Regulating patient access to therapeutics in Denmark: a rhetorical analysis of welfare imaginaries in public controversy

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ABSTRACT
In this article, I argue that the social imaginaries that inform biomedical regulation circulate not only in technical spheres populated by experts but that they are equally articulated (and vehemently contested) in national public spheres in more popular forms of communication. I examine the relation between a national healthcare imaginary and the regulation of therapeutics through a public controversy about access to an innovative therapeutic indicated for spinal muscular atrophy. The establishment of the Danish Medicines Council, a new health technology assessment institution, and its decision to restrict access to an innovative therapeutic sparked controversy in 2017 involving political proponents, adversaries, and patients, among others. In a variety of ways, they rhetorically mobilized or contested the Danish universalist welfare imaginary which contains promises and prospects of solidarity, security, and absence of market forces in universal healthcare, including access to therapeutics. I use a combination of media content analysis and rhetorical close reading methods to analyze how the imaginary was drawn upon in arguments for and against the new regulatory institution.

KEYWORDS: health technology assessment, nusinersen, patient access, regulation, rhetoric, social imaginaries
I. INTRODUCTION
A simple search on global streaming platforms like Netflix suggests that the intricate relations between law, therapeutics, and the market economy have become an object of popular imagination in the last decade.¹ Two of the animating factors seem to be the increase of transparency into complex regulatory processes and the increase of patient involvement in regulatory processes and the public communication about it.² The European Medicines Agency’s long list of transparency policies and their recent introduction of a public hearing modality under the Pharmacovigilance Risk Assessment Committee testify to this.³ But the overwhelming reason, of course, is the recurrence and scale of controversies, scandals, and public health crises that involve therapeutics and their regulation. Such examples include the opioid crisis, the retraction of COX-2 inhibitors, the substitution of levothyroxine, and the slow adoption of HPV vaccine.⁴ Popular accounts of such incidents provide the public with strong cognitive resources for understanding the law, the market, the patient, the healthcare professional, and medical technology in narrative terms. Although such narratives are often dismissed as sensationalist by those with technical expertise, scholars in science and technology studies (STS) and science communication argue that the controversies

¹ The extensive list of internationally distributed, full-length documentaries on the regulation of therapeutics include Anniken Hoel, Cause of Death: Unknown (2017); Kirby Dick, The Bleeding Edge (2017); Chris Bell, Prescription Thugs (2015); Kevin P. Miller, Generation Rx (2008); Donald Mosher and Michael Palmieri, Off Label (2013); Jonathan Marshall Thompson, Drug$ (2018); Dan Schneider, The Pharmacist (2020).

² Mark L. Flear and Martyn D. Pickersgill, Regulatory or Regulating Publics? The European Union’s Regulation of Emerging Health Technologies and Citizen Participation, 21 Med. Law Rev. 39 (2013); R.P. Hagendijk, The Public Understanding of Science and Public Participation in Regulated Worlds, 42 Minerva 41 (2004); Alan Irwin, The Politics of Talk: Coming to Terms with the “New” Scientific Governance, 36 Soc. Stud. Sci. 299 (2006). For a more recent critical discussion see REMAKING PARTICIPATION: SCIENCE, ENVIRONMENT AND EMERGENT PUBLICS (Jason Chilvers and Matthew Kearnes eds., 2016).

³ Dominic Way et al., Medicines Transparency at the European Medicines Agency (EMA) in the New Information Age: The Perspectives of Patients, 19 J. Risk Res. 1185 (2016); European Medicines Agency, Public Hearings, European Medicines Agency Website (2017), http://www.ema.europa.eu/ema/index.jsp?curl=pages/about_us/general/general_content_001432.jsp&mid=WC0b01ac0580a221a4 (accessed Aug. 5, 2017); Brown and Bahri, supra note 2.

⁴ Nancy A. Melville, Side Effects Skyrocket in France With Levothyroxine Reformulation, Medscape.com, Oct. 11, 2017, https://www.medscape.com/viewarticle/886900 (accessed Feb. 16, 2018); Camilla Hiul Suppli et al., Decline in HPV-vaccination uptake in Denmark—The Association Between HPV-related Media Coverage and HPV-vaccination, 18 BMC PUBLIC HEALTH 1 (2018); Niels Dalum Hansen et al., Relationship Between Media Coverage and Measles-Mumps-Rubella (MMR) Vaccination Uptake in Denmark: Retrospective Study, 5 JMIR Public Heal. Surveill. e9544 (2019); William B. Anderson, The Media Battle Between Celebrex and Vioxx: Influencing Media Coverage But Not Content, 27 PUBLIC RELAT. REV. 449 (2001); Kate Faasse et al., Impact of Television Coverage on the Number and Type of Symptoms Reported During a Health Scare: A Retrospective Pre-post Observational Study, 2 BMJ OPEN e001607 (2012); John Gardner and Kevin Dew, The Eltroxin Controversy: Risk and How Actors Construct their World, 13 HEALTH. RISK SOC. 397 (2011). In the European case, regulatory agencies are working systematically to develop tools to engage with the public. See, for example, Priya Bahri et al., Application of Real-time Global Media Monitoring and ‘Derived Questions’ for Enhancing Communication by Regulatory Bodies: The Case of Human Papillomavirus Vaccines, 15 BMC Med. 91 (2017).
they expose are often crucial in the (trans)formation of social imaginaries. As Callon et al. argue, such narratives are more than ‘mere stories’ because they ‘intersect dynamically with the material institutional, economic, technical and cultural forms of society’ and ‘tacitly define the horizons of possible and acceptable action, project and impose classifications, distinguish issues from non-issues, and actors from non-actors.’

The emergence of a ‘public dimension’ of the regulation of therapeutics through the circulation of sociotechnical narratives seems to confirm the well-known thesis in STS literature that scientific knowledge and social order are co-produced. That is, society’s epistemic and normative understandings of the world form interdependently, and, conversely, science and technology do not produce strict paths of dependence for law and regulation. While multiple studies have supported the co-production thesis in various ways, few have taken non-technical (ie popular) narratives and their relation to social imaginaries into account. For regulatory studies of therapeutics, the limited understanding of such narratives in non-technical publics is problematic. Many regulatory institutions are increasingly pressed for external legitimacy by their key stakeholders, as the previously mentioned transparency and patient involvement initiatives illustrate. Understanding the relation between non-technical narratives about regulation and the social imaginaries that inform regulation is key in exploring this set of legitimacy problems more thoroughly.

In this article I empirically examine the relation between the national healthcare imaginaries and the regulation of therapeutics as it emerges in the national public sphere. Which social imaginaries shape the public discourse about therapeutics regulation? What rhetorical function do these social imaginaries have in such discourse? And how is regulation connected to and positioned within national social imaginaries? I apply a combination of media content analysis and rhetorical close reading methods to a case of public discourse about a controversy in the regulation of

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5 Gardner and Dew, supra note 4; Maja Horst, Public Expectations of Gene Therapy: Scientific Futures and their Performative Effects on Scientific Citizenship, 32 SCI. TECHNOL. HUM. VALUES 150 (2007); Ian Welsh and Brian Wynne, Science, Scientism and Imaginaries of Publics in the UK: Passive Objects, Incipient Threats, 22 SCI. CULT. 540 (2013).

6 Michel Callon et al., Taking European Knowledge Society Seriously (2007).

7 Sheila Jasanoff, States of Knowledge: The Co-production of Science and Social Order (2004).

8 Angela Filip et al., The Co-production of What? Knowledge, Values, and Social Relations in Health...: Discovery Service for London South Bank University, 15 PLoS Biol. e2001403, 1 (2017).

9 For a description of the lack of attention to popular narratives, see Sheila Jasanoff and Sang Hyun Kim, Containing the Atom: Sociotechnical Imaginaries and Nuclear Power in the United States and South Korea, 47 MINERVA 119 (2009); Ulrike Felt, Keeping Technologies Out: Sociotechnical Imaginaries and the Formation of a National Technopolitical Identity, in DREAMSCAPES OF MODERNITY: SOCIOTECHNICAL IMAGINARIES and the Fabrication of Power (Sheila Jasanoff and Sang Hyun Kim eds., 2015); Sheila Jasanoff and Sang-Hyun Kim, Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power (2015).

10 For an extended discussion of communicative structures of accountability in regulation, see Julia Black, Constructing and Contesting Legitimacy and Accountability in Polycentric Regulatory Regimes, 2 REGUL. GOV. 137 (2008).

11 Klaus Krippendorff, CONTENT ANALYSIS: AN INTRODUCTION TO ITS METHODOLOGY (2013).

12 Barry Brummett, TECHNIQUES OF CLOSE READING (2010); James Jasinski, Close Reading, in SOURCEBOOK ON RHETORIC: KEY CONCEPTS IN CONTEMPORARY RHETORICAL STUDIES (2001). For a methodological discussion see James Jasinski, The Status of Theory and Method in Rhetorical Criticism, 65 WEST. J. COMMUN. 249 (2001).
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therapeutics. This allows me to systematically examine how social imaginaries are performed rhetorically in various ways and for different ends and how regulation configures within these imaginaries. By tracing the rhetorical articulation of a national social imaginary through the multiple phases of a public controversy and by taking the perspectives of varying stakeholders, I try demonstrate how social imaginaries relate to regulation in multiple ways.

My case study for this analysis is the establishment of the Danish Medicines Council (DMC), a new health technology assessment (HTA) institution that was commissioned in part to increase efficiency in the allocation of healthcare resources with specific attention to therapeutics. Given that the Danish tax-based healthcare system provides universal coverage to all citizens as a social right, an institution that was mandated to potentially restrict access to innovative therapeutics on economics grounds was contentious even prior to its establishment.13 The contention turned into public controversy when the DMC decided not to recommended nusinersen (Spinraza) for standard treatment in 2017. Nusinersen is an antisense oligonucleotide therapy approved for the treatment of patients with all subtypes of spinal muscular atrophy (SMA). While nusinersen holds great promise for SMA patients, it became the object of multiple ethical dilemmas due to the expensive cost and limits of evidence of sustained benefit and safety after regulatory approval.14 The DMC’s decision not to recommend nusinersen for standard treatment for SMA type 2 (in addition to SMA type 1) generated much popular press coverage about the DMC and the need and possibilities for regulating innovative therapeutics.

The key term ‘rhetoric’ is often associated with manipulation and deceit in political discourse. As a specific field of communication research, however, rhetorical scholarship presents research on how symbolic systems, such as verbal language, mediated texts, non-verbal communication, and imagery, are used to perform actions. Key analytical resources include argumentation theory, with which the interrelation and quality of claims, data, and warrants are examined;15 rhetorical situation theory, with which rhetorical utterances are examined as constrained responses to situational exigences;16 and rhetorical genre theory, with which the similarity of rhetorical responses to similar rhetorical situations is examined as a particular form of social action.17 Many rhetorical scholars identify as critical scholars and examine how power is distributed and contested by means of language in order to evaluate public discourse against norms of liberal democracy.18

This article traces the rhetorical strategies that particular actors (national politicians, regional politicians, and patients) employ to justify and advocate their positions in the controversy. Specifically, the article identifies and describes a rhetoric of reluctance, a rhetoric of disappointment, and a rhetoric of transcendence over the course of the

13 Sarah Wadmann, Viden, Værdi og Omstridt Ekspertise: Analyse af den Danske Debat om Lagemiddelprioritering [Knowledge, Value and Disputed Expertise: Analysis of the Danish Debate of the Prioritization of the Medicines], POLITIK 32 (2017), https://tidsskrift.dk/index.php/politik/article/view/81574.
14 Alyssa M. Burgart et al., Ethical Challenges Confronted When Providing Nusinersen Treatment for Spinal Muscular Atrophy, 172 JAMA PEDIATR. 188 (2018).
15 Stephen E. Toulmin, The Uses of Argument (2003).
16 Lloyd F. Bitzer, The Rhetorical Situation, 1 PHILOS. RHETOR. 1 (1968).
17 Carolyn R. Miller, Genre as Social Action, 70 Q. J. SPEECH 151 (1984).
18 Raymie E. Mckerrow, Critical Rhetoric: Theory and Praxis, 56 COMMUN. MONOGRA. 91 (1989).
introduction of DMC and the controversy around nusinersen. These strategies all draw from a national imaginary of universal welfare that provides various actors with commonplace arguments and rhetorical tropes in their performances of reluctance to, disappointment and embrace of regulation.

In the article’s first two sections, Section 1 introduce the two key elements, the Danish Medicines Council and the national welfare imaginary that is rhetorically mobilized in the discourse around nusinersen. Section 2 contains a macrolevel sketch of the universalist welfare imaginary based on political sociology and economy. Whereas the subsequent rhetorical analyses describe how the universalist welfare imaginary is performed, the macrolevel sketch provides a structural understanding of principal welfare principles, policies, and expectations. Section 3 describes the DMC in terms of its legal basis, policies, and procedures. In the four next sections, I explore the nusinersen controversy in depth. Section 4 provides an overview of the coverage as well as the methods applied in the data collection and the analysis of it. Section 5 presents the political discourse that preceded the nusinersen controversy. Here the universalist welfare imaginary is used by national politicians to advocate against establishing a national HTA institution for therapeutics. Section 6 provides a rhetorical analysis of the patient perspectives as they transpire in tabloid coverage of the nusinersen controversy. Patients and their caretakers use the universalist welfare imaginary to express their disappointment with restricted access to nusinersen. Section 7 analyzes political stakeholder perspectives, namely, how an appeal for the embrace of the DMC is articulated and how a new social imaginary emerges in order to explain the contradictions between the promised universality of Danish welfare and the need to restrict access to innovative therapeutics based on cost analyses.

II. SOCIAL IMAGINARIES AND THE UNIVERSALIST WELFARE IMAGINARY

Applying ‘imagination’ and its corollary ‘the imaginary’ as conceptual resources to understand social phenomena is by no means a new endeavor. As Richard Kearney expertly demonstrates, ‘imagination’ and ‘the imaginary’ have been commonplace throughout Western intellectual history.19 Nonetheless, ‘imagination’ and particularly ‘the social imaginary’ have reemerged as concepts across multiple social sciences. 20 In most of this literature, the social imaginary is largely identical to what Emile Durkheim called ‘collective consciousness’, namely, ‘a whole world of feelings, ideas, and images that follow their own laws’ derived from a ‘sui generis synthesis of individual consciousnesses’.21 However, political and cultural theorists argue that social imagination and the shared imaginaries that emerge from it are crucial to democratic society because they enable both the ‘necessary fictions’22 of modern democracy and futuristic visions of the good life. The defining features of modern democratic society are conditioned by collective imagination because the functioning of society is inherently abstract, and foundational notions like nation, citizenship, public sphere, market economy, and

19 Richard Kearney, The Wake of Imagination (1998).
20 Jasanoff and Kim, supra note 9; Jasanoff and Kim, supra note 9; Yaron Ezrahi, Imagined Democracies (2012); Charles Taylor, Modern Social Imaginaries, Public Cult. 231 (2004); Jens Beckert, Imagined Futures (2016).
21 Emile Durkheim, The Elementary Forms of Religious Life (1995), at 426.
22 Ezrahi, supra note 20.
the law take central functions in society by virtue of their imagined status. Moreover, imaginaries extend beyond the present to the future and hold together visions of the good life and expectations about prosperity and security. Before turning to the universalist welfare imaginary, I will briefly review some of the central tenets of the social science literature on imaginaries.

Benedict Anderson’s widely influential *Imagined Communities* marks a useful starting point for the increased attention to imagination in social and political life.23 Combining ethnographic and historical approaches in a study of colonial states as they turn to socialism and later nationalism, Anderson observes that the then-dominant theoretical understanding of nationalism as a primordial, ethnicity-centered collective poorly explained the political changes of the 1970s and 1980s. Against a more realistic account of political communities based on geography and historical sovereignty, he argues that the nation is an *imagined* political community. The systematic invocation of a particular national imaginary is what assembles otherwise temporally and spatially dispersed groups of people into an abstracted yet deeply felt ‘We’. Central to Anderson’s argument is that the imaginary ontology of a nation should not be misinterpreted to mean a false or a less true community. The imagined character of the nation is part and parcel of what makes it a nation and not just any community. Therefore, on a methodologically note, ‘Communities are to be distinguished, not by falsity/genuineness, but by the style in which they are imagined’.24

The 1991 second edition of *Imagined Communities* contained a new chapter about a aspect of imagined communities that Anderson admitted to have underestimated and largely ignored, namely, the role that science and technology plays in creating, sustaining, and transforming national imaginaries. In a more recent book, Sheila Jasanoff and Sang-Hyun Kim make science and technology the point of entry into the theorization of imaginaries and their relation to social and political life.25 Like Anderson they understand imagination to be a social practice that is fundamental to collective life. However, while they are equally interested in the political imaginaries and how they come about and influence the nature of collectives, they adapt an approach influenced more by STS than by political history and ethnography. They advocate a research program that centers on the networked dispersal of institutions and artefacts in the creation, advancement, and contestation of imaginaries. In addition to suggesting that science and technology constitute a style through which a community and its future are imagined (to use Anderson’s terminology), science and technology also constitute an empirical field in which sociotechnical imaginaries are constantly promoted, negotiated, contested, promised, and disappointed at multiple levels of governance and engagements. Extending the analytic scope of imaginaries, Jasanoff and Kim provide a new methodological vantage point that allows analysts to capture imaginaries that hold together grand visions and collective identities as well imaginaries inscribed in the small-scale materiality of contemporary technoscience.

Both Anderson’s and Jasanoff and Kim’s concepts provide important resources for this study. While the universalist welfare imaginary is a product of Scandinavian social

23 Benedict Richard O’Gorman Anderson, *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (1983, ed. 1991).
24 Id. at 6.
25 Jasanoff and Kim, supra note 9.
history and post-World War II imagination, the contemporary public debate about welfare and universal health care emerges from and is shaped by individual experiences with healthcare organizations as well as their materiality and complexity. Furthermore, the universalist welfare imaginary is closely tied to the national welfare state as a form of government, but, as I will demonstrate in the following sections, the governance of access to therapeutics is an area that is difficult to contain within the limits of the national state.

The rest of this section gives an account of the Danish universalist welfare imaginary on a macrolevel with specific reference to political sociology and political economy. The purpose is to give a brief introduction to the social themes that inform the Danish universalist welfare imaginary which will serve as a background for the subsequent sections where I detail how this imaginary is performed rhetorically in the controversy around nusinersen and the DMC.

In order to describe the welfare imaginary a few words on the welfare state itself are needed. Although a notoriously difficult term to pin down, Asa Briggs’ classic definition of the welfare state provides a useful starting point:

‘A welfare state is a state in which organized power is deliberately used (through politics and administration) in an effort to modify the play of market forces in at least three dimensions—first, by guaranteeing individuals and families a minimum income irrespective of the market value of their work or their property; second, by narrowing the extent of insecurity by enabling individuals and families to meet certain ‘social contingencies’ (for example, sickness, old age and unemployment) which lead otherwise to individual and family crisis; and third, by ensuring that all citizens without distinction of status or class are offered the best standards available in relation to a certain agreed range of social services’.

We can observe how the imagination of citizens in the welfare state is implied in the three tenets of this definition. First, the welfare state controls market forces through economic redistribution in order to ‘guarantee’ citizens a minimum of income. Here, a ‘guarantee’ describes how the redistribution is oriented towards the future—comparable to a promise. Citizens are secured a minimum income regardless of the economic value of their work, and, on the level of the individual, the minimum income guarantee enables each citizen to imagine a secure future in which basic needs are covered. On the level of the collective, this imaginary frames economic security of citizens with the imposition of a particular mode of valuation; the fluctuating market value of labor is partly displaced by a fixed minimum value founded in social rights. The welfare state, in other words, actively replaces the market valuation of work and property with the universal valuation of the citizen through minimum income securities. In sum, the universalist welfare state establishes a particular relation between market, citizen, and society where market forces are regulated by the state for the security of citizens. A central function of the universalist welfare imaginary is to justify this order through the rhetoric of security and the promise of solidarity.

Secondly, the mode of valuation that is introduced with the economic redistribution is closely tied to an imaginary of the life trajectory of the individual welfare citizen. In this trajectory citizens are protected against ‘social contingencies’ in all aspects of their

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26 Asa Briggs, The Welfare State in Historical Perspective, 2 Eur. J. Sociol. Eur. Sociol. 221 (1961), at 228.
livelihood throughout their life. This range of programs and rights ideally covers ‘social contingencies’ or life events continuously: paid maternity/paternity leave, free public child care, free public schools and higher education, unemployment benefits, extensive labor rights and workplace insurance, public retirement funds, and economic support for burial services. The formalized life trajectory that is institutionally supported is what Joseph Slaughter has called an ‘enabling fiction’ that creates a social formation through a collective style of imagining as other individuals will encounter the same welfare services in similar life events. To name an example specific to Danish welfare society, following the financial recession of 2008, autobiographical literature about the pointlessness in mandatory reemployment activities for unemployed college graduates (such as job-seeking training courses) articulated a collective ‘style of imagining’. It satirically disclosed how public efforts to help graduates find employment was experienced as embarrassingly banal, condescending, and a waste of time.

Finally, the welfare state entails an equal provision of services to all citizens. Among some comparative political scientists, this universalism distinguishes the Nordic model of welfare from other types of welfare states. In particular, Esping-Andersen’s influential three-part typology of welfare state models includes a (i) universalistic, social democratic regime; (ii) job market-related, ‘liberal’ regime; and (iii) a residual, ‘conservative’ model regime. In a universalist welfare state, an equality of high standard of services is promoted rather than an equality of minimal needs, which is typically the case in the two other types. The high standard of services translates into the need to de-commodify welfare services in order to crowd out the market and construct, in Esping-Andersen’s words, ‘an essentially universal solidarity in favour of the welfare state: ‘All benefit; all are dependent; and all will presumable feel obliged to pay.’

### III. DANISH MEDICINES COUNCIL

The Danish Medicines Council (DMC) was established in December 2016 and operative from January 2017. The key objectives for the DMC are to secure fast and homogeneous use of expensive therapeutics across hospitals and regional primary care facilities, to increase efficiency in the allocation of healthcare resources, and to improve procurement possibilities by intensifying price competition. To those ends the DMC issues recommendations and guidelines for new and existing indications and therapeutics used in hospitals based on scientific evaluations of added clinical value and cost analyses.

27 Joseph R. Slaughter, *Enabling Fictions and Novel Subjects: The Bildungsroman and International Human Rights Law*, 121 PMLA 1405 (2006); Joseph R. Slaughter, *Human Rights, Inc.: The World Novel, Narrative Form, and International Law* (2009).
28 Lau Aaen, *Dagpengeland: en sand historie om aktivering* [Daily Allowances: A True Story about Re-employment Activities] (2012).
29 G. Esping-Andersen, *The Three Worlds of Welfare Capitalism* (1990). For a recent overview of critiques raised against Esping-Andersen, see Christopher Deeming, *The Lost and the New “Liberal World” of Welfare Capitalism: A Critical Assessment of Gosta Esping-Andersen’s the Three Worlds of Welfare Capitalism a Quarter Century Later*, 16 Soc. Policy Soc. 405 (2017).
30 Esping-Andersen, supra note 29, at 28.
31 Danish Regions, *Establishment of the Danish Medicines Council* (2016); Michael C. Havemann and L. Aagaard, *Denmark, The Danish Medicines Council: A New Prioritisation Organ for Medicine Use in Hospitals*, 2 Eur. Pharm. Law Rev. 85 (2018).
The DMC was established under Section 78(3) of the Danish Health Act as a cooperation between the five Danish regional authorities. In the Danish tax-based healthcare system, the regional authorities are politically and administratively accountable for the provision and payment of healthcare services as well as being the legal proprietors of the hospitals. As a result of the healthcare reform of 2007 where 13 counties were transformed to five regions, the regional mid-level of governance was reduced in policy scope and assigned more responsibility. After the reform, regional policy was limited to the healthcare system, but due to their increased size, regions were expected to provide better quality and efficiency in hospital management.32 Regional healthcare budgets are determined in negotiation with the Ministry of Finance on an annual basis and are assigned as a block grant.33

The DMC replaced two existing councils: The Danish Council for the Use of Expensive Hospital Medicines (RADS), which was primarily commissioned to reduce clinical practice variation, and the Coordination Council for the Inception of Hospital Medicines (KRIS), which was commissioned to assess the therapeutic value of new medicines and coordinate potential adoption. The DMC is both a consolidation of the mandates for previous councils and an extension of them. The DMC has a mandate—and as its explicit objective—to take treatment costs into account using a formalized clinical assessment model under the increased involvement of other stakeholders, such as the pharmaceutical industry, patient organizations, and the public.34 The inclusion of cost analyses in the assessment model has been in point of contention and marks the most significant change from preceding organizations.35 Furthermore, the DMC does not apply a formally recognized framework for cost utility or cost-effectiveness analysis although its mandate is to include cost into assessments. Not applying recognized economic evaluation models to juxtapose cost and benefit provides the Council with more discretion in synthesizing its findings to a conclusion about clinical value.36

The Council is organized as a board, a secretariat, and range of expert committees. The board holds the overall responsibility for reaching the council’s objectives and has 15 permanent members and three observers. 12 members (including two chairmen) are appointed by the regional authorities, three by the medical societies, and the remaining two members are appointed by the umbrella organization for Danish patient organizations. Additionally, the Danish Health Authority, the Danish Medicines Agency, and the pharmaceutical industry association each have one observer in the board who may participate in discussion but who cannot vote. The expert committees consist of medical experts in the given therapeutic area as well as at least one patient representative. Expert committees are responsible for defining the protocol for the clinical benefit assessment, for validating the incoming application’s analyses, and for

32 Pernille Tanggaard Andersen and Jens Jørgen Jensen, Healthcare Reform in Denmark, 38 SCAND. J. PUBLIC HEALTH 246 (2010).
33 Danish Regions, Modelbeskrivelse for ny Medicinorganisation [Model for a New Medication Organization] (2016).
34 Sarah Wadmann and Jakob Kjellberg, New Model for Prioritised Adoption and Use of Hospital Medicine in Denmark Aince 2017: Challenges and Perspectives, 123 HEALTH POLICY (NEW YORK). 606 (2019).
35 Id.; Danish Medicine Council, Process and Methods Guide: How the Danish Medicines Council Develops Joint Regional Assessments of the Added Clinical Value of New Medicines and New Indications 1 (2017).
36 Wadmann and Kjellberg, supra note 34.
classifying the therapeutic in question according to seven-step taxonomy of clinical benefit.\textsuperscript{37} The secretariat mainly has a management function for the council’s work.

The DMC makes politically independent decisions but they are not legally binding. As the DMC is established under the purview of the regional authorities, the overall financial and administrative responsibility falls upon the democratically elected members in the regions. Furthermore, the Council’s recommendations are to refer to seven overall principles for prioritization of hospital therapeutics set by the Danish Parliament:

1) ‘Professionalism in assessment of new therapies
2) Independent and objective scientific assessments of therapies
3) Openness in the evaluation process
4) Faster use of new medicines than previously
5) Ensure value for money when recommending new treatments
6) Equality in access to medical treatment with respect to geography
7) Equality in access to treatments for small and large patients’ groups\textsuperscript{38}

IV. THE NUSINERSEN CONTROVERSY

The Nusinersen controversy roughly developed over three cycles as specific responses to DMC decisions. Although it was initially described in the \textit{Christian Daily}, it was sparked by patient narratives in tabloid coverage in October and November of 2017. \textit{Table 1} illustrates the sequence of coverage. The following March and May, the controversy went into its second cycle when patient narratives again ignited discussion and more reactions than previously. This cycle should be seen in connection with the DMC’s announcement that they had scheduled a reconsideration of their assessment of nusinersen for the following April. The third cycle was generated by the DMC’s announcement that nusinersen would be recommended for not only for SMA1 as previously but also for SMA2.

Media content analysis methods\textsuperscript{39} were applied in the collection of public discourse about the nusinersen controversy. The most comprehensive Danish media database, \textit{Infomedia}, was queried for coverage using the brand name ‘Spinraza’. The query was restricted to coverage in national print media because news items are often syndicated and reprinted in regional outlets, and a search including regional media would entail duplicates. In addition to the selected print media, the controversy appeared in national television and social media. To focus, the analysis print media was selected as the only source of data. The query produced 25 results published between May 2017 and November 2018.

\textsuperscript{37} Danish Medicine Council, \textit{supra} note 35.

\textsuperscript{38} Sundheds-og Ældreministeriet, \textit{Principal Paper on Prioritisation of Hospital Medicine}, MINISTRY OF HEALTH (2016), \url{https://www.sum.dk/Aktuelt/Nyheder/Medicin/2016/April/8#x007E;/media/Files-Publikationer_i_pdf/2016/Princippapir-om-prioritering-for-sygehuslaegemidler/Princippapir-om-prioritering-for-sygehuslaegemidler.ashx} (accessed Jun. 12, 2019). My translation.

\textsuperscript{39} Krippendorff, \textit{supra} note 11.
| No. | Date of publication (Y.M.D) | Title of article                                                                 | Rhetorical genre                  |
|-----|----------------------------|----------------------------------------------------------------------------------|-----------------------------------|
| 1   | 2017.05.29                 | Is Magnus too ill to try and save?                                               | Patient narrative                 |
| 2   | 2017.10.17                 | Medication too expensive for 16-year-old Magnus: Minister needs to be involved    | Patient narrative                 |
| 3   | 2017.10.17                 | Medicine Council says no to break-through medicine: kids with rare and deadly    | Patient narrative                 |
|     |                            | disease let down                                                                 |                                   |
| 4   | 2017.11.01                 | Should kids be treated for 44 million?                                           | Analysis                          |
| 5   | 2017.11.02                 | The Medicine Council is doing the right thing                                    | Commentary (editorial)            |
| 6   | 2017.11.20                 | Election tomorrow with the Regions after 10 years: what has been good and bad?   | Analysis                          |
| 7   | 2017.11.22                 | Here are the most important challenges for the Regions                           | Analysis                          |
| 8   | 2018.03.17                 | Incurable children are the baptism of fire for the Medicine Council              | Analysis                          |
| 9   | 2018.03.17                 | Six-year-old Sander gets expensive medicine injected into his back               | Patient narrative                 |
| 10  | 2018.04.16                 | Merle’s medicine is too expensive                                               | Patient narrative                 |
| 11  | 2018.04.18                 | Mariane’s husband has muscular atrophy—why cannot we afford to help him?        | Patient narrative                 |
| 12  | 2018.04.19                 | The important Medicine Council cannot do its job                                  | Commentary                        |
| 13  | 2018.04.21                 | The first big battle in a changed healthcare system                               | Analysis                          |
| 14  | 2018.04.23                 | Politicians should stand by the rejection of expensive medicine                  | Editorial                         |
| 15  | 2018.04.30                 | Danish Regions: we need to dare say ‘no’ when the price of medicines way exceeds the added value | Stakeholder                      |
| 16  | 2018.05.30                 | The Pharma industry must be curtailed if we are to afford nurses                  | Stakeholder                      |
| 17  | 2018.06.01                 | Now Merle gets her medicine                                                      | Patient narrative                 |
| 18  | 2018.06.20                 | Medicine Council: they are never easy decisions to make                           | Stakeholder                      |
| 19  | 2018.06.27                 | Why cannot an 8-year-old get help?                                               | Patient narrative                 |
| 20  | 2018.08.23                 | Parents are rejected in Spinraza cases                                           | Analysis                          |
| 21  | 2018.08.23                 | Merle the Miracle                                                                | Patient narrative                 |
| 22  | 2018.08.24                 | Here’s why Spinraza causes contention                                             | Analysis                          |
| 23  | 2018.08.24                 | Danish People’s Party and Social Democrats: sick children need their medicine     | Stakeholder                      |
| 24  | 2018.09.11                 | Half of the powerful Medicines Council has connections to the pharmaceutical     | Analysis                          |
|     |                            | industry                                                                        |                                  |
| 25  | 2018.11.08                 | For our son a little effect is very large                                        | Patient narrative                 |
V. RHETORIC OF RESISTANCE: PRIORITIZATION OF HEALTHCARE RESOURCES IMPEDES UNIVERSAL WELFARE

While the nusinersen controversy constitutes the climax of public debate about prioritization of healthcare resources, the two preceding decades had seen some public attention to this issue. The public discussion was largely incited and framed by a report from the Danish Council on Ethics in 1996. Subsequently, numerous publications from think tanks and policy councils argued for the need for prioritization, and the reports have increasingly emphasized the non-monetary aspects of healthcare and healthcare costs. For example, in their 2007 report on the prioritization in the healthcare system, the Danish Technology Council strongly argued for prioritization because ‘the healthcare system is a very important public activity. Not just because it provides solutions, but because it symbolically expresses some of the core values of welfare society, namely equality, trust and care.’ Medical societies, whose members were informally making priorities in their clinical practice, also advocated the need to provide clear procedures and external validation of the priority setting. Patient organizations, however, were skeptical and argued that treatment costs could potentially restrict patient access and that imposing such financial concerns would be unethical.

Two events emphasized the public attention further, namely, the 2007 healthcare reform with which regional authorities became politically and administratively responsible for healthcare provision and the significant increase in expenditure of therapeutics in the 2010s. The establishment of the regions provided a centralized political responsibility for healthcare costs and thus a stronger political and rhetorical platform from which to advocate more regulation of the expenses. Furthermore, in the 2010s hospital therapeutics accounted for the largest share of total expenditure for therapeutics in Denmark. As a consequence, resources for other expenses, such as staff hours, are drained by therapeutics.

While the need for prioritization measures was clear among regional authorities, think tanks, and academics, the question was hardly taken up by national decision-makers. National parliamentarians and responsible ministers have historically been reluctant to discuss prioritization in healthcare and even denied any future scenario involving prioritization. Around the same time of the 1996 report by Danish Council on Ethics, the then-Minister of Health, Yvonne Andersen, responded to the growing concern about expenses in a newspaper opinion piece:

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40 Kjeld Møller Pedersen, Medicin—ikke blot et spørgsmål om pris, in Prioritering i sundhedsvæsenet (2015); Det Etiske Råd, Prioritering i sundhedsvæsenet (1996), http://www.etiskraad.dk/&#x007E;/media/Etisk-Raad/Etiske-Temaer/Sundhedsvaesenet/Publikationer/1996-01-01-prioritering-sundhedsvaesenet-redegoerelse.pdf (accessed Jul. 7, 2016).
41 Det Etiske Råd, Etik og Prioritering i Sundhedsvæsenet—hvorfør det er så svært (2013); LiF, Om Prioritering på Sundhedsområdet, https://lif.dk/Politik/Sundhed/Sider/om-prioritering-p&#x00E5_; sundhedsmor8x0E5;det.aspx (accessed Jun. 12, 2019); Dagens Medicin, Prioritering i Sundhedsvæsenet, https://dagensmedicin.dk/konferencer/finder-vi-prioriteringsnoeglen/ (accessed Jun. 12, 2019); Teknologirådet, Prioriteringer i Sundhedsstystemet (2007).
42 Teknologirådet, supra note 41, at 2. My translation.
43 Wadmann, supra note 13.
44 Sarah Wadmann and Jakob Kjellberg, Value-based Procurement of Hospital Medicines (2018), https://www.vive.dk/en/publications/value-based-procurement-of-hospital-medicines-10767/.
45 Pedersen, supra note 40.
Regulating patient access to therapeutics in Denmark

Far most of the resources that are used in the public healthcare system can be justified with a common set of values which only very few would question. It is fundamentally about, if there is an efficacious treatment to an illness, then the treatment should be offered. In a rich welfare society like the Danish one we can afford to treat the sick. There can be no doubt about that.46

The comment is illustrative because it rhetorically compounds appeals to national community, welfare imaginary, and ethical values in an effort to argue against prioritization of healthcare resources. The then-Minister of Health projects the national ‘we’ as a rhetorical proxy for the welfare society. The personalization of the welfare system is important because it makes the ‘common set of values’ more salient. It not only argues that there is a value-based consensus behind the use of resources in the public healthcare system, but it also implicitly argues that it is un-Danish to question the set of values that justify the expenditure. The notion that prioritization contradicts Danish values (i.e., that all citizens patients should receive efficacious treatment because they are members of a rich welfare society) is even more pronounced in a statement made by the then-Prime Minister, Poul Nyrup Rasmussen. Here it is referenced in a news summary:

‘After a consultation [with the relevant political parties] in the Parliament’s Central Health Committee the Prime Minister asserted that in a welfare society like the Danish one it is unacceptable to take the patients hostage in the economic considerations.’47

Whereas the Minister of Health suggested that it would be unethical and thereby un-Danish not to offer treatment, the Prime Minister seems to suggest that it would be cynical to turn patients into economical object and thereby ‘take them hostage’. In both of these cases, ‘economic considerations’ are perceived to contradict patient care. The notion of prioritization is jettisoned in order to secure patient access to new therapeutics with specific reference to ‘a welfare society like the Danish one’.

The two statements about the superiority of moral and societal values to economic values are not limited to the 1990s. In a TV debate prior to the Danish general election of 2015, the two candidates for Prime Minister both denied the necessity of prioritization of medicines in Denmark, and they both made specific reference to the Danish healthcare system. Helle Thorning-Schmidt, a Social Democrat and incumbent Prime Minister, stated:

‘I don’t foresee a situation where we have to prioritize. The citizens expect world class when they meet the Danish healthcare system.’48

The implicit premise that connects the two sentences in this quote is that prioritization will result in a regression of the standard of care, and following this line of reasoning prioritization is in opposition to the ‘world-class’ expectations of citizens and should not be implemented.

46 Yvonne Herlov Andersen, No Title, Berlingske Tidende, Mar. 18, 1995. My translation.
47 Lene Koch, Beta-interferon, Berlingske Tidende, May 13, 1999. My translation.
48 Helle Thorning-Schmidt, Election Debate, TV2, Jun. 5, 2015. My translation.
The contending candidate, Lars Løkke Rasmussen from the Liberal Party, also suspended the question of prioritizing public funds for therapeutics albeit in a different fashion:

'It is clear that we have to find the money it takes, because we must never end up in a situation where a patient who is in need of treatment—where his or her doctor wants to say “we will solve that, this or that way” but then puts his pen back in his pocket.’

Whereas Thorning-Schmidt presents an argument devised with the citizens’ expectations at the center, Løkke Rasmussen pivots around the autonomy of the prescribing physicians. His argument is, in other words, that prioritization should not be implemented because it would thwart the individual physician’s ability to provide care. These views should be read in the context of general election where prioritization is a difficult discussion to have because debaters who will argue for prioritization are likely to be perceived as cynical among the broader public. But as I will show later on, these views reveal a pattern of national politicians denying the feasibility and need for prioritization.

In sum, while there have been concerns among academics and non-profit organizations about the increase of therapeutics spending and the need for prioritizing resources for more than two decades, politicians at the national level have generally denied the need to prioritize expenditure with reference to the values embedded in universalist welfare imaginary. As the two most recent examples show, the arguments have been driven by a rhetorical opposition between prioritization and high standards of care (‘world-class’) or clinician autonomy.

VI. RHETORIC OF DISAPPOINTMENT: PATIENT ILLNESS NARRATIVES

Table 1 and several of the editorials and media analyses suggest that patient narratives have crucial agenda setting force in this controversy. The rhetorical genre that gives voice to patient narratives and their critiques is primarily the tabloid article. While tabloid news is often associated with strong normative evaluation of the quality and character of journalism, I use the term in a strictly descriptive meaning. As one encyclopedic article describes it, tabloid journalism is a ‘particular kind of formulaic, colorful narrative, coupled with dramatic visuals, and usually perceived as distinct from standard, “objective” styles of journalism.’ While these articles may be disregarded as tabloid exposure, the patient narratives perform an important rhetorical function in establishing the patient perspective on the question of prioritization. Tabloid media coverage obviously also increases the political attention to the individual cases, but it provides a genre and an outlet for individual actors who are deemphasized by the nature of population-wide prioritization methods applied in the DMC.

49 Lars Løkke Rasmussen, Election Debate, TV2, Jun. 5, 2015. My translation.
50 While patient narratives are a well-established research object in the medical humanities, the purpose of this subsection is not to perform a comprehensive rhetorical analysis of the patient narrative genre in the nusinersen controversy. Rather, the purpose of this analysis is to describe how patients as a type of actor perform the universalist welfare imaginary to voice their criticism in the nusinersen controversy. For more on patient narratives, see Mike Bury, Illness Narratives: Fact or Fiction? 23 Sociol. Health Illn. 263–285 (2001) and Judy Z. Segal, Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance, 3 Linguist. Hum. Sci. (2007).
51 S. Elizabeth Bird, Tabloid Newspapers, in ENCYCLOPEDIA OF JOURNALISM.
In the beginning of the controversy, the tabloid *Ekstra Bladet* published an article called ‘Medicine Council says no to break-through medicine: Kids with rare and deadly disease let down’. As the first large patient narrative in the controversy, the story can illustrate some of the characteristics of this genre. The primary motive of the tabloid article is to hold the responsible agency, the DMC, accountable: without further details, the headline implies that nusinersen is a breakthrough therapy and that it will have a curative effect on patients. The simplification adds to the conflict of the story: ‘Why deny a therapy that is break-through when children are dying?’ This framing positions the patients and caretakers in a conflictual relation to healthcare providers and thereby brings to the fore the fundamental welfare principle that the state should help citizens meet ‘social contingencies’ with the best standards of care regardless of social position. This conflictual relation is strengthened by the visual and experiential details about patient life without access to nusinersen.

All the patient narratives revolve around a personal case study with a child who suffers from SMA2 and in most cases do not have access to nusinersen as a result of the DMC’s decision. Of the 10 patient narratives, eight of them are accompanied by images which frame the patient’s life in specific physical setting, and seven of the eight illustrated patient narratives located in private setting of the home, often with family members (the exception is no. 9 which is about a boy who does receive nusinersen). The article ‘Medicine Council says no to break-through medicine’ revolves around a personal case story of a boy with SMA2. This article details several scenes from everyday life that infuse the inability to access nusinersen with affect and emotion. The article describes the need to move the patient’s family to a house that can accommodate a big wheelchair, it describes how the patient can only operate a computer mouse with his feet in a very specific position, and it describes how the boy’s playing with neighborhood is inhibited by his lack of mobility. These scenes are interlaced with comments from caretaking parents who express their hope that the DMC will revert its decision, fear that the disease will deteriorate, and disappointment in the Danish healthcare system. The focus on the private sphere and the personal, everyday experience with SMA2 creates a counterpoint to the other actors in the situation. At the level of the text, images and descriptions of everyday situations demonstrate how the SMA2 disease penetrates the life of the patients, particularly their mobility.

Across the patient narratives, there is an appeal to the national collective, similar to that of the politicians prior to the establishment of the DMC. In one of the most cited cases of SMA patients, Chris Nørregaard, who is the father of Benjamin Meng, expressed that he is ‘disappointed in Denmark’ for not getting access to nusinersen due to the DMC’s recommendation. In another case Marian Doctor rhetorically asks ‘why won’t we help’ her husband with the treatment. Referring to the national collective and first-person plural signals shared responsibility that is tied to the whole community, i.e. all citizens in Denmark.

In sum, the patient narratives evoke the universalist welfare imaginary in several regards. As per the genre definition, the tabloid articles frame the patent story as a conflict between patients and DMC, a representative of the welfare state. This illustrates healthcare as a social right to be claimed, including the access to ‘best standards’ of care (i.e. novel therapeutics) to avoid social contingencies. In several cases the caretakers voice their disappointment with specific reference to the national ‘we’.
VII. RHETORIC OF TRANSCENDENCE: STAKEHOLDERS REFRAMING ACT AND SCENE OF REGULATION

If the patient narratives criticize the DMC for their decision to reject nusinersen as standard treatment, commentaries from stakeholders and editorials generally defend the DMC and the need for prioritization, as can be observed from the headlines in Table 1. The proponent stakeholder commentaries perform a rhetoric of transcendence which puts the nusinersen controversy, the prioritization of healthcare resources, and the promises embedded in the universalist welfare imaginary into different spatial and temporal perspectives. In other words, they transcend the imagined boundaries of the welfare imaginary. Specifically, the stakeholders introduce two new cognitive frames, the transaction and the global market, to justify the DMC’s decision. Consequently, they introduce an significant adjustment to imaginary of patient access to therapeutics. This section performs a rhetorical close reading of two commentaries which contribute to the adjustment of the imaginary.

VII.A. Spatial change of framing: therapeutics in the global marketplace

The first commentary to take a position in the nusinersen controversy is ‘The Danish Medicine Council is doing the right thing’. It is an editorial published in the center-left news outlet Information. The editorialist introduces the controversy with reference to the official statements made by the DMC and then puts the situation in a more general perspective adding the transaction and global market frames.

The disposition of the text is instructive of how the new frames are introduced. The structure of the editorial can be broken into three. First, the editorialist explains that after the DMC has made the difficult decision not to recommend nusinersen as standard treatment, the media have ‘published images of sick children who can’t get the medicine’ which have caused some politicians to ‘doubt the fairness of the decision’.

Secondly, the editorialist echoes the argumentation behind the DMC’s decision from the council’s press release: there is a ‘very low evidence of effect’, and the ‘applicant [Biogen, the manufacturer of nusinersen] has put the price unreasonably high’.

Finally, and most interesting for this article’s focus, the editorialist expands the situation beyond the scope of specific indication and drug:

‘The DMC does exactly what it is commissioned to do: challenge the pharmaceutical industry on the dramatic price increases that drain the public health budgets and deteriorate the treatment of other indications where we may get much more value for our money. A global problem that has come to light internationally through stories about the pharmaceutical industry’s drastic and unexplained price hikes’.

Rather than eschew the economic considerations like the national politicians prior to the DMC, the editorialist places the discussion in the context of the global marketplace. The second sentence augments the issue from specific to general. We are told that this is a global and not only a national problem; it involves an industry and not only a company; it involves other indications not only spinal muscular atrophy. The Danish

52 N/a, Medicinråd gor det rigtige [The Danish Medicines Council is doing the Right Thing], INFORMATION, Nov. 3, 2017. My translation.
issue of patient access to innovative therapeutics, in other words, should be understood in the context of global market of therapeutics, not individual patient access.

VII.B. Temporal change of framing: ‘prioritization is here to stay’
Six months later a central stakeholder enters the controversy as its second cycle is under way. Stephanie Lose, the regional chairwoman who is politically elected and oversees all regional government, publishes a commentary entitled ‘We need to dare say “No” when the price of medicines way exceeds the added value’. She references and reiterates the arguments put forth in Information’s initial editorial but adds an important temporal perspective with the opening paragraph:

‘The discussion of prioritization of medicines is here to stay. That is why it is important to take it in the open as the Medicine Council does when they recommend which medicines should count as standard treatment’. 53

Lose clearly asserts that the prioritization debate is not an singular event, but rather that it indicates a more profound change. Whereas the preceding editorial augmented the controversy in spatial terms from a specific situation in Denmark to a situation in the global marketplace, Lose augments the controversy in terms of time. She ultimately argues that therapeutic access should be imagined differently. Rather than the imaginary of therapeutic access in the welfare state, it should be imagined in terms of prioritization through institutionalized decision-making. Lose’s argument echoes an analysis published in the same news outlet a week before with the title ‘The first battle in a changed healthcare system has been fought’.

Moreover, Lose establishes the transaction frame when she emphasizes her point at the end of the commentary: ‘We need to dare say no to overly expensive drugs. Otherwise we won’t have any bargaining power’. The transaction frame is established by replacing the patient aspect of access to therapeutics with transaction aspect.54 Readers are expected to identify as members of an economic community (ie nation with universal healthcare coverage) rather than as (potential) individual patients, and following economic principles, it is in the interest of the economic community to optimize ‘value for money’. Put differently, the DMC is characterized squarely as a ‘market device’55 put in place to negotiate better prices and secure more value for the money spent. As STS scholars Callon and Muniesa argue, the term ‘economic’ suggests the formation of valuation networks in which prices are agreed upon and where thing things are rendered economically ‘commensurable and exchangeable’, but it is also ‘economizing’ in the sense of saving or rationing.56

53 Stephanie Lose, Danske Regioner: Vi skal turde sige nej, når prisen for medicin langt overstiger lægemidlets merværdi [Danish Regions: We need to dare say ‘No’ when the price of medicines way exceeds the added value], INFORMATION, Apr. 30, 2018. My translation.
54 For a discussion of transaction frames more generally, see Olav Velthuis, Talking Prices: Symbolic Meanings of Prices on the Market for Contemporary Art, at 64.
55 Fabian Muniesa et al., An Introduction to Market Devices, 55 SOCIOLO. REV. 1 (2007).
56 Id.
VIII. CONCLUSION

In this article, I have examined which social imaginaries shape the public discourse about therapeutics regulation. The accountability and legitimacy of regulatory institutions have increasingly become an object of popular attention as documentarist narratives and media coverage have detailed controversies over a range of political and bioethical issues. Tracing the conditions for and the development of a public controversy about patient access to an innovative orphan therapeutic (nusinersen) in Denmark, I found that the central social imaginary was—what I have called—universalist welfare imaginary. The universalist welfare imaginary contains, among other elements, the vision and promise of access to the highest standard of care for all citizens, including therapeutics. Importantly, this right to healthcare aligns with the general universalist and egalitarian visions of the Danish universalist welfare state and is regarded a fundamental social right. Furthermore, the welfare promise for all citizens is premised on the exclusion of market economy considerations, as universal high standards are expected to ‘crowd out’ the market.\(^{57}\)

In Section 3 I provided a structural sketch of the universalist welfare imaginary derived from characterizations of the welfare state from political sociology and the political sciences.

The key concern in this article was how these political visions and concepts were performed rhetorically in situations where the regulation of therapeutics was in the public spotlight. The analysis in Section 5 describes a rhetoric of reluctance in the preceding phase of the public controversy around nusinersen. Here, leading politicians at the national level justified their reluctance to establish a national HTA for therapeutics. In 2015, the then-Prime Minister argued that any priority setting in the allocation of resources would result in a healthcare system short of ‘world-class’, which was ostensibly the expectation of the Danish people. In a congruent response, the leader of the Danish Liberal Party argued that prioritization would inhibit the healthcare professionals’ ability to provide optimal care for their patients. In both the patient and provider versions of this argument, a rhetorical opposition between prioritization and welfare imaginary is constructed. Furthermore, earlier political discourse, which also rejected prioritization, imbued this opposition with a national reference as it was considered particularly un-Danish to set priorities for the allocation of healthcare resources. This rhetorical strategy is conservative in the sense that it rejects new regulation on the basis of historically salient visions and promises, and it is populist in the sense that it reduces the complexity of the health economy significantly and unilaterally sides with the broader public without further concerns. In other words, politicians at the national level opted for a continuity of the universalist welfare imaginary.

The rhetorical strategy that was observed in the analysis of patient narratives in Section 6 was based on the same set of beliefs and expectations as the rhetoric of reluctance, but from a less privileged position marked by disappointment. After the DMC’s decision not to recommend nusinersen for SMA2, patients articulated their disappointment in the DMC and by extension the Danish welfare state. Some patients appealed to the solidarity inscribed in the universalist welfare imaginary by addressing the national collective: ‘Why don’t we help [the patients]?’ What is significant about this rhetorical strategy is that it includes a different register of rhetorical resources.

\(^{57}\) Esping-Andersen, supra note 29.
than the two other examples of discourse, namely, the tabloid genre, visuals from the private sphere, and intimate details from personal accounts. These elements from the life experiences of the SMA2 patients were mobilized rhetorically to show the material and bodily reality of the welfare imaginary and the DMC’s decisions.

Finally, proponents of the DMC based their argument in the transgression of the imagined boundaries of the universalist welfare imaginary—what I have called a rhetoric of transcendence. They advocated that the case of the DMC and decision about nusinersen should not be perceived and judged in the context of national welfare. Rather, the controversy was part of a larger situation in the global market economy. They seem to suggest that Denmark was but one market and spinal muscular atrophy was but one indication. Moreover, the nusinersen decision was only the first of many difficult allocative decisions. They seem to suggest that the high standards for welfare services and patient access to therapeutics have run its historical course. This rhetorical strategy illustrates that the introduction of new regulations may challenge existing social imaginaries very directly and the discontinuities wrought by new regulation may become the object of public controversy.