Original Article

Healthy citizenship beyond autonomy and discipline: Tactical engagements with genetic testing

Tamar Sharon
Philosophy Department, Maastricht University, Postbus 616, Maastricht, MD, 6200, The Netherlands.
E-mail: tamar.sharon@maastrichtuniversity.nl

Abstract In recent decades a model of healthy citizenship has emerged, which construes citizens as autonomous, responsible and active participants in the management of their health. While proponents view this as an empowering discourse, critics claim that it creates new forms of discipline and social control. This article argues that there is a need for a shift in the conceptual framework surrounding this discussion – beyond autonomy versus discipline understood as heteronomy – because it obscures the many ways in which individuals engage with healthy citizenship discourse that are not governed by principles of autonomous choice and that do not corroborate fears of normalization and discipline. Michel de Certeau's theory of the creative tactics of everyday life is offered as a useful alternative framework, insofar as it is concerned less with individual autonomy than with the rendering 'habitable' of a given space. Drawing on existing empirical research on people's engagements with genetic risk information, four tactics are identified that escape both healthy citizenship discourse and its critique: translation; selective mobilization; non-disclosure; and a refusal to engage. Thinking in terms of tactics and habitability, it is argued, provides a vocabulary with which to articulate other modes of reasoning, action and moral conduct that are at work.

BioSocieties advance online publication, 13 October 2014; doi:10.1057/biosoc.2014.29

Keywords: healthy citizenship; autonomous choice; discipline; everyday life; genetic testing; governmentality

Introduction

In recent decades health care and health policy in advanced industrialized countries have undergone significant transformations. Against a backdrop of growing health care costs, the rise of chronic disease, biomedical developments and the reconfiguration of welfare provisions, a new model of health promotion is emerging (Bunton *et al*, 1995; Beck and Beck-Gernsheim, 2001; Nettleton, 2006). At the heart of this shift is the idea that prevention of ill health should be a main aim of health policy and that individual citizens should play an active role in managing and maintaining their health. The 'healthy citizen' is construed as a responsible, rational actor, who carefully monitors herself, avoids unhealthy behavior, and cultivates an awareness of her lifestyle and genetic health risks.

Since its emergence, this discourse of healthy citizenship has been the focus of much criticism among social scientists of health and illness. Early critiques raised concerns of ‘healthism’ (Crawford, 1980; Conrad, 1992), ‘geneticization’ (Lippman, 1992; Nelkin and Lindee, 1995), and a ‘normalization’ and ‘disciplining’ of individuals and populations via new means of screening and surveillance (Flower and Heath, 1993; Armstrong, 1995; Lupton, 1995). In these early critiques, healthy citizenship discourse was framed as a pervasive mode of social control that, far from enabling individuals to practice their autonomous choice, would result in a growing health anxiety, (genetically) deterministic understandings of health, and a stigmatization of those who choose to partake in unhealthy behavior. More recently, this critique has been complicated in the social science literature. Empirically, numerous studies have challenged these predominantly dystopic predictions by showing that people do not always comply with suggested or imposed regimes of health care, and often engage with biological and genetic knowledge in creative and unexpected ways (for example Condit, 1999; Rapp, 1999; Lock *et al*, 2007; Nelson, 2008). Theoretically, the development of notions like ‘biosociality’ (Rabinow, 1992; Callon and Rabeharisoa, 2008) and ‘biological citizenship’ (Rose and Novas, 2005) have sought to articulate this complexity, by acknowledging the new types of subjectivities and new avenues for action that are taking shape within the regime of healthy citizenship.

Despite this problematization and nuancing of the critique of healthy citizenship discourse, there remains a significant tendency among critical analyses to frame it as a mode of social control, which compels individuals to align, albeit voluntarily and in more flexible ways, with the imperatives of healthy citizenship. As shall be discussed, this is due in large part to the dual and somewhat paradoxical nature of the concept of power in Michel Foucault’s later work – as both constraining and enabling – from which much of the critical discussions on healthy citizenship draw, and the choice to emphasize its more constraining aspect. As a result, however, the critique of healthy citizenship too often falls back into an autonomy/heteronomy dichotomy, where autonomy is understood as the absence of external constraints, and in which modes of reasoning, responsibility and moral conduct that *do* resist the imperatives of healthy citizenship are easily overlooked.

This is not only problematic conceptually speaking. Importantly, it can also lead to significant discrepancies between discourses of healthy citizenship (both dominant and counter), and various practices; various engagements of users with the technologies of healthy citizenship and the imperative to behave responsibly. In the field of genetic testing for example, a privileged technology of healthy citizenship discourse, which will be discussed in this article, numerous anthropological studies have shown that people engage with genetic risk information in creative and situationally dependent ways, and have brought to light the complex and heterogeneous enactments of genetic responsibility (for example Rapp, 1999; Callon and Rabeharisoa, 2004; Konrad, 2005; Lock *et al,* 2007; Svendsen, 2006). From the perspective of the logic of informed autonomous choice that frames healthy citizenship, these engagements easily come to represent passivity, ignorance and/or irresponsibility. Yet they may instead represent other subjective experiences, other goals and values, and other ways of understanding, that escape a simple logic of autonomous choice and the forms of moral conduct that it prescribes as legitimate, and, by the same token, undermine claims of discipline.

In order to articulate these other modes of action, reasoning and responsibility, a different interpretive framework that moves beyond autonomy versus heteronomy (that is, beyond autonomy versus discipline as heteronomy) is required. I suggest that Michel de Certeau's (1984) theory of the creative tactics of everyday life, by which individuals reinterpret and assimilate a dominant order, is one such an alternative. In the first part of the article I argue for this conceptual usefulness of de Certeau's model.[1] Next, de Certeau's model is used to highlight instances of creative re-interpretation and appropriation of healthy citizenship discourse in the field of genetic testing. I draw on a synthesis of existing studies on people's engagements with genetic risk information. In line with the centrality of the theme of everyday life in de Certeau's model, these are detailed ethnographic studies, often involving interviews, that allow for insight into the use of genetic testing in everyday life by focusing on people's narratives about their deliberations concerning testing and their actions relating to this. Four different tactics are identified that escape the dominant discourse of healthy citizenship and its moral calculus of individual, autonomous choice and risk management, just as they problematize claims of disciplinization and normalization. These are: (1) the translation of genetic information into meaningful narratives; (2) the selective mobilization of genetic discourses; (3) the deferral or non-disclosure of genetic information to family members; and (4) the refusal to engage with medical genetics.

The value of de Certeau's model lies not in any claim that such practices intentionally seek to resist or oppose the regime within which they emerge – which would reiterate a simplistic theory of power in terms of autonomy/heteronomy. Rather, in de Certeau's model the creative tactics of everyday life are a means by which individuals manage to render the space of a dominant regime 'habitable'. Thinking in terms of habitability may allow us to shift the theoretical framework that structures the debate on healthy citizenship away from an autonomy/heteronomy dichotomy. The article thus aims to contribute to attempts to critically evaluate neoliberal rationalities in the health domain that draw on more nuanced accounts of power (Rabinow and Rose, 2006; Lemke, 2011) and logics that are not formulated in terms of emancipation versus constraint (Mol, 2008).

Healthy Citizenship and Its Critique: A Tentative Genealogy

Public health policy in the industrialized world currently takes place within a new model of health promotion that emphasizes citizens' responsibility for their own health. In this new regime of healthy citizenship, citizens are construed as autonomous, active participants in the management of their health, who are capable of making informed and responsible choices, and of reflecting upon the ethical consequences of their actions. From the outset, social theorists of health and illness have been skeptic of healthy citizenship discourse. Alongside early critiques of medicalization, sociologists began denouncing what they saw as a diffuse phenomenon of 'healthism' (Crawford, 1980; Conrad, 1992), in which the primary focus for the achievement of well-being becomes the preoccupation with personal health, a process that

---

[1] De Certeau's work has had a broad influence (see, for example, the numerous journal issues – *Diacritics* 22(2) (1992), *Social Semiotics* 6(1) (1996) and *South Atlantic Quarterly* 100(2) (2001) – and intellectual biographies – Ahearne (1995), Buchanan (2000), Highmore (2006) – devoted to his work). In particular, his ethnography of everyday practices has been useful as a framework that allows individuals a space of agency and plurality of practice within otherwise constraining orders, such as biomedical discourses (Arris, 1997) or the Internet (Franklin, 2004).

decontextualizes and relocates the problem of health and disease onto the individual level. Other theorists raised concerns of 'geneticization' (Lippman, 1992; Nelkin and Lindee, 1995), anticipating that the importance conferred to biological and especially genetic knowledge would result in new forms of genetic essentialism and determinism, and a redirecting of scarce resources from social to strictly genetic determinants of health. Some theorists also apprehended that this would create the conditions for new possibilities of state intervention and the rise of a 'molecular biopolitics' (Flower and Heath, 1993), which would classify individuals in terms of genetic risk and impose particular behaviors on individuals and groups through regimes of genetic screening and surveillance (Terry, 1989; Armstrong, 1995). In these early critical analyses, then, healthy citizenship was envisioned as a rather insidious project that could result in a depoliticization of disease (reformulated as individual pathologies), a growing health anxiety, and the use of genetic knowledge to label, normalize and control individuals and groups.

Over the past decade these predominantly pessimistic analyses of healthy citizenship discourse as a mechanism of social control have been problematized in the social science literature. What we might call a 'second wave' of critique has been characterized by a greater focus on the complex ways that people engage with the imperatives of healthy citizenship discourse. This is not to say that earlier works were in some way detached from people's situated experiences. But that this complexity has more recently been foregrounded alongside an exploration of the complex nature of notions like choice and autonomy, and of the mechanisms by which individuals are enabled by the state to draw on molecular knowledge in order to formulate life and risk management strategies, that is, to govern themselves (Bunton, Nettleton and Burrows, 1995; Petersen and Bunton, 1997; Rabinow and Rose, 2006; Rose, 2007; Lemke, 2011).

These two waves of healthy citizenship critique can thus also be understood in terms of Foucault's earlier and later theorizations of power, a corpus of work that has had a profound impact on the medical humanities over the past two decades (Turner, 1997; Petersen, 2003). Indeed, if earlier critical analyses of healthy citizenship drew mostly on Foucault's work on modes of regulation associated with disciplinary power (Foucault, 1977, 1979), these more recent analyses are inspired by Foucault's later writings on governmentality (for example Foucault, 2008) and those of governmentality scholars (for example Burchell *et al*, 1991; Barry *et al,* 1996). In these works, Foucault shifted his analytical focus from the disciplinary nature of modern configurations of power and their relatively coercive nature, to the ways in which advanced liberal rule seeks to govern through freedom, that is, through the regulated choices of individuals construed as autonomous and responsible subjects who live life as if it were an outcome of choice. This insistence on the dual and somewhat paradoxical nature of the concept of power in this later work – as repressive *and* productive, as simultaneously constraining *and* allowing conducts and ways of being – opens up much room for interpretation and variations in application. Thus, different uses of the concept of governmentality have been made that may be characterized by the emphasis they put on the enabling or constraining aspects of power.

Two takes on power

In the literature on 'biosocialities' and 'biological citizenship' (Rabinow, 1996; Rapp, 1999; Novas and Rose, 2000; Taussig *et al,* 2003; Callon and Rabeharisoa, 2008;

Gibbon and Novas, 2008), for example, largely developed as a reaction to concerns of geneticization and individualization, scholars argue that new types of socialities formed around shared biomedical traits and illnesses have appeared at the intersections between the life sciences, economy and society. Here, the growing awareness of genetic risk, far from leading to a subordination of individuals to a pre-determined genetic fate and to the authority of science, rather transforms identities and relations with medical experts in novel and unexpected ways. Patient groups are seen as forming a new kind of 'biological citizenship' (Rose and Novas, 2005), which reflects broader transformations in people's understandings of themselves as 'somatic' individuals (Rose, 2007), who are willing and able to harness the new possibilities produced by the life sciences. For Rose in particular, the *enabling* aspect of power is emphasized: the modes of subjectification characteristic of advanced liberal societies reflect an 'ethopolitics' that allow for some cultivation of a broader repertoire of human possibilities. Entrepreneurial self-hood, in this reading, is not so much about complying to standards and values defined by a state authority, but about the subjection of oneself to an ethical regime based on aspirations, interests and understandings of the good life that – although they must be socially acceptable – are personally pleasurable.

Other theorists have drawn on the governmentality thesis in ways that are more sensitive to the *constraining* aspect of power. Here the conduct of individuals is linked to political objectives through 'action at a distance', which implies a less overt, but no less effective, form of social control (Bunton *et al*, 1995; Lupton, 1995; Petersen and Bunton, 1997; Coveney, 1998; Harvey, 2010; Veinot, 2010).[2] The responsibilization of health here entails normalizing processes of self-examination and self-monitoring through testing and scanning technologies, and a commitment to self-improvement through regimes of exercise and diet that are framed as means in an on-going maximization of one's health or 'vital capital'. If the 'panoptic gaze' is complicated by the new ideology and techniques of health regulation, it does not so much disappear as it amplifies into a 'net of surveillance', where subjects watch themselves and invite others to do so via social media platforms (Lupton, 2012). Healthy citizenship discourse is configured here as a strategy for simultaneously moderating the burden of individuals on society and of engendering risk minimization (Petersen, 1997). Discourses of empowerment, consumerism and personal choice are thus seen as concealing political economic realities that are often detached from the interests of patients and citizens, while responsibilization masks a real dynamic of abandonment, with questionable effects on 'better health for all', as collective attention is diverted away from health threats posed by social and environmental conditions (Wyatt *et al*, 2010). In this reading, while techniques of healthy citizenship may not constitute direct interventions into people's lives, there is nonetheless a clear alignment between the personal life projects of citizens and the images of social order envisioned by the state, as individuals actively seek to conform to the social expectations of what constitutes a healthy and productive body. Far from delivering on explicit promises of empowerment and autonomous choice, healthy citizenship is thus seen as creating new forms of subjection, discipline and control.

---

[2] This type of governmentality-inspired scholarship can be seen as resonating with some of the critical voices that have been recently raised against the 'biosociality' and 'biological citizenship' literature (Kerr, 2004; Plows and Boddington, 2006; Braun, 2007; Raman and Tutton, 2010). These critiques have argued, in different ways, that the claims to novelty attributed to 'molecularization' and 'ethopolitics' should be nuanced in light of the persistence of traditional forms of 'state' biopolitics.

Despite a clear mobilization of Foucault's concept of governmentality and its problematization of notions of freedom and autonomy as premises for analyzing power, then, this critique draws precisely on notions of freedom and autonomy. It is regularly formulated in a terminology of 'compulsion', 'prescription' and 'imperative', and of an imposition of limits on one's autonomy. In a recent overview, for example, Petersen *et al* (2010, p. 392) write: "Governmentality-inspired work has emphasized … [that] despite the language of empowerment and freedom, this striving for health entails compulsion, added responsibilities to others, and often punishment and social exclusion in the case of those who fail to conform". Similarly, in the conclusion to their recent edited volume on healthy citizenship, Harris *et al* (2010, p. 212) write, "empowerment discourses may be used to constitute citizens' choices in ways that increasingly subject them to external power, rather than enabling them to exercise their own". What (re)emerges here is a reading of power as the imposition of limits on the autonomy of the individual by an external force, of discipline as an absence of freedom. This is to say that the critique of healthy citizenship, in this form, falls back onto a framework of autonomy versus heteronomy – where autonomy is understood as an absence of external constraints – that draws it away from the acknowledgement of the complexities and micro-negotiations of power that have been such an important contribution of Foucauldian studies. To the extent that this critique of healthy citizenship is concerned with uncovering the workings of power at the heart of healthy citizenship discourse, and that this discourse is cloaked in assumptions of autonomy and choice, this may be inevitable. But the restitution of an autonomy versus heteronomy conceptual scheme can also have the effect of framing every action of individuals as helping to perpetuate the overall regime of power; and of thus overlooking or dismissing alternative forms of reasoning, responsibility and moral conduct that may be at work in some forms of engagement with the techniques of healthy citizenship that deviate from those intended by the dominant discourse.[3] These may be alternative normativities that cannot be articulated within the vocabulary of autonomous choice, or 'discipline' understood as an absence of autonomy.

The anti-discipline of Michel de Certeau

The work of the well-known French social philosopher Michel de Certeau offers a different interpretative framework that can help overcome this shortcoming without denying the importance of disciplinary technology.[4] In *The Practice of Everyday Life* (1984), de Certeau attempts to develop a theory of the productive and consumptive activity inherent in everyday life and the ways that ordinary human behavior resists institutional control. He considers presumably mundane, commonplace activities such as walking, shopping and cooking, as so many 'tactics' or opportunities for people to reappropriate the representations and laws of a dominant cultural economy. Not by opposing or rejecting them, but by using them to ends foreign to the system that created them, by adapting them to their own interests and rules.

---

[3] Foucault himself did not attribute the same attention to the concept of resistance as he did to his analysis of modern forms of power. And while his theory of power is closely linked to concrete empirical studies, his concept of resistance is articulated mostly in theoretical terms. This may be a source of ambiguity that makes it easier to interpret strategies of resistance as 'functional' to the imperatives of disciplinary power. See, for example, critiques by Jürgen Habermas (1990) and Nancy Fraser (1989).

[4] Indeed, de Certeau positioned himself as seeking to nuance Foucault's exposition of disciplinary society, of bringing to light what he called an "anti-discipline" (1984, p. xiv).

When people read, for example, they drift across the page, they infer meaning from a few words, and they read the memories of their own childhood into the landscapes of a given text. Like a rented apartment, writes de Certeau, the text becomes a “habitable” space, momentarily borrowed and furnished by the acts and memories of its renters, a territory of others that has been “poached” (1984, p. xxi). It is in this sense that de Certeau famously argues for a substitution of the presumed passivity of consumers with the productive creativity of ordinary people, and recasts consumption as a silent and dispersed ‘other’ production, which manifests itself through the ways of using the products of a given dominant cultural order.

In this theory of everyday practices, while systems of power do structure day-to-day experience via the production of norms, the gaps that necessarily perforate the fabric of power allow for agency within these systems. Not ‘just enough’ agency so that individuals can choose to internalize the meanings and objectives of the dominant order, as is often implied in the critique of healthy citizenship, but enough agency so that they can reinterpret and appropriate them. In this model of power, the question of autonomy or (discipline as) heteronomy is displaced. For de Certeau, it is not a question of sovereign power, of one-directional power emanating from a single source. His model offers an alternative portrayal of power, which, drawing on the concepts of “strategy” and “tactics”, counters one-directionality and polarity (Buchanan, 1992, 2000; Highmore, 2006).[5] Indeed, the relationship between tactics – the negotiations of daily life – and strategy – linked to institutions and structures of power – is not oppositional. It is not a case of a direct conflict between institutional structures and individuals succeeding or failing to confront, to ‘stand up’ to power. Rather, both modes of operation take place simultaneously, in a symbiotic relationship, as it is the givenness of the place of strategy, with its structured meaning, rules and delimitations, that makes possible their circumvention: rendering ‘habitable’ always takes place on an already pre-determined territory.

It is this ambiguous position of tactics, as both inside and yet other, that positions the activity of ‘rendering habitable’ outside of or beyond a theoretical framework of autonomy versus heteronomy. “A tactic”, writes de Certeau, “is a calculated action determined by the absence of a proper locus. No delimitation of an exteriority then provides it with the condition necessary for autonomy” (1984, pp. 36–37). De Certeau thus offers a useful model for conceptualizing how people engage with the technologies and assumptions (the “products”) of the dominant order of healthy citizenship that allows us to identify a variety of practices as creatively interpreting and appropriating the imperatives of knowledge, choice and responsibility that may be overlooked in a theoretical framework of autonomy versus heteronomy.

The Rendering Habitable of the Regime of Healthy Citizenship

Genetic testing: a privileged but ineffective technology of healthy citizenship

Since the completion of the mapping of the human genome over a decade ago, the identification of genetic variants associated with disease has been anticipated to benefit health

---

[5] Though, his work has often been misinterpreted precisely in terms of the rigid, polar model that he contested. See, for example, Frow (1991, pp. 57–58).

in many ways. Original hopes that testing would lead to new therapeutic interventions have, however, been increasingly met with disappointment (Press, 2008). Unlike the paradigmatic single-gene disorders that were the focus of early work in modern molecular genetics, where the presence of a gene confers a certainty that the disease will develop, there has been an acknowledgment that most common conditions are multifactorial and complex. In common conditions, such as heart disease, type 2 diabetes and a number of hereditary cancers, genetic mutations only indicate an increased predisposition to disease, as one element in a highly complex interaction of other biological and environmental factors.[6] Consequently, very few genetic therapies have been developed, and from the domain of direct disease prevention and treatment, the promise of genomic knowledge has moved to the domain of diagnosis and risk management.

This shift in emphasis and the centrality of the notion of genetic risk constitutes genetic testing technologies as an important site for the construction and exercise of healthy citizenship, where the question of how to live responsibly as an 'at-risk' person is a key problematic (Lemke, 2004; Rose, 2007). This problematic is not identical for all types of genetic testing, as various types of testing and testing for various conditions confer varying degrees of probability and clinical relevance, and along this continuum, various possibilities for risk management take shape. At the high end of this continuum of probability, testing for Huntington's disease, for example, is highly predictive. Carriers know with near certainty that they will develop the disease but, in the absence of preventive measures, this information plays a role mainly in preparing for onset, reproductive decision making and communicating carrier status to other family members (Konrad, 2005). Testing for hereditary breast/ovarian cancer, on the other hand, relates to an increased risk of developing these cancers (up to 85 per cent for breast cancer and 60 per cent for ovarian cancer). Here risk management does include preventive measures, ranging from chemoprevention, increased screening, lifestyle modification and prophylactic surgery, as well as questions of procreative choice and family communication (Roukos and Briasoulis, 2007). At the lower end of this continuum testing for something like the APOE gene associated with Alzheimer's disease confers very little clinical relevance and practical implications of testing are unclear (Lock *et al*, 2007). Finally, carrier screening in the context of reproductive decision making (for example fragile X, cystic fibrosis and chromosomal translocations) points to risk management or prevention of a somewhat different kind. Individuals who know they are carriers and risk passing on a condition to their children may use various forms of prenatal diagnosis (amniocentesis, chorionic villus sampling or now cell-free DNA tests), and selection (preimplantation genetic diagnosis). Here risk management refers to preventing the birth of certain kinds of children (Gammeltoft and Wahlberg, 2014).[7]

Despite these different levels of certainty and possibilities for risk management, the shared assumption underlying various forms of genetic testing is that genetic risk information can provide individuals with the basis for making informed decisions concerning their health. As with other kinds of health risks, the importance of genetic risk information is founded on a conception of the individual who adopts a calculating and prudent approach to her life

---

[6] Furthermore, where susceptibility genes for complex and common diseases have been identified using genome-wide association studies (GWAS), they have been found to count for only a small percentage of the known genetic variation in disease risk (Hall *et al*, 2010; Makowsky *et al*, 2011).

[7] I thank an anonymous reviewer for calling this distinction to my attention.

(Petersen, 1997). This fundamentally forward-looking and pro-active attitude makes genetic testing on its various forms a privileged technology of healthy citizenship discourse. Indeed, the healthy citizen in this context does not only seek to modulate her own (genetic) risks, but also extends this prudence to others, to actual and potential family members. She is interpellated to enact a 'genetic responsibility' (Kerr and Cunningham-Burley, 2000; Novas and Rose, 2000; Polzer *et al,* 2002; Koch and Svendsen, 2005), by implementing preventive measures where possible, by choosing not to pass on a genetic disorder, by informing relatives who may also be at risk and by incorporating risk information into a sense of being genetically at risk. In light of this promise of enabling the exercise of genetically responsible healthy citizenship, genetic testing practices have been an important focus of the critique of healthy citizenship discourse. As discussed in the previous section, critics have sought to deconstruct the claim that knowledge produced by genetic testing is necessarily empowering to individuals. First, by showing how the 'choice' to use genetic risk information always entails an obligation to do so (Hallowell, 1999; Kerr, 2004). And furthermore, by arguing that genetic responsibility may lead to increased anxiety, constituting all of us as 'pre-symptomatically ill' (Kenan, 1994), and to genetically deterministic views of disease and identity (Lippman, 1992; Silva, 2005).

A number of studies carried out in recent years, however, suggests that people do not assume genetic identities and forms of responsibilities in as straightforward a way as the discourse of healthy citizenship might hope, and the critique of that discourse fears. Systematic reviews and meta-analyses of quantitative literature on the uptake of genetic testing suggest that providing people with genetic risk information has little effect on health behavior (Marteau and Lerman, 2001; McBride *et al*, 2010). Other studies report that a significant proportion of individuals do not pass on the genetic information they receive to their relatives (Fanos and Johnson, 1995; Wagner Costalas *et al*, 2003; Clarke *et al*, 2005). Furthermore, there is little empirical evidence at this stage to suggest that susceptibility testing is psychosocially harmful (Marteau *et al*, 2005; Heshka *et al*, 2008). These mostly quantitative studies resonate with numerous anthropological studies that focus on the situated concerns of people who undergo testing and counseling and that foreground the complex and creative ways risk information is engaged with in daily life (for example Rapp, 1999; Callon and Rabeharisoa, 2004; Konrad, 2005; Lock *et al*, 2007). Together, these studies all point to a discrepancy between on the one hand healthy citizenship discourse and its critique, and on the other how individuals incorporate (or do not) genetic risk and identity into their everyday health and life decisions. De Certeau's theoretical model can help make sense of this discrepancy, by framing it in terms of four types of creative and transformative reappropriations of genetic risk information and the imperative to take on a genetic responsibility: translation, selective mobilization, deferral or non-disclosure, and a refusal to engage.

Translation

Much of the literature that reports on the low impact of genetic risk information on behavior argues that the means for remedying this lies in more effective communication between the medical community and test takers. Practical recommendations include the development of better patient education strategies, standardized risk counseling protocols for different disorders and 'debriefing' letters that would accompany counseling sessions

(Ayme *et al*, 1993; Wagner Costalas *et al*, 2003; Heshka *et al*, 2008; McBride *et al*, 2010). As McBride and colleagues write in their report on responses to personalized genetic information:

> Key to fully realizing the potential, if any, of personalized genomics for influencing health outcomes is that target populations understand the risks and benefits of testing and can accurately interpret the results and associated limitations. (2010, p. 91)

These recommendations echo one of the underlying assumptions of healthy citizenship discourse – that information plays a pivotal role in enabling people to practice their autonomous choice in responsible ways. Such a health literacy deficit model implies that test takers are relatively passive consumers of genetic risk information, and that the problem lies in the moment or means of information transfer. In de Certeau's model, while reading may appear to be quintessentially passive, it is an anti-disciplinary activity that transforms a text by giving it meaning (1984, pp. xxi and 174); the text depends for its meaning on the manner in which it is used. Accordingly, what may be happening here is not so much a failure of communication or a misunderstanding on the part of test takers, which preempts their capacity for autonomous choice, but transformations of genetic risk information into categories that are meaningful to them. Such creative interpretations of the idea of genetic risk are tactical practices, better understood in terms of rendering the regime of healthy citizenship 'habitable' than about the realization of one's capacity for autonomous choice.

The translation of abstract test results into more concrete and familiar terms, into categories that make sense in light of people's lived experience, is indeed a common tactic that test takers deploy. In particular, the importance of lay beliefs about inheritance in informing people's construction of genetic risk has been shown by many studies to be paramount (Richards, 1996; Hallowell, 1999; Emslie *et al*, 2003; Featherstone *et al*, 2006). Such lay ideas about inheritance, moreover, are usually the result of an overall fusion of the language of genetics with ideas about family histories and family resemblances, both physical and behavioral, that often takes place in surprising and creative ways. In the ethnographic arm of the REVEAL study on susceptibility testing for Alzheimer's disease, for example, Chilibeck *et al* (2011) highlight how test takers sometimes blend, and sometimes play against each other, ideas about genetics and heredity in order to make sense of risk, depending on if results corroborate or conflict with existing beliefs about one's risk in light of family history. Thus, some participants in their study mobilized lay understandings of heredity to make sense of new genetic information, and many associated similarities in physical and social traits with genetic similarity to predict disease risk. The authors argue that while this conflation of genetic information and pre-existing beliefs about risk can be interpreted as a simple misunderstanding of the science, it actually may indicate a more complex and intentional dynamic, by which participants attempt to translate abstract scientific information into more familiar terms. In this sense, lay theories of heredity grounded in everyday social practices are not just 'bad science', but constitute important tools that people actively mobilize in order to evaluate and interpret new genetic information, resulting in a "familiarization of genetics" (2011, p. 1771).

Other studies have also noted how lay understandings of genetic risk are used to translate genetic information into meaningful categories by absorbing and embedding it within familiar tropes that are part of everyday language and can then be worked with. In their study on women in families with Duchenne Muscular Dystrophy, Parsons and Atkinson (1992) report that participants frequently engaged in tasks of translating mathematical percentages and ratios into descriptive categories ("fifty-fifty", "high" or "low" risk, "being able to have boys") as an attempt to make their odds meaningful. These understandings in turn served as the basis for genetic decision making, for what the authors call "categorical recipes for knowledge and action" (1992, p. 454), mainly in terms of reproductive action. Similarly, in their study on the construction of risk for Huntington's disease, Cox and McKellin (1999) argue that the construction of hereditary risk is an intersubjective process that emerges from within the world of routine activities of test takers and their families. They describe how the lived experience of risk develops in a dynamic network where things like geographic and social proximity to an affected family member are as significant as the biomedical understanding of susceptibility to risk. In this sense risk became more problematic for the participants in their interviews as it 'came closer' in terms of familial proximity.

Re-framing the health literacy deficit in terms of tactics takes into account a much more complex and intentional dynamic that is at work in translation. Hereditary risk can be conflated with or intermingled with pre-existing beliefs about risk, and have a fluctuating relevance throughout the life course of test takers and their families (becoming more relevant at critical junctures like diagnosis of a parent or sibling, and then retreating to the background). This is to say that the abstract form of knowledge that scientific constructions of risk offer are only one aspect of how test takers understand, and, ultimately, act upon test results.

Selective mobilization

The 'gap' that emerges between genetic information about heredity, on the one hand, and subjective and social experiences of kinship and risk on the other (Svendsen, 2006), is thus bridged in many ways – and it can become a space for action, for possibility and for agency. Indeed, translation is not only about making risk meaningful, it is also a transformation of meaning to other ends, what de Certeau calls an "other production" that, though not always easily discernible, is an expression of other goals and purposes. The mobilization of genetic risk information for individual goals is a tactic that has been reported in a series of studies that Celeste Condit and her colleagues have carried out over the past decade, where they have looked at how lay people understand and utilize genetic discourses in various settings (Condit *et al*, 2002; Condit *et al*, 2009; Condit, 2011). These studies explore in some detail not only how people respond to claims of genetic causation by means of complex, interpretative processes – deploying tactics of translation – but they have also shown that these processes are frequently guided by individuals' own perceived ends, and that these can differ considerably from public health objectives. These include things like a desire to avoid attributing negative futures to themselves or to their loved ones, to avoid self-blame, to maintain a feeling of control over the future, or to justify or secure what are perceived as existing 'good' or 'bad' health habits.

The authors also document how such personal goals motivate participants to switch back and forth between behavioral and genetic accounts of disease causation in ways that seem random and altogether contradictory to observers (Condit *et al*, 2009). But rather than interpret this shifting between genetic and behavioral discourses as a manifestation of a blatant inconsistency, the authors argue that it should be understood as a behavior that follows its own internal logic, that it is guided by individuals' attempts to optimize advantages, and to further their own perceived interests. A striking example (Condit *et al*, 2009) is how a mother alternates between frameworks of behavioral and genetic causation depending on if her own or her son's disease risk is being discussed. Thus, when asked to address her own risk for heart disease, she seems to doubt the efficacy of behavioral modification ("a lot of sickness in our family, it just goes – seems like it go [*sic*] on and on with the generation"). But when asked about her son's risk for diabetes (in a family with several cases of diabetes), she adopts a more behavioral framework, interpreted as the possibility to avoid the disease by eating well and exercising, something she believed she could help him with. The authors explain that this difference "may reflect a stronger motivation to protect the health of one's loved ones as opposed to protecting the valued habits of one's self" (2009, p. 12). Furthermore, in the case of this woman, not only were different accounts of causation drawn upon to make sense of her own or her son's risk, but she also switched between genetic and behavioral frameworks when discussing these diseases in general or in addressing personal disease risk, as her own or her son's. Here, the stronger emotional involvement seemed to change perception about what could be done to mitigate risk.

This raises some important challenges to the model of the autonomous individual that lies at the core of healthy citizenship discourse, along the lines of recent communitarian (Mulhall and Swift, 1996) and feminist (Mackenzie and Stoljar, 2000; Gould, 2004) critiques. As these theorists argue, the view of the person as an isolated individual, which has been the focus of ethics, and particularly bioethics, in the Western world, is a misrepresentation. People (and the choices they make) do not exist independently of the society and community they are part of. The person is rather a relational, social and connected agent, who makes choices in the context of her relationships and interdependent networks. What is more, genetic understandings of human beings, as a number of theorists have pointed out (Knoppers and Chadwick, 2005; Prainsack and Buyx, 2013; Widdows, 2013), contribute to these conceptual critiques of individual autonomy by offering empirical support to alternative, relational or communal understandings of self-hood. The genetic person, "is not an 'isolated individual' but one who is genetically related both to current groups and to past and future generations … to family groups, ethnic groups and wider communities" (Widdows, 2009, p. 175).

Autonomy, at least in the individualistic and isolationist way that it has been theorized traditionally, is unhelpful in understanding tactics of selective mobilization of genetic risk information. Critics of healthy citizenship discourse would no doubt agree. But these same tactics also challenge concerns that scientific and public health discourses might be taken up by people in a straightforward manner, in disciplining and normalizing ways. In each of the scenarios recounted here, plausible, context-specific motivations can be identified that seem to play an important role in how genetic risk information is interpreted and used. Genetic risk discourses are mobilized when they are seen as useful, disregarded when they are not and reinterpreted so as to be applicable in everyday life. As Condit (2011) argues, we should expect non-consonance rather than consonance of lay appropriations of scientific discourse with the original scientific discourse. Interestingly, this selective if not instrumental mobilization of genetic and behavioral accounts of disease, and the smooth switching between them, also implies an absence of 'geneticization' or genetic fatalism among participants, as was feared by early critics of healthy citizenship discourse. Rather, it may attest to a 'postgenomic' type of thinking (Bates *et al*, 2003; Lock *et al*, 2007; Chilibeck *et al*, 2011), by which the complex interplay of genetic, environmental and lifestyle factors in disease causation is a familiar trope. Reframing this seemingly inconsistent deployment of genetic information as a tactic – that seeks to accomplish something and that aligns with the complexity of molecular genomics – is helpful in explaining and highlighting how test takers are engaged in processes of negotiation and resistance to healthy citizenship discourse.

Deferral and non-disclosure

In the framework of healthy citizenship discourse, genetic responsibility does not only entail an obligation to try to modulate one's own genetic risk. The very nature of genetic conditions is such that their risk implications extend beyond the diagnosis of individuals to other family members. The idea of genetic responsibility thus involves an additional imperative to disclose risk information to any biological kin for whom it may have medical or reproductive implications, thus enabling others to practice their autonomous choice. Nevertheless, the failure to fully communicate risk information to family members is not uncommon, and is a phenomenon that genetic counselors wrestle with (Fanos and Johnson, 1995; Wagner Costalas *et al*, 2003; Clarke *et al*, 2005). Genetic test takers sometimes withhold information, delay disclosure or communicate only partial information to involved relatives. In such cases, we are once more confronted with a discrepancy between the dominant discourse of healthy citizenship and everyday practices. Here too this discrepancy could be interpreted in terms of a deficit model – of moral deficiency or genetic irresponsibility. Conversely, when deferral or non-disclosure of genetic risk information is reframed as a tactic, as a creative appropriation of healthy citizenship discourse, other forms of responsibility and moral conduct, which cannot be explained solely in terms of autonomous choice and risk management, come to light.

Genetic information is often perceived as something harmful, and a concern not to cause anxiety, distress and alarm among family members is frequently cited as a reason for delaying or refusing to disclose information to others (Green *et al*, 1997; Forrest *et al*, 2003; Clarke *et al*, 2005; Wiens *et al*, 2013). This is to say that a desire to protect relatives from potentially harmful information, and feelings of responsibility as the bearers of that information, is often an important motivation for not disclosing information. Clarke *et al* (2005), for example, found that among 65 cases of reported non-disclosure of genetic risk information within families, the desire to shield relatives from distress was the most frequently given reason for not disclosing information. Likewise, in a recent systematic review of literature identifying factors relevant to family communication of genetic risk information, Wiens *et al* (2013) found that the most frequently cited factor was the desire to protect oneself and family from potentially harmful information. In such cases, non-disclosure is not so much a failure to communicate as it is an active decision to engage in a form of familial protectionism. It is often the result of a careful balancing of the acknowledged obligation to communicate relevant information against the desire not to cause anxiety (d'Agincourt-Canning, 2001; Wright *et al*, 2003), what Forrest *et al* (2003) have described as the "disclosure dilemma".

Clarke *et al* (2005) cite a number of processes by which test takers negotiated this dilemma in their study. They often made their own judgments as to whether the potential recipients personally needed the information, or if they could cope with it or would even want to receive it; they engaged in surveillance, watching from a distance for the manifestation of signs of disease until which point disclosure could be deferred; and they took into consideration concerns about the best interests of their relatives. Arribas-Ayllon *et al* (2011) also present a very thorough and revealing discussion of the explanations provided by participants in their study where a high incidence of non-disclosure of risk was reported. They found that people invoke complex rationalizations to justify deferring or delaying disclosure, and often engage in creative strategies to negotiate and maintain some control over how genetic knowledge would affect family members – and themselves – as the bearers of bad news. Similar to some of the tactics identified by Clarke *et al* (2005), these included processes of surveillance, of ‘watching and waiting’ for symptoms in order to determine when the timing of disclosure was right, or moral assessments of character in order to determine who could cope with the information and who would be most capable as a recipient of information that would then require additional negotiation concerning further disclosure.

Such familial protectionism as a motivation for non-disclosure, not surprisingly, has been found to be particularly common among parents of children and young adults (d’Agincourt-Canning, 2001; Arribas-Ayllon *et al*, 2008). In these complex situations, parents seek to balance various forms of responsibility, which can often conflict with norms of individual autonomy, such as the responsibility to know a child’s risk versus the responsibility of being a ‘good parent’ who respects a child’s future autonomy, or the responsibility of deciding the ‘right time’ to tell a child versus the responsibility of protecting a child from information that can cause distress. Rather than disclosing risk information, parents in these situations often opt for monitoring their children’s health and discouraging behavior, for example, that is known to help trigger a condition.

As Arribas-Ayllon *et al* (2011) argue, other intervening forces that are imminent to practices of managing and disclosing genetic risk, namely strategies of preservation, are at play here, and pursue a practical logic that escapes the moral calculus of autonomous choice and risk promoted by healthy citizenship discourse. Non-disclosure should not be seen as a simple failure to communicate, or to fully take on one’s genetic responsibility. In these cases it is in itself a form of care informed by moral reasoning; not a ‘denial’ or ‘emotional blocking’, but itself a means of expression. As with the translation of genetic risk information into intersubjectively meaningful accounts that individuals can work with, and as with the selective deployment of genetic discourses in line with specific goals, non-disclosure can also be a tactical practice that reinterprets the moral imperatives of healthy citizenship and renders them habitable by making them function in a different register, that of familial protectionism.

Refusal to engage

In the logic of informed choice that frames genetic testing as a practice of healthy citizenship, the decision to decline testing in the presence of a known hereditary risk is the most illegitimate of acts. But just as deferral and non-disclosure of genetic risk to relatives can be understood as a tactic that enacts alternative modes of responsibility, a refusal to engage with genetics may also be a tactic that informs alternative forms of moral conduct. Here too, a number of studies highlight that the decision to decline testing can be the outcome of complex moral deliberation.

The moral interpellation of healthy citizenship discourse is perhaps strongest in the context of reproduction, and among individuals who know they are carriers of a genetic disorder and who want to have children. For these individuals various forms of prenatal diagnosis exist to determine the presence of chromosomal or genetic disorders, from amniocentesis to preimplantation genetic diagnosis, effectively constituting them as ‘moral pioneers’

(Rapp, 1999) who must reason their way through new moral situations. The decision not to use these services or, conversely, to carry through a 'risky' pregnancy once the carrier status of parents has been established, is not a commonly chosen reproductive option.[8] But it does occur, and can hardly be dismissed as the result of an absence of moral reflection. In a study on how parents who already have a child affected with a genetic condition respond to prenatal screening and testing, for example, Kelly (2009) found that a majority of parents who decided to have more children chose not to make use of prenatal screening or testing to identify or avoid the birth of an affected child. Contrary to the rationale of risk reduction behind prenatal testing, Kelly reports that many parents did not see testing possibilities as relevant to their sense of responsibility and control. For some, testing was seen as incompatible with their ideas about personhood and societal acceptance of children with disabilities. The experience of already having an affected child was in some cases drawn on as a source of awareness that "having a child with a disability wasn't all bad" (2009, p. 90), or that the parenting skills they developed would enable them to manage the difficulties involved in having another affected child. As Kelly argues, these parents' decision not to seek the use of testing technologies should not be seen as a denial of responsibility, but as a rejection of the framing of responsibility in terms of risk analysis and reproductive control. Declining to engage with genetics here is itself a tactic of responsible parenting, based on a different understanding of the phenomenon of impairment and disability drawn from parents' own lived experience.

In a study on the reproductive choices of 108 mothers who are carriers of the fragile X gene, and who already have an affected child, Raspberry and Skinner (2011) also found that an important group – 22 participants – either purposely became pregnant or continued an unplanned pregnancy, that is, consciously pursued 'risky' pregnancies. The authors found that various accounts were given by these women to construe their choice as a conscious, moral evaluation of the situation, and to construct themselves as responsible, rational agents. These included affirmation of the worthiness of all children (valuing 'difference' and rejecting disability as less worthy), investment in parenthood and family (importance for existing children to have siblings), and a feeling of increased empowerment and life purpose (as a result of the unique parenting skills and advocacy efforts involved in parenting a child with fragile X syndrome). These accounts diverge from typical understandings of genetic responsibility as an imperative not to reproduce or to reproduce 'responsibly' using screening or preimplantation genetic diagnosis technologies, yet they clearly express complex moral deliberation predicated on other understandings of what it means to be a responsible parent. This resonates with what Beeson and Doksum (2001) have called "experiential resistance". In their study on families with individuals affected with cystic fibrosis or sickle cell anemia, they found that for individuals who declined carrier testing and prenatal diagnosis, other important values were at stake than those underpinning genetic risk calculation, such as an unwillingness to equate the meaning of the life of a person with a genetic disorder to their disease.

Refusal to engage can thus be seen as a "legitimate moral enterprise" in itself (Hunich, 2011). In the well-known case of Gino, for example, the Limb Girdle Dystrophy (LGD) patient analyzed by Callon and Rabeharisoa (2004) who lives his life with no explicit reference to medical genetics, refusal emerges as a morally sound practice. Gino's is a triple refusal: he

---

[8] For women who receive a positive prenatal diagnosis, selective abortion is the most frequently reported option (Mutton *et al*, 1998; Mansfield *et al*, 1999).

declines medical treatment, he declines to participate in the local muscular dystrophy association and he declines to know about his children's carrier status. Yet, when pressed for an explanation, Gino explains that though refusing treatment he has his own way of handling life with LGD symptoms (only doing work that allows him to take breaks when needed); that he prefers to spend quality time with friends (going to football matches) to participating in the activities of the local patient organization; and that although he does not push his own children to get tested, he still worries about them. Callon and Rabeharisoa argue that Gino's resistance to participating in these three public arenas is the refusal of a particular form of agency that is imposed as a condition of entering the moral public sphere of medical genetics: that of an actor who arbitrates and freely chooses between options and is therefore responsible for the consequences of his choices. Rather than interpreting this as irrational or immoral, the authors suggest that Gino is instead opting for a different form of intelligence, morality and humanity. Not one that is prescribed from the outside, and that requires one to behave like a "free-willed, autonomous and responsible individual subject" (2004, p. 6), but one that is based in a recognition of the "entanglements" and "attachments" in which individuals are caught (p. 16). Gino's refusal is a tactic that escapes the moral imperative of autonomous choice and risk management of healthy citizenship discourse.

Other accounts also run against the common view of the non-engaged at-risk individual as morally dubious and passive. In her study on how the classification of being at risk for hereditary cancer is interpreted and lived by several members of a family affected by hereditary breast cancer, Svendsen (2006) shows how the refusal of one counselee, Pia, to get tested is a very active means of carving out a habitable space in the face of genetic near inevitability. By declining testing (but agreeing to monitoring), Pia simultaneously resists and contests the value of genetic knowledge and its determinacy. Paradoxically, by maintaining or allowing for the extension of a space of uncertainty in time, she gains some kind of control; not control based on knowing what will happen, but control over the existence of the plurality of possible futures. This is a resistance to the closing down of possible futures. Not knowing, according to Svendsen, allows Pia to invoke a future that is not written out in the terms dictated by genetic causality, a future that is hopeful and open in its indeterminacy. Similarly, Huniche (2011) recounts the case of Colin, a middle-aged man whose mother has Huntington's disease (HD) but who has decided to forego testing himself as well as prenatal genetic testing for his second child (having had his first child without being aware of the HD risk). Huniche also describes Colin's choice as a deliberate, morally charged ongoing act, a form of "experiential engagement", characterized by dealing with concrete manifestations of HD as they arise. This "strategy for living", she explains, is advantageous insofar as it can liberate everyday life from the stifling fear of knowing about HD, and allow for the possibility of engagement with the present and the future (2011, p. 1812). For Colin, as with Pia, Gino and those parents who forego prenatal genetic testing, non-engagement is not a denial of responsibility, but a tactic that creates a space for an awareness and experiencing of other fulfilling dimensions of the life of an affected person within the confines of genetic responsibility.

Conclusion

The different examples discussed here indicate that the ways in which people are affected by genetic risk knowledge, how they interpret it, what they do with it and how and if they share it with other family members is not necessarily governed by the principles of individual autonomy and rational choice that are prescribed by the current dominant discourse of healthy citizenship. This poses significant challenges not only to the dominant discourse of healthy citizenship, but, by the same token, to critiques of healthy citizenship discourse as a form of discipline and a new mode of social control, insofar as they are both embedded in an autonomy/heteronomy dichotomy. While this may be obvious in the case of healthy citizenship discourse, I have argued that it is also often the case for its critique. This is because, concerned with exposing the rhetoric of empowerment and choice as techniques of discipline, this critique tends to slip back into a defense of autonomy understood as a lack of external constraints – even as it mobilizes more complex notions of autonomy and freedom as they have been formulated by the later Foucault.

This is not to say that the endeavor to deconstruct the claims of empowerment and autonomy at the heart of healthy citizenship discourse is not important. But that this should not be done from the place of defending those notions that are being deconstructed. A shift in the theoretical framework, rather, away from autonomy/heteronomy needs to be our starting point. In this article I have suggested that de Certeau's model of the creativity of ordinary people as a tactical mode of operation offers such a fruitful shift of perspective, because the relationship between tactics and strategy is not oppositional but symbiotic in de Certeau's model: it is not a question of dauntlessly 'standing up' to the forces of an external power, but of working upon and within given structures and meaning. The tactics of everyday life do not hold the promise of freedom from a grid of discipline but the promise of habitability, of carving out a livable space where some form of meaningful agency can flourish. The translation of genetic information into intersubjectively meaningful accounts that individuals can work with, the selective mobilization of genetic discourses in personal disease susceptibility, the deferral or non-disclosure of genetic risk information to other family members, and the steadfast refusal to engage with medical genetics discussed here can all be seen as tactical practices in this sense, which reinterpret the moral imperatives of healthy citizenship discourse and transpose them into different registers of everyday life.

As Buchanan (2000) claims, de Certeau's project is not a set of fixed theoretical conclusions, but it makes it possible to open up more spaces where an alternative logic to dominant and explicit orders, an 'anti-discipline', can be addressed. It provides a vocabulary with which to articulate the other modes of reasoning, action and moral conduct that prompt these tactical practices, and by which they can be seen as productive in their own right. In terms of the dominant discourse of healthy citizenship this is invaluable if we want to prevent these practices from being reduced to intellectual or moral incompetence ("Gino is neither an idiot nor a monster", Callon and Rabeharisoa profess). In terms of the critique of healthy citizenship, if this vocabulary can allow us to carefully listen to non-dominant modes of agency that emerge from within the reinterpretation and appropriation of the moral imperatives of healthy citizenship discourse, we may try to nurture these all the while maintaining a critical eye towards normalizing tendencies and economic interests. It can allow us to try to move this critique forward, beyond denunciation, to progressive possibilities that may open up in such situations, and point to more habitable genetic futures.

Acknowledgements

This article has benefited from the generous comments of Jens Lachmund, Ine Van Hoyweghen, Barbara Prainsack, Tsjalling Swierstra and the participants of Maastricht University's STS "Summer Harvest" in September 2012, as well as those of three anonymous reviewers. This research was conducted within the framework of a project on "Healthy Creativity: The Implicit Normativity of Healthy Citizenship" funded by the Netherlands Organization for Scientific Research (NWO).

About the Author

Tamar Sharon is an assistant professor in the Philosophy Department and STS Group at Maastricht University, NL. She is currently working on a Netherlands Organization for Scientific Research (NWO) funded project on how users engage with emerging health technologies in the current landscape of health responsibilization. She is the author of *Human Nature in an Age of Biotechnology: The Case for Mediated Posthumanism* (Springer, 2013).

References

Ahearne, J. (1995) *Michel de Certeau: Interpretation and Its Other*. Stanford, CA: Stanford University Press.

Armstrong, D. (1995) The rise of surveillance medicine. *Sociology of Health and Illness* 17(3): 393–404.

Arribas-Ayllon, M., Sarangi, S. and Clarke, A. (2008) The micropolitics of responsibility vis-à-vis autonomy: Parental accounts of childhood genetic testing and (non)disclosure. *Sociology of Health & Illness* 30(2): 255–271.

Arribas-Ayllon, M., Featherstone, K. and Atkinson, P. (2011) The practical ethics of genetic responsibility: Non-disclosure and the autonomy of affect. *Social Theory & Health* 9(1): 3–23.

Arris, M. (1997) *Against Death: The Practice of Living with AIDS*. Amsterdam: Gordon and Breach Publishers.

Ayme, S., Macquart-Moulin, G., Julian-Reynier, C., Chabal, F. and Giraud, F. (1993) Diffusion of information about genetic risk within families. *Neuromuscular Disorder* 3(5/6): 571–574.

Bates, B., Templeton, A., Achter, P., Harris, T. and Condit, C. (2003) What does 'A gene for heart disease' mean? *American Journal of Medical Genetics Part A* 119 A(2): 156–161.

Barry, A., Osborne, T. and Rose, N. (eds.) (1996) *Foucault and Political Reason: Liberalism, Neoliberalism and Rationalities of Government*. London: UCL Press.

Beck, U. and Beck-Gernsheim, E. (2001) *Individualization: Institutionalized Individualism and its Social and Political Consequences*. London: SAGE.

Beeson, D. and Doksum, T. (2001) Family values and resistance to genetic testing. In: B. Hoffmaster (ed.) *Bioethics in Social Context*. Philadelphia, PA: Temple University Press, pp. 153–179.

Braun, B. (2007) Biopolitics and the molecularization of life. *Cultural Geographies* 14(1): 6–28.

Buchanan, I. (1992) Writing the wrongs of history: de Certeau and post-colonialism. *Journal of the South Pacific Association for Commonwealth Literature and Language Studies* 33: 39–48.

Buchanan, I. (2000) *Michel de Certeau: Cultural Theorist*. London: Sage.

Bunton, R., Nettleton, S. and Burrows, R. (eds.) (1995) *The Sociology of Health Promotion: Critical Analyses of Consumption, Lifestyle and Risk*. London: Routledge.

Burchell, G., Gordon, C. and Miller, P. (eds.) (1991) *The Foucault Effect: Studies in Governmentality*. Chicago, IL: Chicago Universiy Press.

Callon, M. and Rabeharisoa, V. (2004) Gino's lesson on humanity: Genetics, mutual entanglements and the sociologist's role. *Economy and Society* 33(1): 1–27.

Callon, M. and Rabeharisoa, V. (2008) The growing engagement of emergent concerned groups in political and economic life: Lessons from the French Association of Neuromuscular Disease Patients. *Science, Technology and Human Values* 33(2): 230–261.

Chilibeck, G., Lock, M. and Sehdev, M. (2011) Postgenomics, uncertain futures, and the familiarization of susceptibility genes. *Social Science and Medicine* 72(11): 1768–1775.

Clarke, A *et al* (2005) Genetic professionals' reports of nondisclosure of genetic risk information within families. *European Journal of Human Genetics* 13: 556–562.

Condit, C.M. (1999) How the public understands genetics: Non-deterministic and non-discriminatory interpretations of the 'blueprint' metaphor. *Public Understanding of Science* 8(3): 169–180.

Condit, C.M. (2011) When do people deploy genetic determinism? A review pointing to the need for multi-factorial theories of public utilization of scientific discourses. *Sociology Compass* 5(7): 618–635.

Condit, C.M. *et al* (2002) Recipes of blueprints for our genes? How contexts selectively activate the multiple meanings of metaphors. *Quarterly Journal of Speech* 88(3): 303–325.

Condit, C.M., Gronnvoll, M., Landau, J., Shen, L., Wright, L. and Harris, T.M. (2009) Believing in both genetic determinism and behavioral action: A materialist framework and implications. *Public Understanding of Science* 18(6): 730–746.

Conrad, P. (1992) Medicalization and social control. *Annual Review of Sociology* 18: 209–232.

Coveney, J. (1998) The government and ethics of health promotion: The importance of Michel Foucault. *Health Education Research* 13(3): 459–68.

Cox, S.M. and McKellin, W. (1999) 'There's this thing in our family': Predictive testing and the construction of risk for Huntington Disease. *Sociology of Health & Illness* 21(5): 622–646.

Crawford, R. (1980) Healthism and the medicalization of everyday life. *International Journal of Health Services* 10(3): 365–388.

D'Agincourt-Canning, L. (2001) Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics* 15(3): 231–247.

de Certeau, M. (1984) *The Practice of Everyday Life*. Translated by S. Rendall. Berkeley, CA: University of California Press.

Emslie, C., Hunt, K. and Watt, G. (2003) A chip off the old block? Lay understandings of inheritance among men and women in mid-life. *Public Understanding of Science* 12(1): 47–65.

Fanos, J.H. and Johnson, J.P. (1995) Barriers to carrier testing for adult cystic fibrosis sibs: The importance of not knowing. *American Journal of Medical Genetics* 59(1): 85–91.

Featherston, K., Atkinson, P., Bharadwaj, A. and Clarke, A. (eds.) (2006) *Risky Relations: Family, Kinship and the New Genetics*. New York: Berg Publishers.

Flower, M.J. and Heath, D. (1993) Micro-anatomo politics: Mapping the human genome project. *Culture, Medicine and Psychiatry* 17(1): 27–41.

Forrest, K., Simpson, S.A., Wilson, B.J., van Teijlingen, E.R., McKee, L., Haites, N. and Matthews, E. (2003) To tell or not to tell: Barriers and facilitators in family communication about genetic risk. *Clinical Genetics* 64(4): 317–326.

Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison*. Translated by A. Sheridan. London: Allen Lane.

Foucault, M. (1979) *The History of Sexuality, Volume 1: An Introduction*. Translated by R. Hurley. London: Allen Lane.

Foucault, M. (2008) *The Birth of Biopolitics*. Translated by G. Burchell. New York: Palgrave Macmillan.

Franklin, M. (2004) *Postcolonial Politics, the Internet and Everyday Life: Pacific Traversals Online*. London: Routledge.

Fraser, N. (1989) Foucault on modern power: Empirical insights and normative confusions. In: *Unruly Practices: Power, Discourse and Gender in Contemporary Social Theory*. Minneapolis, MN: University of Minnesota Press, pp. 17–34.

Frow, J. (1991) Michel de Certeau and the problem of representation. *Cultural Studies* 5(1): 52–60.

Gammeltoft, T. and Wahlberg, A. (2014) Selective reproductive technologies. *Annual Review of Anthropology* 43, doi: 10.1146/annurev-anthro-102313-030424.

Gibbon, S. and Novas, C. (eds.) (2008) *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities*. London: Routledge.

Gould, C. (2004) *Globalising Democracy and Human Rights*. Cambridge: Cambridge University Press.

Green, J., Richards, M., Murton, F., Statham, H. and Hallowell, N. (1997) Family communication and genetic counseling: The case of hereditary breast and ovarian cancer. *Journal of Genetic Counseling* 6(1): 45–60.

Habermas, J. (1990) Some questions concerning the theory of power: Foucault again. In: *The Philosophical Discourse of Modernity: Twelve Lectures*. Translated by F.G. Lawrence. Boston, MA: MIT Press, pp. 266–293.

Hall, W.D., Mathews, R. and Morley, K.I. (2010) Being more realistic about the public health impact of genomic medicine. *PLoS Med* 7(10): e1000347.

Hallowell, N. (1999) Doing the right thing: Genetic risk and responsibility. *Sociology of Health and Illness* 21(5): 597–621.

Harris, R., Wathen, N. and Wyatt, S. (eds.) (2010) Working to be healthy: Empowering consumers or citizens? In: *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility*. New York: Palgrave Macmillan, pp. 211–224.

Harvey, A. (2010) Genetic risks and healthy choices: Creating citizen-consumers of genetic services through empowerment and facilitation. *Sociology of Health & Illness* 32(3): 365–381.

Heshka, J.T., Palleschi, C., Howley, H., Wilson, B. and Wells, P.S. (2008) A systematic review of perceived risks, psychological and behavioral impacts of genetic testing. *Genetics in Medicine* 10(1): 19–32.

Highmore, B. (2006) *Michel de Certeau: Analysing Culture*. London: Continuum.

Huniche, L. (2011) Moral landscapes and everyday life in families with Huntington's disease: Aligning ethnographic description and bioethics. *Social Science & Medicine* 72(11): 1810–1816.

Kelly, S. (2009) Choosing not to choose: Reproductive responses of parents of children with genetic conditions or impairments. *Sociology of Health and Illness* 31(1): 81–97.

Kenen, R. (1994) The Human Genome Project: Creator of the potentially sick, potentially vulnerable and potentially stigmatized? In: I. Robinson (ed.) *Life and Death under High Technology Medicine*. Manchester: Manchester University Press.

Kerr, A. (2004) Genetics and citizenship. In: N. Stehr (ed.) *Biotechnology between Commerce and Civil Society*. New Brunswick: Transaction Press, pp. 159–174.

Kerr, A. and Cunningham-Burley, S. (2000) On ambivalence and risk: Reflexive modernity and the new human genetics. *Sociology* 34(2): 283–304.

Knoppers, B.M. and Chadwick, R. (2005) Human genetic research: Emerging trends in ethics. *Nature* 6: 75–79.

Koch, L. and Svendsen, M.N. (2005) Providing solutions – Defining problems: The imperative of disease prevention in genetic counselling. *Social Sciences and Medicine* 60(4): 823–832.

Konrad, M. (2005) *Narrating the New Predictive Genetics: Ethics, Ethnography and Science*. Cambridge: Cambridge University Press.

Lemke, T. (2004) Disposition and determinism – Genetic diagnostics in risk society. *The Sociological Review* 52(4): 550–66.

Lemke, T. (2011) *Biopolitics: An Advanced Introduction*. New York: New York University Press.

Lippman, A. (1992) Led (astray) by genetic maps: The cartography of the human genome and health care. *Social Science and Medicine* 35(12): 1469–1476.

Lock, M., Freeman, J., Chilibeck, G., Beveridge, B. and Padolsky, M. (2007) Susceptibility genes and the question of embodied identity. *Medical Anthropology Quarterly* 21(3): 256–276.

Lupton, D. (1995) *The Imperative of Health: Public Health and the Regulated Body*. London: Sage.

Lupton, D. (2012) M-health and health promotion: The digital cyborg and surveillance society. *Social Theory and Health* 10(3): 229–244.

Mackenzie, C. and Stoljar, N. (eds.) (2000) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford: Oxford University Press.

Makowsky, R. *et al* (2011) Beyond missing heritability: Prediction of complex traits. *PLoS Genetics* 7(4): e1002051.

Mansfield, C., Hopfer, S. and Marteau, T.M. (1999) Termination rates after prenatal diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter syndromes: A systematic literature review. *Prenatal Diagnosis* 19(9): 808–812.

Marteau, T.M. and Lerman, C. (2001) Genetic risk and behavioral change. *British Medical Journal* 322(7293): 1056–1059.

Marteau, T.M., Roberts, S., LaRusse, S. and Green, R. (2005) Predictive genetic testing for Alzheimer's disease: Impact upon risk perception. *Risk Analysis* 25(2): 397–404.

McBride, C.M., Koehly, L.M., Sanderson, S.C. and Kaphingst, K.A. (2010) The behavioral response to personalized genetic information: Will genetic risk profiles motivate individuals and families to choose more healthful behaviors? *Annual Review of Public Health* 31(1): 89–103.

Mol, A. (2008) *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge.

Mulhall, S. and Swift, A. (1996) *Liberals and Communitarians*, 2nd edn. Oxford: Blackwell.

Mutton, D., Ihde, R. and Alberman, E. (1998) Trends in prenatal screening for and diagnosis of Down's Syndrome: England and Wales, 1989–97. *British Medical Journal* 317(7163): 922–923.

Nelkin, D. and Lindee, M.S. (1995) *The DNA Mystique: The Gene as a Cultural Icon*. New York: W.H. Freeman.

Nelson, A. (2008) Bio science: Genetic genealogy testing and the pursuit of African ancestry. *Social Studies of Science* 38(5): 759–783.

Nettleton, S. (2006) *Sociology of Health and Illness*. London: Polity Press.

Novas, C. and Rose, N. (2000) Genetic risk and the birth of the somatic individual. *Economy and Society* 29(4): 484–513.

Parsons, E. and Atkinson, P. (1992) Lay constructions of genetic risk. *Sociology of Health & Illness* 14(4): 439–455.

Petersen, A. (1997) Risk, governance and the new public health. In: A. Petersen and R. Bunton (eds.) *Foucault, Health and Medicine*. London: Routledge, pp. 189–206.

Petersen, A. (2003) Governmentality, critical scholarship, and the medical humanities. *Journal of Medical Humanities* 24(3/4): 187–200.

Petersen, A. and Bunton, R. (eds.) (1997) *Foucault, Health and Medicine*. London: Routledge.

Petersen, A., Davis, M., Fraser, S. and Lindsay, J. (2010) Healthy living and citizenship: An overview. *Critical Public Health* 20(4): 391–400.

Plows, A. and Boddington, P. (2006) Troubles with biocitizenship? *Genomics, Society and Policy* 2(3): 115–135.

Polzer, J., Mercer, S.L. and Goel, V. (2002) Blood is thicker than water: Genetic testing as citizenship through familial obligation and the management of risk. *Critical Public Health* 12(2): 153–168.

Prainsack, B. and Buyx, A. (2013) A solidarity-based approach to the governance of research biobanks. *Medical Law Review* 21(1): 71–91.

Press, N. (2008) Genetic testing and screening. In: M. Crowley (ed.) *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*. Garrison, NY: The Hastings Center, pp. 73–78.

Rabinow, P. (1992) Artificiality and enlightenment: From sociobiology to biosociality. In: J. Crary and S. Kwinter (eds.) *Incorporations*. New York: Zone, pp. 234–252.

Rabinow, P. (1996) *Essays on the Anthropology of Reason*. Princeton, NJ: Princeton University Press.

Rabinow, P. and Rose, N. (2006) Biopower today. *Biosocieties* 1(2): 195–217.

Raman, S. and Tutton, R. (2010) Life, science and biopower. *Science, Technology and Human Values* 35(5): 711–734.

Rapp, R. (1999) *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge.

Raspberry, K. and Skinner, D. (2011) Enacting genetic responsibility: Experiences of mothers who carry the fragile X gene. *Sociology of Health and Illness* 33(3): 420–433.

Richards, M. (1996) Lay and professional knowledge of genetics and inheritance. *Public Understanding of Science* 5(3): 217–230.

Rose, N. (2007) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century*. Princeton, NJ: Princeton University Press.

Rose, N. and Novas, C. (2005) Biological citizenship. In: A. Ong and S. Collier (eds.) *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*. Oxford: Blackwell, pp. 439–463.

Roukos, D. and Briasoulis, E. (2007) Individualized preventive and therapeutic management of hereditary breast ovarian cancer syndrome. *Nature Clinical Practice Oncology* 4(10): 578–590.

Silva, V.T. (2005) In the beginning was the gene: The hegemony of genetic thinking in contemporary culture. *Communication Theory* 15(1): 100–123.

Svendsen, M.N. (2006) The social life of genetic knowledge: A case-study of choices and dilemmas in cancer genetic counselling in Denmark. *Medical Anthropology: Cross-cultural Studies in Health and Illness* 25(2): 139–170.

Taussig, K.S., Rapp, R. and Heath, D. (2003) Flexible eugenics: Technologies of the self in the age of genetics. In: A. Goodman, D. Heath and M.S. Lindee (eds.) *Genetic Nature/Culture*. Berkeley, CA: University of California Press, pp. 58–76.

Terry, J. (1989) The body invaded: Medical surveillance of women as reproducers. *Socialist Review* 19(3): 13–43.

Turner, B.S. (1997) Forward: From governmentality to risk, some reflections on Foucault's contribution to medical sociology. In: A. Petersen and R. Bunton (eds.) *Foucault, Health and Medicine*. London: Routledge, pp. ix–xxi.

Veinot, T. (2010) Power to the patient? A critical examination of patient empowerment discourses. In: R. Harris, N. Wathen and S. Wyatt (eds.) *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility*. New York: Palgrave Macmillan, pp. 30–41.

Wagner Costalas, J. *et al* (2003) Communication of BRCA1 and BRCA2 results to at-risk relatives: A cancer risk assessment program's experience. *American Journal of Medical Genetics Part C* 119C(1): 11–18.

Widdows, H. (2009) Between the individual and the community: The impact of genetics on ethical models. *New Genetics and Society* 28(2): 173–188.

Widdows, H. (2013) *The Connected Self: The Ethics and Governance of the Genetic Individual*. Cambridge: Cambridge University Press.

Wiens, M.E., Wilson, B.J., Honeywell, C. and Etchegary, H. (2013) A family genetic risk communication framework: Guiding tool development in genetics health services. *Journal of Community Genetics* 4(2): 233–242.

Wright, C., Kerzin-Storrar, L., Williamson, P.R., Fryer, A. and Njindou, A. (2003) Comparison of genetic services with and without genetic registers: Knowledge, adjustment and attitudes about genetic counselling among probands referred to three genetic clinics. *Journal of Medical Genetics* 39(12): e84.

Wyatt, S., Harris, R. and Wathen, N. (eds.) (2010) Health(y) citizenship: Technology, work and narratives of responsibility. In: *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility*. New York: Palgrave Macmillan, pp. 1–10.