiology of common complex conditions. Yet, despite high expectations and heavy investments in new genomic techniques, studies have highlighted a lack of success in identifying heritable diagnostic markers for common diseases and limited translation into treatments and diagnostics in routine clinical use (Martin and Morrison 2006, Martin *et al.* 2006; Manolio, 2010). In contrast, major successes are deemed to have come from the identification of somatic (i.e. non-inherited) mutations in cancers and the development of targeted treatments.

This 'lack of progress' has prompted considerable debate within the biomedical literature (Manolio *et al.* 2009, Eichler *et al.* 2010), with some suggesting that the underlying model of genetic causation is flawed and overstates the role genes play (Zuk *et al.* 2012). At the same time, investment in new techniques continue, leading to new iterations of expectations. It is claimed, for example, that whole genome sequencing could 'lead rapidly to clinically significant findings' (Need and Goldstein 2009: 491). Within genomics, then, we see shifting and divergent discourses, a down-grading of expectations in some quarters, but continued intellectual and economic investments in others.

Drawing across the micro studies and wider surveys we have reviewed, we see a changing focus of scientific interest and social science attention to more complex and dynamic accounts of disease than anticipated by the geneticisation thesis. We also see developments unanticipated by Lippman, including debates about the geneticisation of race, and the therapeutic use of genomic techniques in conditions unrelated to inherited traits. The rise of this genomic paradigm over the last 15 years, with its emphasis on complexity and interaction, has therefore come to eclipse the sometimes crude genetic determinism that underpinned Lippman's original thesis. Important changes in scientific concepts, discourses and practices are therefore reflected in the social science literature. However, despite the move to more complex models of the role of genetic factors in disease aetiology, the underlying expectations about the power of genetics and genomics to transform biomedicine remains intact in some quarters, despite critical reflection to the contrary.

### *The geneticisation of clinical practice*

Doubts about the impact of genetics in the clinic are reinforced in detailed studies in clinical settings. As noted above in relation to CF, there may be dissonance between, scientific and clinical ways of categorising the condition, and genetic testing has not proven decisive for diagnosis in clinical practice (Hedgecoe, 2003, Kerr, 2000). Ethnographic work in the genetics clinic, focusing on dysmorphology (Featherstone *et al.* 2005, Latimer 2013, Shaw 2003), reinforces this observation that even for ostensibly classically understood genetic conditions, genetic testing is not prioritised over other forms of clinical knowledge: 'there is no single hierarchy of knowledge-types' (Featherstone *et al.*, 2005: 571). Latimer (2013: 24) finds that clinicians move between using highly reductive portraits to stand in for the syndrome or the genotype such that 'geneticisation of the body at these moments risks not

deconstructing but destroying the human', and adopting more holistic approaches, where the children are seen as more than the sum of their parts. Rabeharisoa and Bourret (2009: 697) highlight collaboration rather than tensions between the clinical and research domains, but again attest to the difficulties in adjudicating between phenotypic information and genetic information, arguing that far from being reductionist, 'genetics reinforces the complexity of pathological categories'.

Similar conclusions have been drawn in the area of common conditions. Cox and Starzomski's (2004: 161) study of polycystic kidney disease (PKD) found that 'recent advances in genetic knowledge and techniques [have] had a minimal impact on the clinical management and social construction of PKD'. They propose a number of factors that might 'mitigate geneticisation' (Starzomski 2004: 161), including the clinical emphasis on preventing and treating renal disease, the management of the condition along with all other kidney disease, the orientation of nephrology health care providers and their reluctance to engage with the hereditary aspects of PKD, the variable expression of PKD, and the availability of non-genetic diagnostic techniques. In the area of heart disease, Will *et al.* (2010: 916) similarly find that clinicians distinguish little between those with inherited and other forms of high cholesterol, and that 'DNA testing appeared distant from both the production of a diagnosis and from management decisions'. In a further example, Hall (2004) found that health care professionals at a coronary care unit reported that they were reluctant to mention genetics in patient consultations and that they were likely to foreground lifestyle issues for fear of inducing fatalism.

In marked contrast, Hoedemaekers and ten Have's (1998) study of the medical literature concerning carrier and prenatal screening programmes for  $\beta$ -thalassaemia proposes the enthusiastic uptake and advocacy of genetic technologies by health professionals and is critical of the considerable implicit pressure exerted by medical and public discourses on parents to opt for selective abortion. This hints at a possible distinction between the diagnosis and management of existing conditions and prenatal screening practices. A further study that considers prenatal programmes adopts a co-productionist perspective, explicitly drawing attention to the regulatory, cultural and economic aspects of the uptake of technologies). Pavone and Arias (2013), consider the high levels of pre-implantation genetic diagnosis in Spain and find that this is mediated by local and national factors including the strength of IVF clinics, the technical focus of the national regulatory body and the influence of embryologists and stem cell researchers in it, and the link made between private IVF treatment and tourism. Reinforcing a point we have made in an earlier section, they argue that geneticisation does not take into account disciplinary differences (here between embryologists and gynaecologists) and conclude that 'geneticisation dynamics might be strongly mediated by local, institutional, social, and cultural factors' (Pavone and Arias 2013: 237). This work is important in providing detailed empirical investigation that links clinical practices and their regulation with disciplinary differences as well as local cultural and economic influences.

Contrary to the expectations of the geneticisation thesis, these studies highlight the complex relationship between bioscientific and clinical understandings of disease, the relatively circumscribed influence of geneticists, the diversity of clinical practices, as well as the wider influences on such practices. As Hedgecoe (2009: 2) argues 'the geneticisation thesis tends to assume that clinicians are passive recipients of new genetic technologies, simply adopting them as and when they are available'. Hedgecoe's own work and the studies discussed here suggest this view is largely unfounded and underscore the limitations of the widely held assumption that genetics and genomics will transform medicine. These studies demonstrate that medical practice is much more than just the application of scientific knowledge.



## Geneticisation, popular culture and lay discourses and practices

In examining the potential cultural impact of the new genetics some have focused on the nature and power of the metaphors used in their explanation (e.g. Fox-Keller 1998, Nelkin 1994, Nijhout 1990). The great promise of genetics and genomics was boosted, it was claimed, by the use of a set of core essentialist metaphors, especially that of 'the book of life' which carries 'instructions' for the making of organisms (Hellsten 2002). This was the prominent metaphor, together with 'maps' and 'blueprints' (Lippman 1992), used in scientific and popular accounts of the Human Genome Project.

In terms of popular cinema, Franklin (2000) and Stacey (2010) both offer different versions of what they call the 'genetic imaginary'. Franklin writes about the 1993 Hollywood film *Jurassic Park* which shows the power of genetic science to recreate life through the new practices of the genomic biosciences, as further demonstrated by the media attention given to the cloning of Dolly the Sheep. Stacey considers films such as *Gattaca* (1997), *Alien: Resurrection* (1997) and *Code 46* (2004) that focus on genomics and cloning. She notes that her 'starting point for thinking about the cinematic life of the gene is to interrogate [...] a set of very tangible anxieties surrounding the reconfiguration of the boundaries of the human body, the transferability of its informational components, and the imitative potentialities of geneticised modes of embodiment (Stacey 2010: 8).

In addition to these analyses of cinematic representations, much of the analysis of popular culture has used the press coverage of genetics and biotechnology as both indicators of and influences on public perceptions. Based on the UK press, Bauer (2007, 2009) has described 'the public career of the gene' and trends in public sentiment from 1946 to 2002. The most striking historical change is the exponential rise in the number of stories about genetics which takes off in the mid 1980s and peaks in 1999. However, in a review of US magazine articles about genetics, Condit *et al.* (1998) found the discourse of the 1990s was significantly less deterministic than discussions from the 1960s and 1970s.

While essentialist metaphors may have prevailed in scientific communication, their reception seems to be mediated by the cultural frames of their audiences (Condit 1999, 2004). Evidence suggests that everyday public understandings do not see genes as primary or sole determinants. People consider that the salience of genetics varies for different conditions and that genetic factors do not rule out the role of other, environmental, factors (Bates *et al.* 2003, Parrott *et al.* 2003). Evidence from the UK suggests that perceptions related to the causation of traits and diseases have not changed significantly over the period 1995 to 2010 (Richards and Black 2017). Research in the US, however, suggests, at least for some stigmatised conditions, such as obesity, mental illnesses, and addictions, belief in the importance of genes as causal agents might have increased with the development of the new genetics (e.g. Phelan and Link, 2012, Singer *et al.* 1998). Freese and Shostak (2009: 117) concluded from their review of work on public perceptions of genetic causation that we do not know whether there has been 'any overall shift toward a belief in genetics, as obviously widespread notions of the importance of breeding and inborn characteristics long predate the discovery of DNA'. This might suggest that the 'new genetics' and its reporting in the media have had little effect on public perceptions and that widely held social representations are resistant to the cultural shifts associated with geneticisation.

This is further supported by studies with people who have genetic susceptibilities for common diseases which suggest that lay understandings are fairly durable, even in the face of clinical experiences. Weiner (2009), for example, reports that people with familial hypercholesterolaemia do not necessarily foreground genetic elements in their personal accounts of heart disease. Even in the case of hereditary cancers, Scott *et al.* (2005) report that

genetics does not trump other aspects of disease aetiology in lay understandings. These studies stress continuities with established lay knowledge rather than transformations.

Nevertheless, in studies of the social and psychological consequences of clinic visits and the predictive genetic testing that may be offered for breast cancer and other Mendelian diseases, an explicit discourse of geneticisation has gained some theoretical purchase. An important, but contested site for such claims has been kinship and family relationships. Finkler (2005: 1060) asserts that the ‘cultural currency of scientific discourse concerning beliefs in genetic inheritance in American society influence[s] people’s lives in almost all areas of existence, including ethical, legal and social domains’. Finkler argues that kinship has been medicalised (which others have read as geneticised, e.g. Gibbon 2002) through the family pedigrees which are created in cancer genetic clinics. Contrasting the work of Finkler on breast cancer and Rapp (1999) on prenatal screening, Franklin (2013:301) observes that: ‘for Rapp, existing social definitions of kinship can supersede geneticisation, displacing it in favour of stronger, pre-existing kinship ties’. Rapp’s findings chime with other studies that look at patients’ responses to emerging genetic and related technologies (e.g. Featherstone *et al.* 2006, Mamo 2005). These suggest that lay understandings and practices do not follow directly from clinical framings, thereby challenging the attributions of agency implied by the geneticisation thesis. This foregrounding of lay agency aligns, in general, with the arguments of Novas and Rose (Novas and Rose 2000, 2004, Rose 2001). Yet the findings counter their wider suggestions in that genetic ties may be less central than they propose, and people may fail to adopt the genetically informed identities they anticipated (e.g. Lock, 2008, Weiner, 2011).

DNA technologies have also been deployed in spheres outside the clinic, notably in direct-to-consumer markets, and DNA genealogy testing represents one significant area. Nash (2004:1) analyses two examples of popular representations of genetic testing in popular genealogy, arguing that ‘geneticised genealogy’ draws on discourses of family relatedness to produce new biosocial groups ‘in the form of Y-chromosome genetic brotherhood, Mitochondrial DNA clan membership and global genetic kinship’. Nelson (2008) provides an ethnography of genetic genealogy testing and attends to the potential geneticisation of race through a nuanced account of the way African American and black British consumers of these tests pick their way through genetic information in the context of family histories, and their endeavours to make the biological biographically meaningful. Nelson (2008: 775) demonstrates their ‘efforts to reconcile “nature” and “culture” into identity’ and in doing so lay bare simplistic either/or readings of ‘race’. Prainsack and Hashiloni-Dolev (2009) sound further caution to any expectations of simple determinism in this area. Drawing on several examples, particularly attempts to distinguish ‘Jewishness’ through genomics, they suggest a ‘complex relationship between genes, individual/collective identities and politics’ (Prainsack and Hashiloni-Dolev 2009: 412).

It therefore appears that genetic discourses, DNA tropes and symbols have become part of our everyday worlds, and popular culture is imprinted with a genetic imaginary. There is some disagreement about whether genetics has become more dominant in popular representations and lay understandings and whether these have become more deterministic over time. Contrary to the fears of geneticisation, studies from clinical settings and of direct-to-consumer tests suggest that lay understandings are relatively durable and genetic framings are unlikely to replace wholesale existing identities and social ties. Geneticisation has been critiqued for neglecting lay agency and these studies demonstrate the way lay people may resist or be selective about the aspects of genetics they integrate into their lives. These discussions suggest misapprehensions in the core assumptions underpinning the geneticisation thesis regarding the relationship between scientific knowledge, popular representations and cultural change.

*Reflections on geneticisation*

In summary, it is clear from our review that relatively few of the original claims of the geneticisation thesis have been realised: genetic discourses have only (partially) become dominant in the laboratory; simplistic determinism and reductionism has been replaced by complexity; society has not become stratified along genetic lines in the way imagined by Lippman; genetic knowledge has only had a limited impact (so far) in the prediction of common disorders; and geneticists have had relatively little power in redefining health problems. We will argue, however, that genetic ideas still constitute a powerful social imaginary within both science and the media, and genetic discourses remain central to future health research agendas.

*Understanding the process of sociotechnical change*

In retrospect, the original geneticisation thesis rested on what now seems a rather simplistic and naive linear model of the process of sociotechnical change, in which new scientific knowledge is readily translated into the clinic, and powerfully shapes the wider social and cultural world. However, it should be stressed that this view was widely shared at the time in science, industry, policy and the social sciences.

In the last 20 years a much more complex understanding of the way in which scientific knowledge shapes sociotechnical change within biomedicine has emerged, and the research reviewed here has contributed to this shift in a major way. This review has shown that in most areas where (biomedical) hopes and (social and ethical) fears failed to materialise this was not due to ethical problems or effective regulation. Instead, this was the result of a complex mix of the intransigence of nature, powerful existing narratives about the causes of disease, other competing forms of knowledge and professional expertise, and the challenge of translation and commercialisation. In our review we have demonstrated that social scientists have increasingly elucidated and engaged with the complexities of these sociotechnical entanglements. We have also flagged theoretical and empirical work that stresses the role and responses of lay actors, who are all but absent in the original formulation of geneticisation. Thus, disease categories are multiply understood and neither clinicians nor lay people are passive recipients of genetic knowledge or technologies.

*The persistence and performativity of the genetic imaginary*

While the geneticisation thesis, based on a particular model of the role of genes in determining disease, has been superceded, we suggest that many of the expectations and promises that genetics and genomics would transform human health and health care remain intact. For example, in scientific discourses and media representations around disease aetiology, and in the formulation of agendas for future research. In this sense, genetics and genomics remain the central elements in a powerful 'genetic imaginary'. An imaginary is a collectively embraced actionable future in which technological change will bring about certain positive, culturally intelligible results (Jasanoff and Kim 2009). At the heart of this imaginary is the notion that the causes of many diseases are fundamentally rooted in our biology and the internal working of genes and DNA. By understanding the molecular basis of disease we can create a new kind of medicine. As scientific knowledge has developed these ideas have been couched in more complex language and based on the use of new tools and technologies, but the foundational assumptions remain intact. This genetic imaginary has deep historical roots in the birth of molecular genetics and genetic engineering organised around the 'molecular vision of life' (Kay 1993). However, the genetic imaginary is being continually remade and rearticulated. Previous expectations of the power of genetics have been forgotten, such as the existence of single genes for common disorders, or re-named, such as in the shift from 'personalised' to 'precision' medicine. At the same time, new hopes are being constructed around the

development and application of waves of novel biotechnologies, the most recent of which include gene editing, the growth in biological drugs, and whole genome sequencing.

Narratives in which future scientific and technological progress will transform biomedicine and healthcare have persisted over the last 20 years. So why has the genetic imaginary remained so powerful and attractive despite the difficulties in its practical realisation? We argue that the major reason for this is its performative function and alignment with powerful social and economic interests. Lippman's formulation of the geneticisation thesis was clearly framed within a critical political economy of health and medicine, yet what is striking from our review is the near complete absence of social science work in this tradition relating to geneticisation. In this light, we argue that the genetic imaginary and its framing of health problems as internal in origins and open to technological interventions, plays an important role in obscuring the social origins and determinants of illness. As a theory, it has also played a powerful performative role in mobilising resources for genetic and genomic research, legitimising the emphasis on pharmaceutical solutions (Williams *et al.* 2011), and framing health problems in largely individualistic terms. The genetic imaginary can thus be seen as a regime of perceptibility (Shostak and Moinester 2015) embedded in a particular political economy which serves the interests of the state, industry and the professions and where: 'individual level rather than social structural understandings of health risks, and clinical rather than population level interventions – that gave genetics its cultural power – persists today' (2015: 232). In this sense, our arguments align with Lippman's broad framing of the field and her overarching project. Our analysis, however, places into question the specifics of her analysis and the expectations they embed. We consider this further in the following subsection.

#### *Social science, reflexivity, and the making of genetic futures*

Reflecting on the findings of our review, we observe that one of the few areas which was successfully geneticised was the work of those social scientists and bioethicists who anticipated major ethical dilemmas, new forms of biological subjectivity and biosociality, and major transformations in healthcare and the economy associated with genetics and genomics (e.g. biomedicalisation). Geneticisation as an expectation of the future has helped to marshal resources and allies in the social sciences. At the same time, their work can be thought of as helping to reinforce and echo geneticists own anticipations of the future of their research and its social significance, and has therefore played an important role in coproducing the genetic imaginary.

Despite our conclusion that the geneticisation thesis, as originally formulated, is redundant, there remains significant social science research to be undertaken in the future given the enduring power and persistence of the genetic imaginary. Critical studies will continue to be needed of the development, application and consequences of the latest waves of emerging biotechnology, such as genome editing and whole genome sequencing. It will also be important to chart the historical and contemporary transformation in the genetic imaginary, highlighting areas of continuity and change, as well as opening up alternative discourses that emphasise the social dimensions of health and illness. Given the gap mentioned above, further work on the political economy of genetics and genomics is needed that systemically analyses, for example, the shaping of health research agendas (the influence of different stakeholders, beneficiaries and their expectations, the alignment with larger political or strategic interests).

Furthermore, given the relatively large investment, by social science standards, into social and ethical scholarship in this area, what broad lessons might we learn from this experience that we could bring to bear in the analysis of other emerging technologies? We would suggest that as social scientists we need to be wary of claims to novelty, pay attention to history, and in particular to the history of past promise-making, to place sociotechnical complexities at the forefront of our analyses, and be wary of making predictions. This is not to argue for a

'futureless sociology', which as Adam (2011) rightly points out, seems largely indefensible in a world where the effects of technoscience might be felt far beyond the present. In this respect, Fortun (2008: 288) calls for social scientists to adopt both a sceptical, but also an open position in relation to emerging technologies, where expectations are treated with due diligence, arguing: 'What's needed is an analytic adroitness, a tolerance for contradictions and paradoxes [...] and sustained critical involvement'. This, surely, is one vital lesson we can learn from the work we have reviewed here and which strikes us as highly relevant to social scientific investigation of other fields.

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