When Policy Becomes Material. Enacting Criteria in Distributing Genetic Medicine

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Dr. Erik Aarden  
Institute of Political Science  
RWTH Aachen University  
Aachen, Germany  
Erik.aarden@ipw.rwth-aachen.de

**Abstract**

An area of policy-making for health care that often receives relatively little attention is the distribution of services in Western-European public provision schemes. Often decision-making in this area is left to administrative organizations that are considered to base distributive criteria on technical criteria rather than political preferences. However, this assumption cannot sufficiently explain cross-national differences in criteria and distribution. For truly understanding the production of various forms of in- and exclusion it is therefore necessary to include the materiality of medical care in the analysis.

This paper supports this argument by presenting a cross-national comparison of the distribution of access to specific genetic health care technologies. Building on a framework that centers around the notion of ‘co-production’ of distributive policies and medical technologies the paper identifies distinctive patterns of incorporating genetic technologies in health care provision in Germany, the Netherlands and the United Kingdom. It will furthermore demonstrate how these patterns are produced through both policy measures and criteria and distinctive characteristics of genetic testing on embryos, breast cancer risks and high cholesterol predispositions.

The analysis of distributive patterns in various European countries will show how particular groups of patients or people at risk are likely to be excluded from publicly provided health care. In conclusion, the paper will question these consequences in light of values such as equity and solidarity in health care and present some perspectives on policy making that include materiality and the policy challenges it presents.
1. Introduction

By now, it has become a near platitude to argue that European welfare systems are under pressure to reform. Historically linked to the oil crises of the early 1970s and theoretically to the phenomenon of ‘stagflation’ that deeply challenged Keynesian ideas about the beneficial economic outcomes of state spending, welfare states are broadly, though not unanimously, believed to be retrenching, converging and to be engaged in a ‘race to the bottom’ (Mechanic & Rochefort, 1996). In the case of social health care delivery, which will be the focus of this paper¹, the main causes for reform pressure are sought in exogenous factors such as aging of the population and the increasingly broad application of ever more complex and expensive medical technologies (Aaron & Schwartz, 1990). In response to these pressures, both theorists and practitioners in health policy and economics have sought to develop methods for reducing health care expenses – often calculated relative to gross domestic product. These cost reduction methods commonly apply a fairly reductionist and positivist understanding of provider and consumer decision-making in health care based primarily on financial incentives and scientific abstractions. In this scenario, ways to improve cost-efficiency in health care build mostly on consumer co-payments, performance-based payment for providers and elements of a market economy (Le Grand, 2009; Porter & Teisberg, 2004), while the driving force behind quality improvement is based on evidence-based medicine, in which ‘evidence’ is almost exclusively understood in terms of large-scale, randomized trials (Kulkarni, 2005). To be sure, both principles and outcomes of these measures are by no means uncontested, but they form the dominant paradigm of contemporary health care policy-making nonetheless.

Challenges to existing welfare and medical provision systems that are a lot harder to deal with theoretically, are those arising from the changing character of Western states, societies and the roles they have historically filled. The gradual unfolding of welfare states in most Western countries is often described as a key project in the process of modernization (de Swaan, 1988; Wagner, 1990). Although different states have followed a wide variety of distinct and erratic paths in developing welfare arrangements and welfare was not imagined as a project with a predetermined outcome from the start, there appears to be a strong correlation between the establishment of modern nation states and welfare. In its most simplified form, one that does not account for cross-national differences or theoretical disagreement about the driving forces behind welfare expansion, it is relatively uncontested to claim that with industrialization, urbanization and state-formation from the mid-nineteenth century onwards the newly prominent state administrations increasingly adopted measures to protect their population from excesses of the capitalist production system and provide them with minimum financial means, health care, education, etc. They thereby overtook private and civil society initiatives in these areas, turning the state into a more prominent element of social order

¹ It is an unresolved issue whether health care delivery should actually be understood as part of the welfare state. Main reasons why this is argued not to be the case is that, in general, medical care is not provided directly by the state and that there is an important and powerful third party that plays a significant role, which is the medical profession. However, considering the responsibility for the availability and affordability of health care that most countries have adopted as part of a ‘communitarian’ outlook on medicine after World War 2 (Pickstone (2000)), I believe it makes sense to position medicine within the broader discussion on welfare states.
than it had thus far been. Over the past few decades, exactly this role of the state has become increasingly questioned. This happened not just in terms of the policy reforms discussed above, but also more generally in relation to social theories identifying a shift from modernity to a new historical phase. In relation to globalization, democratization, social de-stratification, the rise of new technoscientific risks, etc. several authors question the contemporary role and functions of welfare arrangements. Social theorists Francois Ewald and Ulrich Beck, for example, argue that contemporary ambiguous, uncertain likely both spatially and temporally far-reaching risks cannot be covered by existing insurance and welfare approaches based on calculation, prediction and control (Beck, 1999; Ewald, 2002). How this shift to post-, reflexive, or liquid modernity will affect welfare states remains an open question, but one we will begin to explore in this paper.

Substantively, this paper will focus on the incorporation of genetic technologies in health care provision schemes in three Western European countries. Genetic technologies understood broadly speak to both forms of pressure to existing welfare arrangements put forward above. They tend to be expensive, highly specialized means of diagnosis for which it is (still) a challenge to determine their most appropriate and cost-effective loci of application (Boenink, 2008). At the same time, genetic technologies that are currently available are believed to be only a vanguard for a dawning revolution in health care (Perpich, 2004; Weinshilboum, 2002). This revolution will imply a radical shift in our understanding of health, disease, and medicine, replacing a paradigm of diagnosis and treatment with one of prediction and prevention. Even though this revolutionary outlook on the consequences of genetic research has been broadly criticized—and with good reason—molecular biology does appear to be consequential for how we understand health, disease, and ourselves (Redclift & S. Gibbon, 2006). Furthermore, in the context of social health care provision a debate about how to deal with the reimbursement of procedures based on identifying and preventing risks, rather than diagnosing and treating existing maladies, is starting to emerge. But instead of engaging in the development of criteria for reimbursing preventive medicine, I will take a broader perspective and analyze how existing health care systems deal with genetic technologies that are already there. In brief, my substantive argument is that Western European welfare states incorporate genetic technologies and distribute access to these technologies through a complex web of regulations, categories and mechanisms that collectively produce implicit, culturally bound imaginaries of what distributive justice in health care ought to look like. I will describe these imaginaries in terms of a number of philosophical perspectives, but use this as a heuristic to highlight cross-cultural differences. It does not imply that, say, the utilitarian imaginary I identify in the United Kingdom has been an explicitly chosen direction for distributing health care access, nor that the Brits meet all the parameters of theoretically ‘sound’ utilitarianism.

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2 Two lines of argument predominate in the criticism of revolutionary rhetoric on genetics and medicine. First, critics claim that the relations between genes, environment and disease are too complex to allow for widespread use of genetic prediction in health care (Evans, Skrzynia, and Burke (2001); Holtzmann and Marteau (2000)). Second, the application of genetic technologies is said to be extensively influenced by the institutional and cultural contexts in which the technologies are included (Hopkins, Martin, Nightingale, Kraft, and Mahdi (2007)).

3 This approach was inspired by an article on various perspectives on distributive justice embedded in science and technology policies in various countries (Cozzens (2007)). See also section 4.
Theoretically, I will argue for the value of what I call, following Hagendijk (Hagendijk, 1996), a cultural constructivist understanding of science, technology and society. I will elaborate this perspective in the next section as an alternative and supplement to more established perspectives in policy analysis. To arrive at this point, I will first make a brief foray into the welfare state literature and argue for the value of a discourse analytic approach to policy analysis. I will specifically draw on Maarten Hajer’s work in this regard. Discourse analysis can be particularly valuable, so I claim, in understanding how policy makers deal with more fundamental uncertainties like the ones introduced above, since they focus on the ‘text and context’ (Schmidt, 2008) of policy making – discussing practices, institutions and categories as dynamic rather than fixed entities in the policy making process. Nevertheless, in a second step I will argue that discourse analysis has a blind eye towards technology. This has as an important consequence that the distributive effects of particular policy constellations are difficult to assess through discourse analysis. While I will empirically elaborate this critique through the example of the delivery of genetic technologies in health care, it is in line with a broader literature focusing on the role of instruments or devices in policy implementation and the economy, developed in science and technology studies (STS) (Callon, Millo, & Muniesa, 2007; Lascoumes & Le Gales, 2007). Thus, I will draw from STS to investigate how various institutions, categories and practices establish health care reimbursement in practice. On that basis I will further develop an understanding of how distributive justice in health care is imagined through context-specific co-production of health care organization and technology. As I will further argue, culturally specific processes of co-production ultimately produce distinct forms of biomedical citizenship, a concept that is helpful for understanding the effects of materialized welfare imaginaries in terms of inclusion and exclusion.

In the third section of the paper, I will employ this theoretical framework to describe the provision of genetic technologies in health care in Germany, the Netherlands and the UK. In each of these countries, which were selected on the basis of their distinct health care systems and distinct policy approaches to genetics in health care, I analyzed three particular technologies. I will discuss one of these, diagnosis and treatment for a hereditary predisposition for high cholesterol called familial hypercholesterolemia, in more detail, while briefly touching upon the other two. In the fourth section I will elaborate the forms of biomedical citizenship that underlie practices of providing genetic technologies in these three countries, while also outlining the effects of these imaginaries in a more basic, on the ground sense. Finally, in the concluding section I will return to the challenges for contemporary welfare states and indicate how my approach can contribute to a more profound understanding of the problem and possible solutions in both theoretical and practical terms.

4 The distinction between health care systems that I used for case selection is the relatively crude distinction between tax-based systems such as the British National Health Service (NHS) and insurance-based systems such as Statutory Health Insurance (GKV) in Germany and population-wide health insurance in the Netherlands (van der Zee and Kroneman (2007)). In terms of policies for genetics in health care conceived broadly, I distinguished between the existence of broad ranging policy initiatives in the Netherlands and the UK (Department of Health (2003); VWS (2000)) and the absence of those in Germany. These selection criteria are altogether aimed at finding variation between the cases that had been included, but should in no way expected to have significant explanatory force in what follows.
2. Understanding policies for welfare under pressure

The development of welfare states, and of state involvement in health care provision, can broadly be understood as a process that ran in parallel with state formation, involving a relocation of responsibilities from the private to the public domain. Generally, the origins of the welfare state are associated with urbanization and industrialization as it unfolded in the course of the nineteenth century, but at no point does there appear to be a conscious decision to build an encompassing welfare state. The expansion of welfare services, which shifted into full gear particularly after the Second World War, is sometimes described in terms of a ‘welfare creep’; a steady, unintended expansion of welfare arrangements throughout the twentieth century. In the process, the state took on increasing responsibility for the well-being of its citizens, which lasted until various forms of criticism mounted in the 1970s, with neoliberalism taking a dominant position. Ever since, the expansion of welfare arrangements appears to have moved past its peak and there is increasing talk of welfare state retrenchment. Welfare state retrenchment is not only motivated ideologically, but also with reference to geo-political transformations that are argued to turn welfare into a luxury traditional Western nations can no longer afford (for a more extensive historical overview, see (Castles, Leibfried, Lewis, Obinger, & Pierson, 2010).

Towards a discursive understanding of health care reform

The early origins as well as later transformations of the welfare states have been interpreted in significantly different ways across various sociological, economic and political theoretical schools of thought (Schuyt, 1991). It is not my aim here to address these various schools in detail, but to position my argument on a discursive understanding of welfare state policy, it may be useful to consider some different perspectives on welfare policy making. In a review of various perspectives on the politics of welfare state retrenchment, Starke (Starke, 2006) discusses various responses to the question when, why, and how welfare state retrenchment can be considered successful. Some of the responses he identifies point to the necessity of addressing socio-economic pressure, the role of political conflict, particularities of relevant institutions and the role of ideas in setting agendas, framing an issue and policy learning. While Starke argues that these positions leave a number of questions unanswered, his review can also be read as an overview of the variety of questions posed and answered within particular analytical frameworks. Returning to various theoretical perspectives on reforms in health care policy, we can then see how the dominant paradigm of cost-efficiency and evidence is unable to escape a necessity-based view of the problem of health care expenditure. Furthermore, this approach conceives of health care in a mechanistic fashion, in which adaptations to specific functions of the machine can keep it functionally within a given wavelength of cost relative to GDP. Such a perspective is fundamentally unable to deal with the kind of transformations under scrutiny here. Similarly, institutionalist understandings of health care systems runs into problems since they often rely heavily on notions of path dependency and punctuated equilibrium in explaining stability and change (Schlesinger, 2005). Change is a phenomenon that is difficult to deal with in terms of institutions, especially when it is particularly the effect of technological change on health care provision that we are interested in.

Discourse analysis, however, does provide us with an approach to analyze change and stability in health care reforms. It addresses the content and context of the politics of welfare reform,
thus providing an extra analytical lens in addition to those that focus on the role of economics, policies and institutions in reforms (Schmidt, 2002). Moreover, welfare state institutions, mechanisms and categories as they exist today can themselves be understood as ‘sedimented discourses’ (Torfing, 2002) that promoted increasing state intervention in various domains of social life from the nineteenth century until well after World War 2 (Wagner, 1990). In particular, discourse analysis makes it possible to not only address how policy making and implementation processes unfold, but can also provide insight into the meaning of what unfolds within these processes.

To substantiate the expectations about the analytical power of discourse analysis, I will develop the approach on the basis of the perspective elaborated by Maarten Hajer in his book on environmental politics (Hajer, 1995) and a number of later theoretical pieces (Hajer, 2005; Hajer & Laws, 2006). A starting point for Hajer’s discourse theory is that discourses define the world they talk about in particular ways and are thereby a part of reality and not just a medium to talk about it. Discourse analysis thus presents an alternative to policy analysis focusing on action, interests and power, by enabling an understanding of socio-political practices. In these practices, the world is defined and categorized, but definitions and categories can only become influential through reproduction and reconfirmation. The ongoing struggle over ‘discursive hegemony’ between various discourses can thus explain both change and permanence, which extends to the domain of institutions and social ordering, since institutions and order are both deeply implicated in particular discourses. At the center of Hajer’s work on environmental policies are the concepts of storylines and discourse coalitions, with the latter forming around the former. In the case of environmental problems in the 1970s and 1980s, the dominant storyline was one of ‘acid rain’. Around the storyline of acid rain, which represents only some of the problems confronting the environment and is scientifically contested, coalitions formed of diverse actors who could recognize acid rain as a problem and build their involvement in the policy-making process around it. As Hajer stresses, this does not imply that acid rain, or the problem of forests dying from it, was not real, but rather that the way it was represented is more relevant in the political domain.

Hajer further elaborates this notion of a discourse as a particular representation of a public problem by pointing to the importance of metaphors and the presentation of an emblematic issue (such as acid rain) in building a storyline. Furthermore, he indicates that the study of discourses, consisting of storylines and coalitions holding the discourse afloat, can show how the cognitive commitments of the various actors involved contribute to social order. Discourses frame policy problems in particular ways, distribute responsibilities and thus structure and institutionalize the roles of various actors involved. Relating this tentatively to the dominant ‘cost-reduction’ paradigm in health care it thus becomes understandable why various health care systems in Europe have established institutions that function as a kind of gatekeeper for the reimbursement of medical care by assessing the efficacy and cost-effectiveness of medical procedures on the basis of a predetermined set of criteria. It also makes clear that the challenges of predictive and molecular forms of medicine can most likely not be met within this discourse that evaluates the value of a procedure on the basis of how and at what cost it contributes to curing disease. Hajer and Wagenaar similarly argue that a discursive understanding of politics can contribute to a better understanding of the changing nature and topography of politics in what they call the network society (Hajer & Wagenaar). Among other things, a discursive analysis can deal with the challenges of changing spaces, dynamics and relations in and for politics, including politics in the face of radical uncertainty.
Thus, one can read the discursive conception of politics as a promising avenue for understanding the challenges genetic technologies pose for health care policies. I will argue, however, that in order to understand the effects of existing institutionalization and categorization in terms of health care access, we require a more profound understanding of the ‘materials’ governed through health care policies.

Analyzing policy effects; the importance of matter

As indicated above, in Hajer’s understanding of politics, the dying trees associated with acid rain are real, but as such bear little relevance for the unfolding discourse around acid rain as an emblem for environmental change. An approach grounded in constructivist studies of science and technology, however, would argue that the trees themselves play a central role in the discourse, since the trees are implicated in a network of circulating references where natural phenomena are translated into graphs and texts that describe the state of the world (Latour, 1999). As Latour’s example of changing vegetation in the Amazon forest in Brazil shows, the environmental problem of the retreating Amazon forest does not speak for itself but is produced through the circulation of materials, notes, pictures, scientific articles, etc. between nature and the way it is represented and translated into, ultimately, scientific fact. This implies that neither the retreating Amazon forest nor the dying trees due to acid rain are ‘real’ in and of themselves; they can only become real when studied and interpreted in particular ways that create their own legitimacy in the process of circulation. In describing the genesis of scientific facts (that may or may not feature in political debates) in terms of circulation in a network of divergent actors, scholars in the social studies of science show an interest in the practices where facts are generated that is not unlike Hajer’s emphasis on discourse practices. A core principle in the social study of science that is particularly characteristic of this field of study is the notion that facts and values, truth and falsity, and nature and society should be treated symmetrically. The notion of symmetry was originally proposed by David Bloor and other authors in the sociology of scientific knowledge who maintained that the same social processes and phenomena should account for the success and failure of scientific truth claims (Bloor, 1991). Later, it was expanded by people such as Latour and Callon who claimed that the ‘social’ and the ‘natural’ are outcome of processes of network building and that therefore neither can be presupposed in order to explain the other (Callon, 1986).

The proposal to treat nature and society in a radically symmetrical fashion can provide an informative addition to discourse analysis. First, it draws the external ‘facts’ and controversies around them, about which Hajer remains largely agnostic, into the discourse. Disagreement about the facts is central to discourse, since the facts are usually not convincing enough to settle a dispute and often are subject to different interpretations themselves. Second, presenting the production of scientific facts as an operation in network building provides an alternative, dynamic understanding of

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5 It is between the version of symmetry proposed in the sociology of scientific knowledge and, in the context of technology, social construction of technology (Pinch and Bijker (1987)) and the notion of generalized symmetry in what is known as actor-network theory that one of the main areas of dispute within science, technology and society studies (STS) lies. An early version of the debate that still presents most of the relevant issues can be found in Pickering (Pickering (1992)). For a rather fierce debate between two of the main representatives of both traditions, see Bloor (1999) and the response by Latour (1999).
power that incorporates discourses and coalitions, as well as technological means, scientific credibility, etc. At the same time, this approach is not without its problems. One point of criticism directed at Latour and others is that their conception of symmetry invites a *tabula rasa* understanding of the context in which a network unfolds, as if anything is possible, and support can be drawn from any direction to strengthen the network of actors that promote a particular knowledge claim as truth. There is relatively little attention for existing institutional and cultural constraints and non-human actors (which play a vital role in constituting a network that does not distinguish between nature and society *a priori*) too easily get attributed an active, conscious and goal-oriented role in settling scientific controversies. As historian of science Simon Schaffer has pointed out in a review of one of Latour’s books, fellow humans ultimately decide on the basis of their existing beliefs, commitments and options for acting which truth claim they hold to be credible (Schaffer, 1991).

A more productive approach to the construction of both scientific facts and technological artifacts that accounts for the two-way interaction between the natural and the social is therefore to understand science and technology as both product and producer of their social, cultural and historical context. In this direction, Hagendijk (Hagendijk, 1996) proposes a ‘cultural’ constructivism in which the possibilities and restrictions that are particular to a given context influence the production of both science and social order. This notion of a ‘co-production of science and social order’ has been most extensively elaborated by Jasanoff (Jasanoff, 2004), who argues that science and technology “account for many of the signature characteristics of contemporary societies” (p.13) and therefore deserve extensive social scientific study. In particular, she proposes the perspective of co-production to describe the mutual constitution of scientific knowledge and social order in explicit connection with their cultural background and the exercise of power. Science and technology, so Jasanoff argues, are deeply political and should thus be analyzed for how they relate to social organization in terms of the constitution of identities, institutions, discourses and representations. Only a profound understanding of the nexus connecting the technical and the political can provide substantive insight into the political challenges science and technology present (Valkenburg & Aarden, forthcoming).

The notion of co-production provides the basis for understanding the distribution of access to genetic technologies in three European countries, which I will elaborate further below. But before turning to this particular case, I will further elaborate the analytical framework here. The notion of co-production itself remains rather broad and abstract, but suggests that, due to the interrelated development of the technical and the social, the obvious cross-national differences in health care organization have consequences for medical technology (Jasanoff, 2005; Parthasarathy, 2007). These differences go beyond the analytic capacities of different types of welfare states as captured by the common Bismarck/ Beveridge distinction (Burau & Blank, 2006), or even the ‘worlds’ of welfare capitalism as classically described by Esping-Andersen (Arts & Gelissem, 2010; Esping-Andersen, 1990). His model addresses a number of variables to distinguish between different clustered trajectories of welfare states that are similar in terms of organization and outcomes. However, Esping-Andersen’s focus on outcomes in terms of social stratification, while useful for making broad analyses across the agglomeration of services forming the welfare state, is too abstract to identify the kinds of distributive distinctions we focus on here. I therefore propose an alternative understanding of health care provision in terms of ‘therapeutic cultures’, which “refers explicitly to
the historical evolution of a distinctive set of institutionalized relationships among the state, industry, physicians and disease-based organizations.” (Daemmrich, 2004, p.4). Originally applied to a comparative study of drug regulation in Germany and the U.S., this concept fruitfully explores the interactions between various historically grounded institutions and actors in producing particular approaches to medical technologies in specific national contexts.

In the case of public health care provision, national therapeutic cultures share a number of characteristics that are of particular relevance. First, none of the national arrangements makes all forms of health care equally available to all. Instead, health care arrangements employ institutions, sets of criteria and mechanisms aimed at ‘sorting out’ which medical procedures are covered through public means and who has legitimate access to these procedures. Such classification work is not neutral, however (Bowker & Star, 1999). It relies on making distinctions between preferred systems of distribution, defining identities, highlighting particular characteristics at the expense of others, etc. For example, in defining and classifying disease, biological reasoning gets preference over other forms of explanation (Bowker & Star, 1999) and distinctions on the basis of gender carry vastly different weight than those on the basis of, say, race or sexual orientation (Epstein, 2007).

Furthermore, even apparently factual medical categories, such as disability, can differ substantively between national contexts and have important consequences for further distribution of resources (Stone, 1985).

Second, in the case of social health care provision, the distributive consequences of classification have profound significance for the positioning and self-imagery of the state. Certain welfare arrangements, which in most countries include health care, are both explicitly and implicitly understood as indicators of a nation’s prosperity and civility. States thus imagine themselves through the socio-technical project of providing state of the art health care in a manner that is affordable to all citizens. In that sense, it is fruitful to think about the socio-technical imaginary (Jasanoff & Kim, 2009) of state-sponsored health care in terms of citizenship. However, to use citizenship as a productive analytic category in the context of changing welfare states, I follow Pfisters (Pfister, forthcoming) conception of citizenship as a dynamic and essentially contested process. In his book, he approaches citizenship in terms of practices, rather than as an abstract, juridical concept. According to Pfister, citizenship ought to be studied in its multiplicity of practices ‘on the ground’, where citizenship is implicated in the establishment and reproduction of institutionalized relationships between state and citizen. These relationships include what Pfister describes as the Janus-faced nature of citizenship, which refers to the phenomenon that citizenship organizes access to societal resources and thereby draws boundaries between included and excluded groups. Many authors in the social studies of medicine and life sciences have followed a roughly similar approach in recent years, but have emphasized that in- and exclusion is increasingly motivated on the basis of the individual’s biological constitution. Starting from the perspective of co-production in this paper, I contend with such biologically or molecularly inspired notions of citizenship (see e.g. (Nguyen, 2005, Nguyen, 2005). Instead, I will be speaking of biomedical citizenship, a concept that highlights how biomedical classification structures access to societal resources in conjunction with organizational practices of distribution in health care and state policies (Biehl, 2004). Understanding distribution in terms of citizenship makes the political question of who gets excluded on what grounds all the more urgent, since it stresses the structural, institutionalized nature of specific forms of exclusion.
In the following discussion I will particularly focus on co-production processes in the context of classification and allocation of citizenship around genetic medical technologies. As I will show, classification entails practicing a preference for a particular diagnostic approach and categorization of the respective diagnostic results in a particular institutional, regulatory and political context. On the basis of such classification, I will further show how resource allocation takes shape and what this implies for the various imaginaries of biomedical citizenship in various national contexts.

3. Classification and allocation of genetic health care; some empirical insights

In the previous section I have argued for a theoretical framework for analyzing the effects of the incorporation of new technologies in transforming health care provision arrangements grounded in discourse analysis and social studies of science and technology. A discursive analysis of the welfare state can provide insight into how the welfare state unfolds beyond the more exogenous categories of actors, institutions and policies that explain the context, but much less the text (or content) of welfare state reforms. Insights from a cultural constructivist or co-productionist strand of STS, in addition, provide a lens that also incorporates the materiality of how welfare arrangements operate through classifications and imaginaries. It is this ‘material text’ of how health care provision arrangements in the Netherlands, the United Kingdom and Germany perform classification and allocation work that I will focus on in this section. I will draw from case studies on three particular technologies and their incorporation in health care arrangements, which were selected on the basis of their saliency in professional and public debates and their distinctive characters as ‘genetic technologies’. Thus, I studied pre-implantation genetic diagnosis as a form of reproductive genetics mainly concerned with ‘traditional’ genetic syndromes, assessment of hereditary breast cancer risks as an example of a predictive application of genetics in the context of a relatively common disease, and diagnosis of familial hypercholesterolemia, an inherited predisposition for high cholesterol, as an example of a ‘risk of being at risk’ often associated with public health. Below, I will describe the latter case study most extensively, while presenting the main insights from the other two to support my broader conclusions in the next section.

A Brief Primer for Familial Hypercholesterolemia

Familial Hypercholesterolemia (FH) can in its broadest form be described as a hereditary predisposition for high cholesterol. High levels of cholesterol, in turn, are associated with a significantly increased risk of coronary heart disease, due to narrowing of the blood vessels (which is called atherosclerosis) caused by ‘plaques’ built up from excess cholesterol the body cannot process. Together with other cardiovascular conditions, coronary heart disease counts as the most important cause of death, at least in developed countries, and is therefore an issue of major concern in the

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The various cases are discussed more in-depth in my dissertation (Aarden (2010)), which is currently under revision for book publication. Separately, the studies of the various technologies have been published with slightly different emphasis in the main argument in (Aarden, van Hoyweghen, Vos, and Horstman (2009)) for PGD, (Aarden, van Hoyweghen, and Horstman (2011b)) for breast cancer predispositions and (Aarden, van Hoyweghen, and Horstman (2011a)) for FH. For an earlier attempt I made to combine STS insights with policy analysis using the example of PGD, see (Aarden, van Hoyweghen, Horstman, and Vos (2008)).
context of public health (Luepker, 2004). For this reason, there is also a lot of interest in identifying possible hereditary factors in the origins and development of cardiovascular diseases, but with the exception of a few disorders that can be linked to abnormalities on a particular gene (so-called monogenic disorders) (Nabel, 2003) this has so far had relatively modest value in terms of preventing the overall occurrence of cardiovascular diseases (Humphries, Ridker, & Talmud, 2004). Familial Hypercholesterolemia is usually considered to be an exception, although it is a predisposition with remarkably flexible definitions and associated diagnostic approaches.

The label of familial hypercholesterolemia is used to describe several forms of hereditary dysfunction of the cholesterol pathway, a term that describes the various physical processes that are needed to remove cholesterol from the bloodstream. In principle, each of the various steps in the pathway can be affected by changes to the genetic material, but some of these changes have more direct and easily traceable consequences than others. Which of the various genetic predispositions are classified as actually being FH varies considerably between different therapeutic cultures, as do the primary diagnostic procedures used for identifying FH. Below, I will go into more detail with regard to the various definitions of FH, which range from what is often described as its classic form, which originates from mutations in a gene that regulates the extraction of low density lipoprotein (LDL) cholesterol from the blood, to genes resulting in an increased risk correlated with lifestyle and environmental factors (Soutar & Naoumova, 2007). I will demonstrate how the various possible definitions of FH have gained prominence in each of the three European therapeutic cultures studied here by the formation of coalitions of various actors around them. I will further demonstrate that the formation of these coalitions affects the definition of FH, the employment of specific diagnostic methods and the institutionalization and allocation of family risk assessment and preventive services. At the end of this section, I will corroborate these findings with brief discussions of the other two case studies.

**FH as a Monogenic Public Health Problem in the Netherlands**

In the Netherlands, a very forceful discourse was formed around an understanding of FH as a surprisingly common, life-threatening, but relatively easily treatable disease. This description of FH was first brought forward by a patients’ association and a researcher and physician specialized in FH. They argued, in the words of the physician, that people with FH were ‘scandalously undertreated’, particularly to the extent that FH should not be understood as an individual condition, but one that affects various members of a family. Thus, on the basis of this view of FH and statistics suggesting that the disease was more common than was often thought (Lansberg, Tuzgöl, van de Ree, Defesche, & Kastelein, 2000), the patient organization and this physician started arguing for a dedicated program aimed at identifying people with FH within families. For this purpose, a Foundation for the Detection of Hereditary Hypercholesterolemia (StOEH) was established. This foundation first started identification of people with FH at a modest scale through research grants, but the originators of the detection program soon managed to convince the Ministry of Health and other administrative organizations in health care of the necessity of this program. This resulted in expansion of the program through a grant for ‘developmental medicine’ around the turn of the century, and continuation and further expansion in 2004 and 2010. By 2004, the program was recognized as a pilot for large scale genetic testing within the Dutch population by multiple organizations (CvZ, 2004), and it was recognized as a more or less regular screening program (similar to those for breast or
colon cancer) once it was administratively positioned with the Center for Population Screening of the National Institute for Health and the Environment (RIVM) in 2006.

An important factor in the remarkable success of this program, which is often cited as an example in other countries, is that it applies a very strict definition of what FH is that is in line with a diagnostic approach rooted in large-scale screening. The most succinct version of this definition is presented in a patient information leaflet stating that: “Presence of the deviating gene[s] provides 100% certainty that someone has FH. Vice versa, absence of the deviating gene indicates that someone does not have the disease and cannot get it either” (StOEH & RIVM, 2006). The definition of FH is thus entirely restricted to mutations on two genes, LDL-receptor (LDL-R) and Apoliporotein B (ApoB), which play a vital role in regulating cholesterol levels in the bloodstream. Both are also relatively straightforward genetic factors, since in both cases it concerns one particular gene with an autosomal dominant pattern of inheritance (meaning that inheriting an affected gene from one parent will cause a child to have the disease). Despite the fact that over 800 possible mutations on the LDL-R gene, which accounts for the majority of FH-cases, are known (yet only two on the ApoB gene), it is relatively easy to identify whether someone has one of these mutations. This is particularly so when identification takes place on the basis of family relationships, as we will see below. In the Dutch FH-discourse that focuses on gene mutation carriers, people with mutations on either of these two genes are considered to have a substantively increased risk of developing life-threatening levels of cholesterol, a risk that can nevertheless be reduced by starting aggressive treatment with cholesterol-lowering pharmaceutics (mostly statins) as early as possible. Clearly, this perspective adds urgency to the call for a dedicated identification program.

The Dutch screening program for FH thus relies mostly on genetically testing two specific genes within families. This is done by StOEH, but before screening can take off, a first case of FH within a family has to be identified. This is the so-called proband. Here it is important to note that in order for the program to be successful, medical professionals from outside needed to be included in the emerging coalition around a purely molecular genetic understanding of FH. After all, primary care physicians and specialists in lipid disorders are the ones initially confronted with people with high cholesterol and are therefore the ones who need to assess whether it might be hereditary. For these kinds of physicians guidelines for scoring high cholesterol patients were therefore developed, and despite some protests among GPs they were incorporated in standards for diagnosing high cholesterol (Nederlands Huisartsen Genootschap, 2007). The scoring system allocates points to patients on the basis of criteria such as the earlier occurrence of high cholesterol and heart disease in the family, cholesterol measurements and physical characteristics\(^7\). For persons scoring more than 7 points, FH is considered to be as good as certain, for individuals scoring six or seven, it is considered probable. Once possible secondary causes for high cholesterol are excluded, these people qualify for the national screening program, which runs entirely outside of the existing infrastructure of academically based genetics clinics.

The family proband, identified on the basis of the scoring system described above, is tested most extensively, since for this person it is unknown which of the many possible LDL-R and Apo-B

\(^7\) Excess cholesterol can start forming reservoirs in the iris or around the tendons. These so-called xanthomas are clear indications of an inborn inability to process cholesterol properly, but usually only appear at a later age.
mutations is actually present. Only when a mutation can be identified does further screening in the family start – “no mutation, no StOEH”, one of the physicians involved summarizes. When a mutation has been found, all first degree family members of the proband are contacted with a letter informing them about the program and offering the possibility of a genetic test. This genetic testing unfolds somewhat differently than with the proband. With the mutation that runs in a particular family already being identified, a nurse employed by StOEH visits family members who participate in the program at home and takes a blood sample. This blood sample is tested exclusively for the mutation found in the proband at the laboratories of the Academic Medical Center in Amsterdam; a form of diagnosis that “takes an hour and costs a quarter”. While diagnosis of the proband, including genetic testing, is reimbursed via insurance companies, further genetic testing is paid from the program’s budget. Mutation carriers are put on an elaborate treatment regime for lowering their cholesterol levels; the so-called ‘cascade’ screening method continues with first degree family members of this mutation carrier who have not been tested yet, etcetera.

The program, understood as a pilot for genetic screening by governmental organizations, will most likely not continue endlessly. As one program administrator indicated, the larger the percentage of patients that have been found, the more expensive it becomes in relative terms to maintain a screening infrastructure to identify the last few cases. Nevertheless, it seems that the discourse coalition started by a patient organization and some physicians has successfully drawn medical professional organizations, health care administrators and the Dutch state into a particular genetic understanding of FH. This understanding of FH has been consequential not only in terms of policy-making and the organization and allocation of health care to a particular group of people, but also for how the disease is defined and which criteria and techniques are considered to be appropriate means of diagnosis. That this conception of FH is by no means self-evident will become clear when we turn our attention to the approach in the United Kingdom.

FH as a Complex Hereditary Disease in the United Kingdom

Even though many physicians highly involved in treating people with FH praise the Dutch screening program, it is extremely unlikely that something similar will be developed in the United Kingdom. In interviews, physicians and administrators indicated several reasons why they thought this to be so. These reasons ranged from the less centralized administration and resource allocation of the National Health Service, to questions about the diagnostic value of genetic testing, and claims about a sheer lack of financial means to establish such a program across the whole of the UK. Probably all of these factors play a role, but they are likely related to an extent that earmarking funding alone would most likely not suffice. In any case, the coalition that forms the FH discourse in the UK does not have a driver as strong as in the Netherlands and consists of an organization maintaining a register and set of phenotypic (i.e. non-genetic) criteria for diagnosis, a community of lipid specialists that shows considerable disagreement with regard to the value of genetic testing, local funding authorities in the National Health Service and a Department of Health sponsoring various smaller scale service development initiatives. Clearly, this is not a coalition building a unified screening program, but one that has produced a more fragmented and complex approach to FH.

Familial Hypercholesterolemia is only rarely diagnosed by means of genetic testing in the UK. At the time of my study, only two laboratories around the country provided genetic testing for FH, which was not covered by NHS funding. Instead, diagnosis of FH is based on criteria developed on the
basis of statistics held by a national register of FH patients, the so-called Simon Broome register. These criteria, which allow for the identification of FH patients once secondary causes of high cholesterol have been excluded, consist of (1) an elevated level of cholesterol, (2) the presence of physical characteristics in first or second degree relatives (3) a family history of heart infarcts, and (4) a family history of high cholesterol levels. Anyone meeting the first two of these two criteria automatically qualifies as an FH patient; anyone meeting the first and either the third or the fourth is classified as a probable FH patient. The diagnosis of FH in the United Kingdom thus focuses less on the possible hereditary causes of high cholesterol and more on its clinical manifestations. This means that there is a slightly different population that is addressed than the one in the Netherlands, and a question that is significant in the British context is whether that is a good or a bad thing. On the one hand, there are physicians who argue that genetic testing is important for the confirmation of clinical diagnoses and for being able to identify (mostly younger) mutation carriers who do not yet show any phenotypic signs of FH. On the other hand, others argue that to rely too much on genetic testing would mean that more complex cases of hereditary high cholesterol not directly attributable to a small set of genes would go unrecognized and untreated. Genetic testing should therefore only be applied in cases where it is difficult to diagnose on the basis of the Simon Broome criteria, for example “where you’ve got a very shrewd suspicion, but no [family history information]”. This perspective is apparently shared by the National Institute for Health and Clinical Excellence (NICE), which is responsible for developing best practice standards for British health care. In a 2008 report on FH NICE stated that “healthcare professionals should offer people with a clinical diagnosis of FH a DNA test to increase the certainty of their diagnosis and to aid diagnosis among their relatives” (NICE, 2008), p.7). Through such guidance, the dominant definition of FH in the UK is further stabilized.

Besides the near absence of genetic testing as a diagnostic tool, there is another important difference between the Netherlands and the UK in how FH is diagnosed and treated. Whereas the Dutch genetic screening approach required the development of a new medical infrastructure, diagnostics in the UK largely uses an infrastructure developed in the 1970s. Quite similar to the Dutch situation, however, professional medical geneticists are not involved to any significant degree in FH. Diagnosis and treatment of FH and other disorders related to lipids is the territory of physicians specialized in cardiovascular problems who run so-called lipid clinics within hospitals. These lipid clinics specialize in cardiovascular risks and lipid disorders that are too complex for other disciplines to deal with. These include FH, which does not only require quite aggressive pharmaceutical treatment (since lifestyle changes in the case of an inborn inability to process cholesterol often has very little effect), but also requires further consideration of the risks for an individual patient’s family members. Like in the Dutch screening program, lipid clinics mostly get their patients from general practitioners who do not succeed in lowering their patients’ cholesterol levels.

The role of the British state, as represented here by the Department of Health, is less explicit than that as administrator of the screening program in the Netherlands. Nevertheless, the Department of Health significantly contributes to an understanding of FH as a serious disorder by both directly and indirectly funding research on FH as a ‘common’ disorder. Simultaneously, the state supports the current, fragmented approach to FH implicitly by investing in two separate research projects that investigate phenotypic and genetic forms of cascade screening respectively. Both projects are part of more extensive investment schemes that aim at “implementing genetic
processes within mainstream NHS”, as one clinician described it. In one of the projects, a number of lipid clinics screen their patients’ families according to the same cascade method that is used in the Netherlands, which identifies new patients among a proband’s first degree relatives, then moves on to diagnosing the new patient’s relatives, and so on. But rather than using genetic testing, this project applies clinical diagnostic criteria from an international consortium studying FH – criteria that are preferred over the traditional Simon Broome criteria since they are age and gender specific. The idea behind this project is to develop a national screening program in the long run, but also to streamline services in the participating clinics right now. The other project involves a different set of lipid clinics, follows the same cascading approach, but does diagnose on the basis of genetic testing. The aim here is not to develop a screening program, however, but to assess the discrepancies between the kinds of patients that can be identified through genetic and phenotypic means and to find out what the practical consequences in terms of finances, workload, etc. of broader application of genetic testing would be.

In the UK, various factors thus contribute to the persistence of a fragmented, complex understanding of and diagnostic approach to FH. There is limited availability of genetic testing for FH; at the same time, the value of such testing is much more openly disputed than it is in the Netherlands with reference to cases of FH that would not qualify as such in the Dutch context. Like in the Netherlands, there is furthermore a strong association between the organizational characteristics of health care (particularly the Simon Broome register and the infrastructure of lipid clinics), the definition of FH and the application of particular diagnostic methods. The state, finally, largely confirms the existing situation and seeks to develop genetic services further along the lines that have been set out in practice. As we will see, the relatively active role of the state in financing and coordinating developments around FH in both the UK and the Netherlands contrasts starkly with the framing of FH in Germany.

FH as a Rare Hereditary Risk Factor in Germany

In Germany, familial hypercholesterolemia is all but invisible in health care. Only a very small group of physicians pays significant attention to the condition and mostly define it as a risk factor, rather than a disease in its own right. A relatively limited number of independently operating genetic laboratories offer genetic testing for various forms of FH and no academic research program for diagnosing and treating FH has been established. Like in the other countries, medical geneticists are barely involved in diagnosis and treatment of FH. The only organization with a significant interest in FH is the so-called Lipid Liga, a medical professional organization that focuses on diseases related to lipid metabolism. This organization has produced guidelines on the diagnosis and treatment of various forms of FH, but as a representative of this organization noted, there is relatively little professional interest in cholesterol in Germany and existing clinics specialized in lipid disorders are decreasing in number, since most of the relatively straightforward cases of high cholesterol are now treated by general practitioners or cardiologists. Against this background, the lack of interest for hereditary forms of high cholesterol may not be surprising; in addition, the fragmented nature of decision-making on health care due to both a strong corporatist tradition and the significant role of the various federal states in health policy making also does not help.

The German Lipid Liga describes FH as a serious condition in a guideline that distinguishes (in name more than in diagnostic approach) between FH caused by LDL-receptor deficiency and a form
called familial defective ApoB (Deutsche Gessellschaft zur Bekämpfung von Fettstoffwechselstörungen und ihren Folgeeckrankungen, 2006). Both forms of FH should be diagnosed on the basis of three criteria; measurement of the level of low density lipoprotein (LDL) cholesterol, a family history of coronary heart disease and LDL cholesterol measurements for a first degree family member. When significant results are found for the first and either the second or the third criterion, a person is considered to have FH and should therefore receive cholesterol lowering treatment. Yet the criteria outlined by the Lipid Liga appear to find relatively little resonance in practice. Most physicians speak of FH as a relatively rare risk factor for high cholesterol among more common ones such as lifestyle, rather than as a disease in itself. Only relatively rarely do these physicians (who are ever more rarely actual specialists in lipid disorders) consider the possibility that a high level of cholesterol that does not respond to lifestyle changes may be hereditary. Even more rarely do they conclude that there is reason for genetic testing to confirm a diagnosis of FH.

The option of genetic testing takes a particular shape in Germany, largely due to the relatively autonomous position of physicians and the way health care is financed. Medical doctors can request a laboratory test, including a genetic test, from a medical laboratory whenever they see it fit to do so. Compared to the other two countries, criteria and procedures for genetic testing are thus less restrictive and much is left to the individual physician’s interpretation of a particular case. What is more, insurance companies in Germany have no insight into the reason why a physician decided to prescribe a particular test. The catalogue of reimbursable services in independent outpatient clinics (clinics that are not part of a hospital) states that a genetic test prescribed by a qualified physician has to be reimbursed, regardless of its exact application. Nevertheless, one physician working in a laboratory testing for FH explained that genetic testing is virtually only applied for ‘differential diagnostics’, which means that it has to have diagnostic or therapeutic value. This is for example the case when a patient has a heart attack at a very early age (before the age of thirty), which might be an indication of homozygous familial hypercholesterolemia. In that case, this person has two damaged copies of one of the FH-related genes and is almost completely unable to process cholesterol. Such a patient needs to be treated with lipid aphaeresis, a procedure for removing cholesterol from the blood that is not unlike dialysis for kidney diseases. In addition, results from a genetic test may be useful for assessing the risk of high cholesterol for family members and for making reproductive decisions.

German laboratories that offer genetic analysis for FH usually offer one or more out of three options. The possibility of testing LDL-R and Apo-B genes has been mentioned before. In addition, some laboratories also offer a genetic test for a form of FH that is called autosomal recessive hypercholesterolemia (ARH). While the former two genetic backgrounds present a very similar clinical picture, ARH can in principle be distinguished from the two dominant varieties by looking at patterns of high cholesterol and coronary heart disease within a family history, since a recessive form only strikes when genetic mutations are inherited from both parents. When such a pattern can be found it is thus sensible to test for ARH rather than one of the other genes. In testing LDL-R and ApoB, however, health care regulation plays a surprisingly significant role. Since cost-effectiveness is an important criterion for clinical conduct in Germany, several laboratory physicians indicated to follow what one of them described as “stepwise diagnostics”. This implies that one gene is analyzed first, with the other one following only when nothing is found. In practice, this usually means that the ApoB-gene, for which only two mutations are known, is tested first, even though the majority of
mutations are located on the LDL-R gene. Thus, despite the relative autonomy physicians have in prescribing genetic testing for a patient covered by social health insurance, financial considerations in German health care play a significant role.

As indicated above, the German state plays virtually no role in the classification and allocation processes around FH, other than setting the boundaries for health care practice and reimbursement. With a few exceptions (e.g. Schuster, 1995), there is also fairly little interest in developing family-based services for hereditary conditions among both physicians and health care administrators. Several reasons for this state of affairs have been suggested, ranging from an alleged taboo on medical genetics to the inertia of a fragmented health care sector. This has resulted in quite limited visibility for FH, particularly when compared to the prominent attention for this condition in the Netherlands and the UK. Consequently, there is a rather weak definition of FH as a risk factor for high cholesterol, the genetic nature of which may be picked up by individual physicians and may then result in genetic testing. Nevertheless, the way such genetic testing subsequently unfolds is closely related to the institutional possibilities and restrictions of German health care organization. This suggests that for Germany, like for the other countries, the eventual distributive effects of health care allocation are co-produced between the health care system and the diagnostic definition and methods applied to FH.

To the cases of preimplantation genetic diagnosis and assessment of hereditary breast cancer risks I have applied an analysis that is similar in approach to the one presented above. Processes shaping application and allocation of preimplantation genetic diagnosis, which is a procedure in which genetic testing for particular characteristics is applied to embryos created in vitro before implantation, revolved primarily around the question which applications of the procedure were deemed appropriate. Regulation therefore often played a prominent role, but the case also showed a remarkable distance between what was clinically considered to be acceptable and what was considered to be appropriate for coverage by public health care provision. Thus, in the United Kingdom a relatively broad domain of applications licensed by a national authority established in the context of regulating embryo research ran into restrictions that resulted from the local allocation of health care funds, where financing for commonly applied procedures often prevailed over financially supporting a broad array of services. In the Netherlands, equally broad applications that are overseen less formally by a clinical working group also range more broadly than the applications that are reimbursed under a criterion of international commonness and standard of practice. In Germany, finally, a ban on embryo research that was only adapted to allow PGD very recently (July 2011) created a form of preimplantation diagnosis performed before the merging of parental genotypes, which found applications in academic clinics that were different from those in outpatient clinics – with the former being considered appropriate for reimbursement and the latter not. Thus local differences in financing in the UK, an interpretation of what a common application is internationally in the Netherlands, and specific interpretations of a criterion of ‘necessary’ care in Germany can be identified as important factors in resource allocation in the case of PGD.

In the case of breast cancer risk assessment, there is a much stronger link between classification of various risk categories and the allocation of monitoring and prevention. In addition, the question whether risk assessment should rely primarily on genetic testing or on family history statistics was significant for the formation of risk categories. Thus, the primacy of genetic testing in
Germany, which results from organizational incentives, reduces the allocation of preventive measures to a distinction between women with an identified genetic mutation and those without. The gradual decrease between mutation carriers and percentage based risk categories in the Netherlands translates into distinctively formalized, structured and supported offerings of monitoring and prevention to various groups of women at risk. Finally, the links between statistical risk categories and the institutional structure of the NHS results in an uncertain situation with regard to the availability of monitoring services in the UK, particularly where scarce resources need to be divided between hereditary risks and those identified in the national mammography screening program. In conclusion, one could therefore consider the way Germany’s therapeutic culture deals with breast cancer risks as one that is grounded in a molecular understanding of risk, the Dutch as one that is statistical and the British as one that is essentially organizational.  

4. Imagining Citizenship in three European Therapeutic Cultures

In this paper, I argued for a cultural constructivist understanding of genetic technologies in Western European health care provision to complement discursive approaches to welfare state reforms. I applied an analytic perspective focusing on the co-production of science and social order in order to identify how technical and social change together contribute to particular patterns of allocating access to health care. Here I will pick up this argument again, on the basis of the case studies introduced above, and argue that an analysis of how European cultures both technically and organizationally configure biomedical citizenship does, in fact, provide a window onto the imaginaries of justice underlying the distributive practices of these therapeutic cultures. In doing so, I will characterize the three therapeutic cultures in terms of various approaches to distributive justice; an approach I draw from Susan Cozzens who used it to identify various options for structuring science and technology policies towards specific social ends (Cozzens, 2007). As Cozzens indicates, the various approaches do not so much present themselves explicitly in policies, but are rather manifested implicitly through policy design, implementation and subsequent practice.

Starting from such an approach to sociotechnical imaginaries of health care provision I classify biomedical citizenship in the UK as utilitarian, in the Netherlands as communitarian and in Germany as contractarian (see also Aarden, van Hoyweghen, & Horstman, 2010). In the United Kingdom, policies for the National Health Service can more generally be described as a balancing act between comprehensiveness of the services on offer and universalism with regard to the proportion of the population that has access to health care (Oliver, 2005). This balancing act translates into quite a particular approach to genetic services in the NHS. As the notion of ‘mainstreaming genetic services’ cited in the context of FH shows, most genetic technologies are integrated into existing NHS structures as much as possible. They then also become subject to existing distributive considerations, which place universalism over comprehensiveness. This is particularly visible in the context of genetic services that often address relatively small patient populations. Thus, local and regional allocation of financial resources means that no money is made available for a procedure as rare as PGD, funding  

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8 Of course, in both of these cases there are more complex interactions between genetic technologies and health care organizations. Here I have briefly summarized the main conclusions in order to support my characterizations of distributive effects in each of the countries with more material than only the case of FH.
for breast cancer monitoring is made available for population rather than hereditary screening and the definition of FH aims to be inclusive rather than specific. This means that, overall, the limited resources available for the distribution of health care access are allocated in such a way that they maximize utility by being (in principle, if not always in practice) available to as large a percentage of the British population as possible.

In the Netherlands, there is a tendency to create dedicated institutional spaces for developing new technologies and integrating them into health care. The screening program for FH is an obvious example, as are the various risk categories with associated monitoring guidelines in the case of breast cancer. Between these dedicated spaces and health care provision overall there is a similarity in how access is allocated that can be illustrated with the notion of ‘common’ health care that features in the reimbursement of PGD. This notion is not entirely exclusive, in the sense that only health care that is standardly provided internationally is reimbursed. This may be the case for forms of care incorporated into regular health care, but not for those in the dedicated experimental spaces. Here other measures are taken to assure the availability of financial resources for not only the majority of patients but also for specific, clearly defined minorities. This double approach of allocation addressing both the majority and minorities in the Dutch population can be classified as communitarian.

In Germany, finally, the incorporation of genetic technologies in health care is restricted by both the discretion of medical professionals and the strong corporatist relations between various actors in health care. Medical professionals in most cases develop guidelines for the application of particular procedures and relations between the state, insurers and medical professional organizations significantly complicate the integration of new services (Altenstetter, 2003). Particularly these corporatist relations, attributing clearly defined roles to various actors also feature quite prominently in the allocation of medical care. As the case study above showed, the regulations that apply to the reimbursement of health care have quite a profound influence on how medical care is provided, for example in structuring genetic testing for FH, keeping the state out of the development of medical services and, in the case of PGD, setting strict boundaries between sectors with regard to reimbursement. Moreover, the processes of allocating access according to particular distributions of roles and responsibilities also means that distributive effects disappear in the background, with the exclusion of non-mutation carriers form monitoring services for breast cancer risks as the most striking example. Distributive justice in Germany thus takes a contractarian form, with the rules of conduct as established in the social contract for health care taking preference as criteria over actual distribution of resources.

What do these various forms of biomedical citizenship imply? In a broad, theoretical sense they provide insight into the imaginaries the various therapeutic cultures implicitly employ when considering what a just distribution of health care resources entails. I will return to this point in the concluding section in relation to the uncertainties and ambiguities contemporary European welfare states are confronted with. Yet the variation in biomedical citizenship across European therapeutic cultures, although not an absolute or static distinction between countries that, after all, have fairly similar levels of economic development and provision of social services, also has a more basic, ‘on the ground’ significance. Ultimately, the analysis presented above focused on boundaries between in- and exclusion of citizens in Europe from medical services. In this context, the notion of biomedical
citizenship can contribute to gaining insight into which groups of people are at risk of being systematically excluded from health care provision. These will mostly be relatively small groups, but in cases such as so-called ‘orphan diseases’ systematic exclusion can become deeply problematic. It is therefore important to take note of the fact that small groups with rare conditions run the risk of being systematically excluded in the UK; groups without strong organization and representation and people falling outside the self-imposed boundaries of more prominently present groups run that risk in the Netherlands; as do groups unable to navigate the regulatory and institutional structures of health care in Germany (which appear to have a preference for including biomedically demonstrable conditions).

5. Conclusions

In this paper I set out to present an analysis of the distributive politics of public health care arrangements (with reference to the welfare state conceived more broadly) that provides an alternative to the dominant paradigm in health policy analysis based on actor interests, path dependencies and a rather abstract understanding of health care as a practice, and a complement to discursive understandings of the welfare state as a coalition of diverse actors, which – put extremely briefly – gathered around the storyline of an expanding set of services that were considered a sign of humanity and solidarity until the 1970s and 1980s, and increasingly adopted an alternative story of self-sufficiency, activation and welfare as a last resort since. An important point in my argument is that neither tradition has succeeded in fully valuing and understanding the transformative role of science and technology since, at least, the rise of modern industrial societies in the nineteenth century. Moreover, it is my contention – in which I am by no means alone – that science, technology and the ordering of social affairs develop in close interaction with each other and do so in significantly distinct ways in various cultural contexts. On the basis of this perspective, which centers around the notion of co-production, I analyzed the complex practices of public health care delivery in three European cultural practices with the aim of identifying imaginaries of distributive justice that implicitly shaped the ways biomedical citizenship – referring to the publicly allocated rights, duties and patterns of in- and exclusion in the context of contemporary biomedicine – took shape. I further argued that it was possible to identify such imaginaries in the various case studies I presented here, which provide valuable insights into the distributive patterns that lie at the very basis of various health care arrangements. In that sense I believe that the kind of analysis I proposed here can contribute to a response to some of the most basic questions about technical and organizational change in health care (Who wins? Who loses? How so? See also Shakespeare, 2005), which are perhaps also the most difficult to come to grips with.

However, I would also like to make a slightly different argument in this concluding section, one that is more practical in nature. Not only can a cultural constructivist approach to technology and society help in understanding the effects of various kinds of transformations, it also opens these transformations up to public scrutiny and debate. A culturally sensitive understanding of the co-production of medical technology and health care delivery can thereby shed a new light on the challenges that confront contemporary welfare states. Seemingly technical issues can become part of a broader pallet of options we, as democratic societies, can choose from. To give an example,
knowing that a molecular understanding of FH in the Netherlands is not naturally given and is partially formalized through financing decisions by a governmental institution should, in principle, make it possible to ask the question whether this definition is the one most deserving of public funding. The question thus shifts from; should we fund this screening program or not, to; which kind of diagnostic approach is most appropriate to allocate limited funding to – which may also be one relying exclusively on cholesterol measurements. Of course, this does not mean that every funding decision should be publicly scrutinized; as Bijker and colleagues argued convincingly, there are plenty of cases where the problem at hand is sufficiently clearly defined, the options are relatively uncontroversial and ‘experts’ can in principle take the decisions (Bijker, Bal, & Hendriks, 2009). In more controversial, ambiguous and complex cases, however – which are increasingly frequent and to my opinion include the broad question how to incorporate predictive forms of medicine in curatively oriented provision arrangements – we could use a little more of what Sheila Jasanoff has described as ‘technologies of humility’ (Jasanoff, 2003). Herewith she refers to ways of discussing, representing, imagining and deciding about sociotechnical issues that acknowledge the shortcomings of prediction, control, and calculation and allow room for normative considerations, cultural specificities and individual experiences. In this context, it is particularly valuable to take a comparative approach, not to copy solutions developed elsewhere, but to gain a better understanding of the various problem definitions, possible solutions and their complexities, which makes it possible to draw a sharper picture of one’s own.
References


