“TOGETHER FOR HEALTH”?
HOW EU GOVERNANCE OF HEALTH UNDERMINES
ACTIVE BIOLOGICAL CITIZENSHIP

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ABSTRACT

This paper explores the potential for active biological citizenship in the discursive space opened by the Community law rights to receive cross-border health care services. By focusing on the European Patients’ Forum and the European Public Health Association as examples of actors facilitated by the European Union, the paper notes how this space might provide some opportunities for patients’ strategic engagement, but also how EU governance discourse is shaping and undermining the potential for activism.

INTRODUCTION

The author has previously suggested that patients might be developing an identity as biological citizens in the European Union (EU) context1 through their exercise of Community law rights2 to receive cross-border health care services paid for by their home health care sys-

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1 See generally Mark L. Flear, Developing Euro-Biocitizens through Migration for Healthcare Services, 14 MAASTRICHT J. EUR. & COMP. L. (SPECIAL ISSUE) 239 (2007).

2 Community law is the law of the European Community. This was founded by what is now termed the European Community Treaty in 1957. The Community is one of three pillars comprising the EU, which is the umbrella organization founded by the Treaty on European Union in 1992. Community law rights arise from the operation of the doctrines of direct effect (which renders Community law enforceable before national courts, see Case 26/62, N.V. Algemene Transport-en Expeditie Onderneming Van Gend & Loos v. Neth. Inland Revenue Admin., 1963 E.C.R. 1) and supremacy (which requires the precedence of Community law over national law and policy where there is a conflict, see Case 6/64, Costa v. ENEL, 1964 E.C.R. 585; Case 11/70, Internationale Handelsgesellschaft mbH v. Einfuhr-und Vorratsstelle für Getreide und Futtermittel, 1970 E.C.R. 1125; Case 106/77, Amministrazione delle Finanze dello Stato v. Simimenthal S.p.A., 1978 E.C.R. 629.). See also PAUL CRAIG & GRÁINNE DE BÚRCA, EU LAW: TEXT, CASES, AND MATERIALS 6-7 (4th ed. 2008).
tem in certain circumstances. This paper explores the potential for active European biological citizenship in the discursive space opened by those rights. Although the aim of this article is not to develop a normative basis for the role(s) of civil society in EU health governance, the exploration of the discourse is not free from normative impulses. The author welcomes attempts to expand freedom of choice within public services and to give increased control to patients. Directly effective Community law, when combined with careful use of national social policy and Community competences, can help to reform national health care services in ways that do not necessarily entail an abandonment of the core value of equality of provision they were founded to introduce and safeguard. Activism, whether through the wielding of rights or other strategies such as the exploitation of their emancipatory rhetoric, is a welcome engagement by patients in the systems that govern them.

In considering the discursive space opened by the Community law rights, the article does not provide an empirical analysis of all interactions between EU governance, its main legislative and executive institutions (European Commission [Commission], European Parliament, Council of Ministers, and Economic and Social Committee) and civil society. Indeed, this has already been attempted by others in the area of


EU health governance. While the author takes it as a given that discourse leaves an imprint on action and governance outputs, he leaves it to others to determine the extent in this context. Instead, the author’s interest lies in the necessarily prior exercise of interrogating the discourse. This article analyzes the key representative examples of the discourse on civil society in the immediate area of health. These originate from the Commission. This paper, however, does not consider how and why the discourse emerged, except insofar as those issues impact the paper’s central purpose. The EPF and EPHA are used to suggest that EU governance discourse is colonizing the discursive space opened by the Community law rights. A neutered or passive form of activism is fostered. This can, however, be resisted, for instance through renewed exploitation of the rhetorical aspect of human rights, the notion of participation in republican citizenship discourse, and the exploitation of networks of actors and resources.

The focus on active citizenship in the discursive space is particularly apt given a couple of recent developments in the health context. One is the opinion of Advocate General Ruiz-Jarabo Colomer for the European Court of Justice (ECJ) in Aikaterini Stamatelaki v. NPDD Organ-

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5 Scott L. Greer et al., Mobilizing Bias in Europe: Lobbies, Democracy, and EU Health Policy-making, 9 EUR. UNION POL. 403 (2008) [hereinafter Mobilizing Bias in Europe]; Scott L. Greer, The Changing World of European Health Lobbies, in EUROPEAN UNION LOBBYING (David Coen & Jeremy Richardson eds., forthcoming 2009) (on file with author) [hereinafter The Changing World of European Health Lobbies]. Civil society actors are open to various definitions, but are taken to include nongovernmental organizations and public interest associations: Richard Bellamy et al., Introduction: From National to Transnational Citizenship, in MAKING EUROPEAN CITIZENS 1, 22 (Richard Bellamy et al. eds., 2006). Biosociality refers to forms of collective action that arise in relation to the biological self.


nismos Asfaliseos Eleftheron Epangelmation (although not followed in this regard by the ECJ’s judgment), in which the free movement aspect of the Community law rights was explicitly overlaid with “the right of citizens to health care, proclaimed in Article 35 of the Charter of Fundamental Rights of the European Union (EU Charter).” This signals the growing importance of rights and citizenship discourses in the EU’s developing health governance “patchwork.” To this purpose, there is a growing tendency in the literature to see the Community law rights as manifestations of EU citizenship. The potential for activism also seems to be recognized by Advocate General Geelhoed in his opinion in The Queen, on the Application of Yvonne Watts v. Bedford Primary Care Trust and Secretary of State for Health, where he notes how patients are “undoubtedly stimulated by the Court’s case law in this field.” This paper briefly explores how the rights might foster activism through the discursive space they open.

The second development is the increasingly apparent political desire for EU involvement in health. This is demonstrated in particular by the potential amendment to Article 152 of the European Community Treaty (the EC Treaty) (the legal basis for Community action in public health) by the Lisbon Treaty (signed December 13, 2007, but voted down by a referendum in the Republic of Ireland on June 12, 2008, and therefore at risk of faltering since adoption requires unanimity among the

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9 I refer to health governance and not just health care governance, since the latter fits within the former. This conveys the EU’s growing role in health and not just health care.
Member States of the EU, which is now unlikely unless Ireland votes “Yes” in a rerun). Such political desire is also apparent in the recent key example of the discourse on civil society involvement in EU health governance: the Commission’s White Paper entitled, “Together for Health: A Strategic Approach for the EU 2008-2013” ("Together for Health"), published on October 23, 2007. This document seems to point to a more intensive period of Community activity in health care systems, through EU level governance that entails involvement by various actors, such as the Member States and stakeholders like health care providers and patients. In EU discourse, civil society actors like the EPF and the EPHA are generally deemed and hoped to provide a link for participation between the EU’s citizens and its system of governance, which might generate input legitimacy as a means of enhancing outputs. This tendency is most apparent in the Commission’s White Paper on European Governance (“European Governance”) and subsequent initiatives, as well as in the articulations of others, such as the Economic and Social Committee, politicians, and scholars. The EPF and the EPHA are two of the clearest examples of collectivization or biosociality, and are therefore especially worthy of exploration as sites of strategic engagement by patients qua EU citizens. This paper explores how the discourse of partici-

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14 Cf. Trubek, Nance & Hervey, supra note 7 (discussing the various actors involved in cancer policy in the EU).


17 See, e.g., Bellamy et al., supra note 5.
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...pation within EU governance relates to the discursive space and the kind of activism it produces.\(^{18}\)

The focus on exploring the potential for activism supplements the liberal citizenship-as-rights strain of EU citizenship discourse with the republican notion of citizenship-as-participation, which emphasizes the importance of practices\(^{19}\) that require active involvement, especially as regards the associational networks that foster the polity and breathe life into governance.\(^{20}\) In considering the potential for active citizenship, Foucault’s notion of governmentality is utilized. This refers to those things that organize the conduct of conduct, in particular, the range of knowledges and techniques that regulate everyday life and constitute, define, and organize the strategies used by individuals in their dealings with each other.\(^{21}\) The signature of governmentality is its effect of omnes et singulatim (all and each). Whether totalizing, regulatory, and operating on the population or individualizing, disciplinary, distinguishing, and operating on the body,\(^{22}\) power often works in both ways simultaneously, automatically, and without intention.\(^{23}\) Power circulates and is dispersed

\(^{18}\) Of course, patients’ organizations and activism have been of growing importance since the 1980s, and so are long present at a national level (where they are becoming more important). See Nikolos Rose, Biological Citizens, in The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century 131, 148 (2006).

\(^{19}\) Id.; See generally Antje Wiener, ‘European’ Citizenship Practice: Building Institutions of a Non-State (1998).

\(^{20}\) See Bellamy et al., supra note 5, at 7-9 (bypassing the communitarian citizenship-as-belonging model).


\(^{22}\) Lecture Two: 14 January 1976, in Society, supra note 21, at 23-40; Lecture Eleven: 17 March 1976, in Foucault, Society, supra note 21, at 239-63.

\(^{23}\) See Foucault cited works supra note 21. Michel Foucault, Discipline and Punish: The Birth of the Prison 27 (Alan Sheridan trans., 1977) [hereinafter Foucault, Discipline]; Michel Foucault, The History of Sexuality: Volume One: The Will to Knowledge 92-98 (Robert Hurley trans., 1978) [hereinafter Foucault, History of Sexuality].
through the polity, and it is relational, so there is always scope for resistance by the subjects that act as its “relays.” 24 This paper stresses this double edged nature of power as the paper unfolds. Power also produces, organizes, and conditions subjects even to the extent of reflexivity, 25 and those subjects use its manifestations such as discourse to govern themselves. This article focuses on EU governance discourse because it “transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it.” 26 This, in essence, is why exploring the discursive space, its colonization by EU governance discourse, and their strategic importance for activism by biological citizens in the EU form the subject of this paper: so that patients are more able to discern the way in which they are governed and, should they deem it necessary, engage with and seek to change it.

Section II of this paper explains how Community law rights are partly the consequence of patients’ strategic engagement 27 and open a discursive space where patients’ claims can be articulated. This article suggests that it is the indeterminacy or open texture of the Community law rights and their imbrication with the rhetoric of human rights and health, rather than their substantive content, which is most amenable to exploitation by the vast majority of patients—those who do not move 28—in challenging and democratizing the provision of publicly funded health care in their Member States. The rights also produce subjectivities. 29 The discursive space opened by the rights creates opportunities for further engagement by patients, especially as it is textured by civil society actors and EU governance discourse.

Section III of this article provides a partial map of that space as it is being populated and textured by the EPF and the EPHA. Of course, any discursive strategy for engagement with EU governance must bear in mind the wider institutional environment, however that is not my focus in this paper; the aim is not to provide a complete strategy for engagement with EU governance. Rather, only a brief sketch of the governance

26 FOUCAULT, HISTORY OF SEXUALITY, supra note 23, at 101.
27 Flear, supra note 1, at 241.
28 The Community law rights operate where there is an inter-state provision or receipt of health services. Thus in order to benefit directly from the rights a patient must be covered by the health care system of one Member State but receive health services in another Member State.
29 See generally Flear, supra note 1.
architecture is provided in order to contextualize the two actors and facilitate interrogation of the discourse. A governmentality perspective reveals how EU governance discourse appears to be colonizing the discursive space opened by Community law rights. EU governance talk produces further subjectivities and, most importantly, a neutered or limited form of active citizenship, a point reemphasized in the conclusion of the paper where a discursive strategy for renewing activism is proposed.

II. OPENING THE DISCOURSE SPACE FOR ACTIVE BIOLOGICAL CITIZENSHIP IN HEALTH CARE

Community law rights provide patients with a limited right to “exit” their home health care system as regards provision, but not payment. This is a form of “flexible citizenship” in that patients pay for services in one Member State through taxes or insurance contributions, but consume the public goods they fund in another Member State. The growing imbrication of the Community law rights with EU citizenship discourse serves to highlight the multivalent and active potential of rights for EU citizens. Stamatelaki highlights how concerns over human rights increasingly underpin the ECJ’s rationale in making judgments in this area. This also signals how human rights rhetoric imbricates and infuses the market element of the Community law rights with notions of entitlement and, by extension, the obligation of Member States to pay for the services patients receive abroad in certain circumstances. The Community law rights also provide patients with added “voice,” perhaps transforming the “silent world” of the doctor and patient through increased “voice” for patients within their home health care system.

Yet, in a Foucauldian vein, rights are double-edged, in that they have a disciplinary and regulatory aspect, as well as an emancipatory potential derived from their indeterminacy or open texture and rhetorical

31 See sources cited supra notes 6, 11.
33 See Public Services and European Law, supra note 11, at 271; Hervey, supra note 11, at 196-97.
potential as a way of articulating claims. The emancipatory potential is explored further below; however, the focus is now on the rights’ disciplinary and regulatory aspect as techniques of “governing through freedom.” Rights discourse is depoliticizing and is underpinned in this context by other depoliticizing discourses and rationalities such as those of (most obviously) the market, but also liberalism (as highlighted in the use of liberal legal discourse) and neoliberalism (purporting to construct rational market actors). Wendy Brown explains how depoliticization involves “removing a political phenomenon from comprehension of its historical emergence and from a recognition of the powers that produce and contour it,” giving way to “an ontological naturalness or essentialism [that] almost inevitably takes up residence in our understandings and explanations.”

Individuation is facilitated by these depoliticizing discourses and rationalities as well as the imbrication of more particular disciplinary and regulatory medical, economic, and legal discourses. Consider the focus on the condition of the individual in assessing whether there is “undue delay,” which if found, creates an entitlement to a grant of prior authorization for hospital treatment abroad. As clarified by the ECJ in V.G. Müller-Fauré v. Onderlinge Waarborgmaatschappij OZ Zorgverzekeringen UA and E.E.M. van Riet v. Onderlinge Waarborgmaatschappij ZAO Zorgverzekeringen, “undue delay” is determined by reference to the needs of the individual patient, extending beyond the “patient’s medical condition at the time when authorization is sought” and his/her “medical history” to consideration of “where appropriate . . . the degree of pain or the nature of the patient’s disability which might, for example, make it impossible or extremely difficult for him to carry out a professional activity.” In other words the patient’s ability to function as an optimal economic actor is relevant in determining “undue delay,” but non-economic factors, such as the patient’s family life, are not. The limited Community law right to treatment abroad is directed at maintaining the energies required for optimal economic activity.

35 BROWN, REGULATING AVERSION, supra note 21, at 15.
36 Case C-385/99, Müller-Fauré v. Onderlinge Waarborgmaatschappij OZ Zorgverzekeringen UA, 2003 E.C.R. I-4509, ¶ 90 (stating that regard must be had to “all the circumstances of each specific case” and “due account [must be taken] not only of the patient’s medical condition at the time when authorization [sic] is sought but also of his past record.” The statement is as it appears in Case C-157/99, Geraets-Smits v. Stichting Ziekenfonds VZG, 2001 E.C.R. I-5473, ¶104, except for the ECJ’s clarifications, which are given in italics. “Medical history” replaces, but appears to be synonymous to the term “past record,” used in Geraets-Smits and Peerbooms). See also Flear, supra note 1, at 245 n. 32.
The focus on “undue delay” is in contrast to the usual methods of rationing scarce public resources, such as the use of waiting lists and taking into account the needs of all patients. In *Watts*, the ECJ emphasized the point further by stressing the importance of making a case-by-case assessment. So, for example, the ECJ instructed the United Kingdom (UK) court to determine whether Mrs. Watts, had endured “undue delay” in waiting for a hip operation in England before traveling to France, paying for the treatment herself, and then seeking reimbursement from the National Health Service (the UK’s health care system). If she had endured “undue delay,” her local health authority (a primary care trust) had to reimburse the cost of her treatment in France.

By extension, the Community law rights also have implications for patients qua subjects. Power that creates, orchestrates, and organizes subjects and juridical power is no different. Indeed, Wendy Brown and Janet Halley explain how juridical power is “importantly productive of identity and subjectivity,” particularly since identity becomes an important potential site of discipline and regulation. As actual or potential bearers of Community law rights, patients are constructed within a neoliberal frame and freighted with agency and responsibility. Yet, as rights bearers, patients are rather passive subjects, albeit relatively more active than the docile subjects they are usually conceived to be in welfare and medical discourses. As Thérèse Murphy puts it, when writing in a connected area, the:

once “silent world” of doctor and patient is said to have been transformed. It is no longer populated by the generic, all-knowing doctor and the generic, always-silent patient. Diseased bodies have become individuated, speaking beings; they are patients with voice, visibility, and rights.

Patients remain a rather passive subject because they are now constructed by the depoliticizing discourses, particularly liberalism (as highlighted in the use of liberal legal discourse), neoliberalism, and

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37 Case C-372/04, The Queen v. Bedford Primary Care Trust & Sec’y of State for Health, 2006 E.C.R. I-4325, ¶44.
38 On the facts it seems unlikely that she had endured ‘undue delay’.
39 Although Foucault reduced the importance of the state in his analysis for the purpose of emphasizing a different conception of power and its sources.
41 Thérèse Murphy, *Health Confidentiality in the Age of Talk*, in *FEMINIST PERSPECTIVES ON HEALTH CARE LAW* 155, 163 (Sally Sheldon & Michael Thomson eds., 1998).
42 WALTERS & HAAHR, supra note 21, at 42-63.
therefore, rights and the market. These undermine the scope for activism.

Neoliberalism deserves particular emphasis because, as Brown explains, individuals are constructed as entrepreneurial actors in every sphere of life. Moreover, neoliberalism:

[R]educes political citizenship to an unprecedented degree of passivity and political complacency. The model neoliberal citizen is one who strategizes for her or himself among the various social, political, and economic options, not one who strives with others to alter or organize these options. A fully realized neoliberal citizenry would be the opposite of public minded; indeed, it would barely exist as a public. The body politic ceases to be a body but is rather a group of individual entrepreneurs and consumers . . .

Consonant with Brown’s point, Jo Shaw notes how Community law rights are very much a top-down process, which of course undermines the discursive potential for activism. Others note how the ECJ’s protection of human rights—most clearly represented for the purposes of this paper by Stamatelaki—signals “delegated citizenship” or “elitist citizenship,” part of the more general trend in which regulatory tasks are delegated to trusted experts.

Thus, the subject is individuated and therefore disciplined as an entrepreneur, consumer, and citizen, but also as a body. In relating to, and as conceived by, their Community law rights, patients might be what Nikolas Rose terms “somatic individuals,” “beings whose individuality

44 Jo Shaw, European Citizenship: The IGC and Beyond, EUR. Integration Online Papers, Oct. 1997, at 12, available at http://eiop.or.at/eiop/texte/1997-003a.htm. Cf., Newdick, supra note 3, (“The European Court of Justice (ECJ) has developed a notion of health care rights in which individuals within social health care systems may be free to enforce their personal claims to health care without regard to their impact on other people”).
is, in part at least, grounded within . . . [their] fleshy, corporeal existence, and who experience, articulate and judge, and act upon . . . [themselves] in part in the language of biomedicine.” As Rose explains, the increased emphasis on health, biomedicine, and genomics engenders an ethic in which health maximization is privileged. Hence, it might be:

... inevitable that many contemporary biological citizens should now feel that they have acquired rights to the treatment of their sickness and disabilities and that others—politicians, health authorities, doctors—should be held accountable and be required to recompense or compensate them for their conditions.

It is no surprise, therefore, that patients are exploiting Community law in order to derive rights for the treatment of their conditions. Further, the somatic individuality of patients is emphasized in the ECJ’s test for “undue delay” through the use and infiltration of medical knowledge into juridical power, such that national authorities are required to have regard to inter alia “the patient’s medical condition at the time when authorization is sought and, where appropriate, of the degree of pain or the nature of the patient’s disability . . . but also . . . medical history.”

The focus on the body highlights another dimension of patients’ subjectivity: biological citizenship. According to Nikolas Rose and Carl Novas, “biological citizenship” is a term used to describe “all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species.” Biological citizenship signals the importance of governmental

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48 Rose, supra note 18, at 26 (emphasis added).
49 Id. at 25 (emphasis added).
intervention in life, what Foucault denoted “biopower,” in figuring the relationship between the individual and the polity, thereby signifying the multi-faceted, heterogeneous nature of EU citizenship.

Moreover, since power is relational, biological citizenship also signals the active, bottom-up potential for citizens’ engagement. The Community law rights and the practices engendered by and interacting with them, such as civil society actors and governance processes, are taken to be elements of biological citizenship in the EU context. Citizenship’s ability to accommodate new forms and conceptualizations—here, with an emphasis on the EU and the “biological”—is unsurprising, provided one acknowledges that it has many valences, it is not limited to the national level, and that, when re-envisioned at the EU level, it goes beyond a few EC Treaty articles or “market citizenship,” and is instead present in the many ways that the EU engages between the citizen and the Euro-polity in the sphere of the “biological,” as well as the ways in which citizens interact with that engagement. This is not to undermine the relevance of social citizenship, which attempts to enhance substantive equality and repair the injuries wrought to the body politic by economic liberalism. Instead, recast as an element of biological citizenship, and drawing on governmentality, exercise of the Community law rights becomes one form of strategic political action and contestation for reform of the provision of publicly funded health care.

Indeed, besides disciplining and regulating patients and, therefore, as part of EU governmentality, necessarily being part of power’s

53 Trubek, Nance & Hervey, supra note, 7.
54 Cooper, supra note 32, at 168.
56 Cf. Newdick, supra note 3.
58 Ong, supra note 21, at 15 (addressing the importance of the discourse of rights as a strategy in the transnational sphere).
aperture,\(^\text{59}\) the Community law rights also appear to have an emancipatory potential, which is derived in large part from their imbrication with the rhetoric of human rights. The destabilizing effects of litigation can be seen as a way of highlighting the failings of health care systems and the social problems that help generate them.\(^\text{60}\) Rights also generate a feeling and ethic of entitlement. Especially when bearing in mind the dimension of biological citizenship, patients seem to be exploring what Stychin terms the “unruly edge”\(^\text{61}\) of EU citizenship, the potential it has “to mean something more” than the economic end of free movement, an “excess which might be exploitable in the cause of active, democratic citizenship.”\(^\text{62}\) This “something more” seems to be the rhetorical aspect of rights discourse, which is well noted as potentially emancipatory, and is highlighted by Brown when she muses that it is “in their abstraction from the particulars of our lives—and in their figuration of an egalitarian political community—that . . . [rights are] most valuable in the democratic transformation of these particulars.”\(^\text{63}\) Therefore, the Community law rights create an operational and rhetorical opening for the emergence of new types of subjects and new spaces for politics at the EU level.\(^\text{64}\)

One indication of the creation and development of such a discursive space is the change in public discourse demonstrated by the often acute focus of media in highlighting the shortcomings of domestic health care provision and the benefits of going abroad for treatment. This discourse encompasses patient migration to locations outside the EU. Yet, treatment obtained within the EU as a consequence of the right to migrate for health care services gets a special focus, most likely because of the actual or hoped for requirement that the home health care system will pay for the treatment received abroad.\(^\text{65}\)


\(^{60}\) Flear, supra note 1, at 256-257.


\(^{62}\) Id. at 292 (original emphasis).


\(^{64}\) Cf. SASKIA SASSEN, *TERRITORY, AUTHORITY, RIGHTS: FROM MEDIEVAL TO GLOBAL ASSEMBLAGES* 278-79 (2006) (this refers to the dynamics of globalization).

abroad, advanced by the media and Internet (digitization), and the then potential application of the right, created pressure on the UK government to get treatments for patients faster, and to issue new guidelines on sending patients abroad. As Advocate General Geelhoed states in his Opinion in Watts, “[p]atient mobility is also stimulated through the availability of more information... on the possibility of obtaining medical treatment in other countries and through the activities of intermediaries, such as care brokers.”

Clearly, EU and national political elites, the media, and the professional classes control much of the meaning making in advanced industrial societies. They are making use of rights rhetoric and help to underpin the development of the discursive space opened by the Community law rights. Importantly, the EPF and the EPHA, considered more fully very shortly, are also making use of rights rhetoric in their advocacy of various patient centered developments at the EU level. For instance, the EPF’s use of the discursive space is perhaps best emphasized through the following statement:

[EPF] believes that ALL patients, no matter their condition, background or nationality, have a fundamental and legitimate human right of access to information about their health, medical conditions and the availability of treatments including knowledge of the best available management of their disease. It is a question of solidarity, equity and patients’ rights.70

The EPF supports the development of a Patients’ Rights Charter (as well as other efforts to clarify patients’ cross-border rights in the EU), which was stimulated by the Community law rights and finds foundational support in Article 35 of the EU Charter. EPHA has also sup-


66 See generally, McHale, supra note 6, at 278.
ported such efforts. Tamara Hervey and Jean McHale were correct to expect “an increased reference to the rhetoric of rights, in both legislative and judicial contexts, and an increased scope for rights discourse to frame the regulation of health within the EU.”

In addition, reactive practices of biological citizenship have arisen through social movement activism that was, in part, a response to the proposed codification of patients’ Community law free movement rights in the now failed Bolkestein services directive. Such activism represents a strategy of direct action and exploitation of the discursive space through the articulation of opposition to the market’s intrusion into the social sphere, supposedly represented by the involvement of Community law.

This collective action seemed to exhibit the three elements that, when synthesized, typify social movements (1) a campaign against authorities, (2) a social movement repertoire such as use of the Internet, the media, and pamphlets to forward their agenda, and (3) so-called WUNC displays, those that demonstrate worthiness, unity, numbers and commitment. Yet, as this paper suggests, the discursive space is being colonized and the emancipatory edge of the Community law rights is being blunted by EU governance discourse and the neutered actors it creates or catalyses, such as the EPF and the EPHA.

III. EU GOVERNANCE DISCOURSE AND PASSIVE ACTIVISM: THE EXAMPLES OF THE EUROPEAN PATIENTS’ FORUM AND THE EUROPEAN PUBLIC HEALTH ALLIANCE

Both the EPF and the EPHA are examples of the biosocial or collectivizing dimension to patients’ strategic engagement with EU go-

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72 HERVEY & MCHALE, supra note 6, at 410 (emphasis in original).
74 See Spectrezine Weblog, supra note 73; Basketter, supra note 73; Monbiot, supra note 73.
75 CHARLES TILLY, IDENTITIES, BOUNDARIES, AND SOCIAL TIES 216-17 (2005).
vernance and their population of the discursive space. This section begins by describing these actors, after which an overview is provided of their location within EU governance as members of the EU Health Forum (Health Forum). Subsequently, some general points are made about activism within the discourse on civil society involvement in EU governance. After which the examples of the EPF and the EPHA are used to highlight some further problematic elements of that discourse, in particular the production of neutered activism. The EPF and the EPHA are stimulated or fostered by the EU, and are linked to and operate at the EU level, through the Health Forum, which is the main way of integrating these actors into EU governance. The Health Forum provides recommendations for policy making, but does not form part of the formal legislative process.

The EPF and, to a lesser extent, the EPHA are supported by the Internet, which in other contexts is noted as providing an effective medium for non-elites to communicate, particularly in struggles around human rights, the environment, and health issues like AIDS. The Internet potentially facilitates biosociality by supporting the use and development of the discursive space opened by the Community law rights without the necessity of “running through” the EU’s institutions. As Sassen points out, the Internet allows local initiatives to become part of a wider network of activism, “without losing the focus on specific local struggles.” Moreover, “cyberspace is, perhaps ironically, a far more concrete space for social struggles than is the national political system,” making it an “enabling environment” for the emergence of patients as political actors. Whether or not this is so for the EPF and the EPHA remains to be tested. Indeed, use of the Internet might be an elite strategy. Still, since such an assessment lies outside the scope of this paper, it is sufficient to

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79 Sassen, supra note 64, at 373-74. See also DIGITAL FORMATIONS: IT AND NEW ARCHITECTURES IN THE GLOBAL REALM (Robert Latahm & Saskia Sassen eds., 2005).
80 Sassen, supra note 64, at 366.
81 Id. at 373.
82 Id. at 374.
83 Id. at 375.
note the potential importance of the Internet in helping to support activism and resist the neutering effects of EU governance discourse.84

To describe the EPF and the EPHA in turn, the former “is the umbrella group of pan-European patient groups active in the field of European public health and health advocacy.”85 The members encompass NGOs in the area of public health, including patients’ organizations. Other members are organizations representing health professionals and trade unions, representatives of health service providers and health insurance, and industry representatives with a particular health interest. Membership depends upon meeting certain standards on, inter alia, democracy and funding.86 The organization was created through reflexive engagement with the opportunities (and perhaps threats) provided by the EU, and after a call in January 2003 by the “Commission and other EU institutions to have one pan-European patient body to address and consult on issues of interest to patients in the European health care debate.”87

It appears that group interests are being focused, aggregated, and represented88 by integration into Community consultation and legislative processes.89 The EPF pools its members’ resources to work “on horizontal issues affecting all European patients and supports individual members’ initiatives that will benefit the community.”90 As a result, the Community law rights to migrate for treatment are helping to draw new boundaries of solidarity within and among organized interests. This oc-

87 What is the European Patients’ Forum?, supra note 85.
89 Where they are now recognized by the Commission and European Parliament in the European Patients’ Forum. The Forum was created in response to the Commission’s announcement in 2003 that it wanted to deal with one single patients’ group for the whole of the EU. What is the European Patients’ Forum?, supra note 85. The Forum was created in response to the Commission’s announcement in 2003 that it wanted to deal with one single patients’ group for the whole of the EU.
90 Id.
The EPF’s aims are to provide strategic opportunities for engagement with the EU, in particular “to ensure that the EU’s health strategy is open, transparent, and responds to the public concerns. The intention is to provide an opportunity to organize consultations, to exchange views and experience on a wide range of topics, and to assist in implementation and follow-up of specific initiatives.”\(^9\) The EPF is the self-proclaimed “genuine voice of European patient groups,” making it “the point of reference for the European Commission and the European Parliament.”\(^9\) The EPF speaks of being “keen to further collaborate”\(^9\) with institutions such as the Commission and the European Parliament, as well as the European Medicines Agency (EMEA),\(^9\) and the Committee for Medicinal Products for Human Use (CMPHU). The EPF is also keen to collaborate with other “stakeholders in the public health area,”\(^9\) including the Standing Committee of European Doctors and the Standing Committee of European Nurses.

The EPF has apparently influenced patient mobility and accessibility of treatment abroad. For instance, the EPF responded to the Commission’s consultation on health care by emphasizing the importance of receiving high quality health care as close to home and as quickly as possible; but adding that where cross-border health care is used, patient safety needs to be ensured, in particular through the availability of high quality, timely, and accurate information in the patient’s own language. The EPF also highlights the “way forward” by identifying “a policy mix including a legally binding instrument, a political ‘tool’ (e.g., a Patients’ Charter) and robust and effective management systems.”\(^9\) Influence has

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92 What is the European Patients’ Forum?, supra note 85 (emphasis added).

93 Id. (emphasis added).

94 Id.


96 What is the European Patients’ Forum?, supra note 85.

97 Response From the European Patients’ Forum Regarding the EC Consultation on Health Services, http://www.eu-
also been exerted in other issues, such as through sitting on the EMEA/CMPHU working groups, matters related to pharmacovigilance, product information, interaction with patients, and information. In addition, some members have been involved in relevant Commission working groups on patient mobility. The EPF is also embedded in the European Parliament Health and Consumer Intergroup, where it provides the Secretariat of the Group.98

Turning to EPHA, it represents over 100 non-governmental (NGOs) and other not-for-profit organizations, thirty-five of which are pan-European or networks, making it the largest pan-European public health NGO.99 EPHA “aims to promote and protect the health interests of all people living in Europe and to strengthen the dialogue between the EU institutions, citizens, and NGOs in support of healthy public policies.”100 Perhaps more so than the EPF, the EPHA has as a central role in monitoring the impacts of EU policymaking on public health and the creation of awareness amongst EU citizenry and civil society actors of developments in EU governance such as the so-called Open Method of Coordination (OMC).101 All with the aim of helping to promote a contribution by EU citizenry to the policy making process and take practical action to take part in appropriate programs. The EPHA also seeks to support collaboration and partnerships between relevant civil society actors that are active at the European, national, and local levels on health promotion and public health.102 Like the EPF, the EPHA is also involved with the European Parliament, where, with the European Consumers’ Organization,103 it provides secretarial assistance to the Health and Con-

99 EPHA – the Largest Pan-European Public Health NGO, supra note 98.
101 See also Trubek, Nance & Harvey, supra note 7.
sumer Intergroup in the European Parliament,\textsuperscript{104} which is a forum for dis-
cussion between health OMC and Members of the European Parliament
with a special interest in health issues.\textsuperscript{105} The Health Intergroup has been
active since 1994, and the Consumer Intergroup since 1989.\textsuperscript{106} EPHA is
also enmeshed in the EU’s developing network of civil society actors
that deal with health care issues, such as the Social Platform.\textsuperscript{107}

The overview of the location of the EPF and the EPHA within
EU governance focuses on the place of the Health Forum, its central me-
chanism for engagement, after which this article focuses on the discourse
relating to civil society involvement, as presented in the EU’s overall
health strategy, “Together for Health.” Further work needs to be done on
the place of the Health Forum and its representation of civil society within
EU health governance, as well as the role of individual members such as
the EPF and the EPHA within that governance, and the relationship(s)
of non-incorporated social movement activism with that governance.
Analyses of EU health governance\textsuperscript{108} stress its continuing development,
the absence of hard law measures (because of the weakness of current
legal bases for the adoption of legislation through the Common Commu-
nity Method and domestic political opposition), and, therefore, the re-
liance on soft law measures and processes (which perhaps paradoxically
seem to have found some political support).\textsuperscript{109}

In thinking about these regulatory techniques it is important to
begin with the aforementioned strategy,\textsuperscript{110} and then go on to explore pre-
vious EU action. “Together for Health” “puts in place an overarching,
strategic framework for work on health at the EU level, and sets the di-
rection of travel for the coming years. The strategy encompasses work
not only in the health sector but across all policy areas.”\textsuperscript{111} Within the

\textsuperscript{104} Id.
\textsuperscript{105} Id.
\textsuperscript{106} Health and Consumer Intergroup in the European Parliament, About the Health and Consumer
\textsuperscript{107} An umbrella organization for Brussels-based social NGOs almost entirely funded by the Com-
mmission, for more information see Social Platform, http://www.socialplatform.org/ (last visited
Nov. 8, 2008). See also De Israel de Jésus Butler, Non-Governmental Organisation Participation in
the EU Law-Making Process: The Example of Social Non-Governmental Organisations at
the Commission, Parliament and Council, 14 EUR. L. J. 558, 571.
\textsuperscript{108} See references in supra, note 6; Hervey & Vanhercke, supra note 10.
\textsuperscript{109} See generally Hervey & Vanhercke, supra note 10.
\textsuperscript{111} Id.
Health and Consumer Protection Directorate-General (DG SANCO), the strategy is supported by the Commission’s health program. Research funding is provided by DG SANCO and other areas, such as “Framework 6” (preceding “Together for Health”), which funded “Europe for Patients,” and now “Framework 7.” Pursuant to Article 152 of the EC Treaty, health is a horizontal issue that must be taken into account in all policy areas. In terms of cooperation between Member States, there is also a High Level Committee on Health, an informal body composed of senior officials from Member States and candidate states, which advises the Commission.

The Commission also engaged ministers from the Member States and representatives of civil society to participate in a “high-level process of reflection (HLPR) on patient mobility and health care developments in the European Union.” The process resulted in a report agreed to at a final meeting on December 8, 2003. According to the Commission, this “represent[ed] a [political] milestone by recognizing [sic] the potential value of European cooperation in helping Member States to achieve their health objectives.”

This process fed into the adoption of a Communication on patient mobility and health care developments in the EU. The Communication provided for the establishment of a High Level Group on Health Services and Medical Care in order to take forward the work identified in the Communication. The High Level Group commenced its work in July 2004. The Group is comprised of experts from all twenty-seven Member States. The group provides the means for “persuasive con-
vergence” of national law and policies.118 There are also ongoing efforts to bring about Community action on health care, in order to clarify the application of Community law in practice.119

The Commission launched a public consultation on what action is necessary.120 Both the EPF and the EPHA provided responses to the consultation.121 In addition, a health and long term care strand of the streamlined OMC on social protection and social inclusion has been developed. The Health Forum is literally mentioned at the bottom of the web page on “Together for Health.” The Health Forum “serves as an information and consultation mechanism to ensure that the aims of the Community’s health strategy are made clear to the public and respond to their concerns,” and:

[Pro]vides an opportunity to representative organizations of patients, health professionals, and other stakeholders, such as health service providers, to make contributions to health policy development, its implementation and the setting of priorities for action.122

The Health Forum is comprised of two “complementary elements”123 (1) an Open Forum acting as “a platform for general exchange of information and for a discussion with a broader range of groups and interested parties”124 and (2) the Health Policy Forum, comprised of a “consistent set of member organizations, for the discussion of key policy areas.”125

118 Hervey & Vanhercke, supra note 10.
123 Id.
125 EU Health Forum, supra note 122.
Having sketched the location of the EPF and the EPHA within EU governance, some general points can be made about the discourse on civil society involvement (focusing on the rationales at play and extracting lessons from “European Governance”), and then use the examples of the EPF and the EPHA to highlight some further problematic elements of that discourse, in particular the neutered activism produced. The article does not suggest that EU governmentality represents formal policy, since power’s operation is often automatic rather than intentional; instead, the objective of this paper is to interrogate EU health governance discourse in order to reveal its technologies, rationalities, and problematic aspects, thereby rendering it more transparent to those it governs.

To begin with, although neither the Forum nor the EPF and the EPHA are mentioned in “Together for Health” explicitly, the Health Forum in particular, and indirectly the EPF and the EPHA as two of its members, are clearly implicated. Interestingly, this occurs through the discourse of human rights. The document makes references to this discourse, in particular the EU Charter, which it then uses to highlight the importance of citizen “participation in and influence on decision making.” This provides the most immediate frame for the relations between the EU system of governance and civil society actors. It should, of course, also be noted that the involvement of such actors is also due to the emphasis given in “European Governance,“ which referred to civil society involvement and problematized it as a means of enhancing input legitimacy for more effective outputs, and so constitutes a wider frame, creating a degree of path dependency for EU governance practice in “Together for Health.” Of course, Giandomenico Majone, in particular, has stressed the importance of technocratic governance and depoliticization in the EU’s regulatory process. According to Majone, only effective administrative procedures are required in order to ensure accountability.

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126 Together for Health, supra note 13, at 4.
127 Id.
and legitimacy.\textsuperscript{129} Human rights now imbricate concerns about democratic inputs and they help to legitimate governance outputs.\textsuperscript{130} As such, human rights are perhaps put at the service of EU governance as an additional rationale for civil society involvement. Patient NGOs like the EPF and the EPHA are clearly seen as points of contact or conduits through which patients interact more directly with the EU’s system of governance. Indeed, both the EPF and the EPHA receive funding from the EU under the Commission programs in support of active citizenship.\textsuperscript{131} This demonstrates the way in which EU governance discourse colonizes human rights discourse and then deploys it in order to supposedly enhance the effectiveness and legitimacy of governance.

The rationalities of EU health governance are revealed by interrogating what it problematizes. For instance, there is reference in “Together for Health” to the risks, challenges, and opportunities provided by the Internal Market in health care services.\textsuperscript{132} This constitutive outside depoliticizes, naturalizes, and enhances the case for EU involvement and agency and reveals some of its rationales. There is not merely rationality of optimization, but also of normalization found in technologies that create, classify, and seek to control anomalies in the social body, that is, those arising from the operation of the free movement of patients, such as unpredictable or too much outflow of patients from health care systems. EU governance here is biopower, and it is supposed to isolate these anomalies and then normalize, to quote Paul Rabinow, “through corrective or therapeutic procedures.”\textsuperscript{133} These are “determined by other

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\textsuperscript{130} Governance outputs has been the subject of renewed focus under the Lisbon Agenda, which aims to make the EU more competitive. See European Commission, Lisbon Strategy Key Documents, http://ec.europa.eu/growthandjobs/key/index_en.htm (last visited Nov. 9, 2008). See generally, European Commission, Citizenship, http://ec.europa.eu/citizenship/action2/measure2_en.html (last visited Nov 9, 2008).

\textsuperscript{132} See generally, \textit{Together for Health}, supra note 13. The internal market is defined by Article 14(2), European Community Treaty as “an area without internal frontiers in which the free movement of goods, persons, services and capital is ensured in accordance with the provisions of this Treaty.” The internal market is the Community’s central project and the basis of further integration. For a summary of the risks, see HERVEY & MCHALE, supra note 6, at 138-144.

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related technologies,”134 in EU governance through, for instance, the reporting procedures for the identification and dissemination of best practice in the OMC, and attempts to generate EU governance responses to the free movement of patients.

EU funded research supports these attempts to correct anomalies in the social body.135 Thus, “Europe for Patients,” the development of which was prompted by cases creating the Community law rights, involves leading researchers on health care systems,136 and is beginning:137

[T]o contribute scientific evidence that will enable policy makers at EU and national level to take concerted and coordinated action to allow Europe’s citizens/patients to benefit from enhanced mobility in Europe.138

The research results will “achieve/contribute” to the:

[F]ormulation of advice on how to overcome obstacles to creating policies on patient mobility that benefit patients and health authorities—through actions at different levels (regional, national, [and crucially] European) employing (interestingly) legal, organizational and regulatory approaches.139

Such developing approaches utilize, derive their force, and so are underpinned and legitimized by the gathering, selection, normalization,
and centralization of knowledge and the valorization of science. Put
simply, this is governance by and through knowledge. As with the
Community law rights, the operation of power/knowledge through the
legal, organizational, and regulatory approaches will doubtless discipline
and regulate. As Foucault points out, “power and knowledge directly
imply one another . . . there is no power relation without the correlative
constitution of a field of knowledge, nor any knowledge that does not
presuppose and constitute at the same time power relations.” 140 Moreover,
it is in discourse that “power and knowledge are joined together.”141

Yet since power is double-edged, EU funded research and the
discourse it produces might also enhance awareness, aggregate interests,
and strengthen the arguments made by individual patients and their collectivities, such as the EPF and the EPHA, in dealing with EU health governance and, most importantly, its health care systems. In other words, EU funded research might also enhance the agency of the EPF and the EPHA, as well as their legitimacy as sites of engagement with EU governance. While both have made strategic use of Community law rights discourse, there are indications that EU funded research is furnishing them with further resources, with implications for their relations with other civil society actors and EU governance, as will be discussed further shortly.

As expected, the problematic and rationality of legitimacy is also particularly prominent. The article notes above how Community law rights freight individual patients with agency and responsibility. So too does the neoliberal discourse imbricating and colonizing rights discourse. Litigation under Community law and other forms of EU level stimulation of civil society activity in health governance represent subtle technologies and rationalities of power to create, orchestrate, and organize individual and especially collective agency. Mitchell Dean explains how these technologies attempt “to engage us as active and free citizens, as informed and responsible consumers, as members of self-managing communities and organizations, as actors in democratizing social movements, and as agents capable of taking control of our own risks.” 142 This self-government and agency is reinforced by the rationality of legitimacy when it stresses the importance of involvement and consultation of citizens.

140 FOUCAULT, DISCIPLINE, supra note 23, at 27.
141 FOUCAULT, HISTORY OF SEXUALITY, supra note 23, at 100.
142 WALTERS & HAAHR, supra note 21, at 75.
However, as will be explained, the rationality of legitimacy limits this agency to entrepreneurialism and the focus remains on generating outputs for legitimating EU health governance, with input from patients constructed as limited. The EU uses various discourses that are otherwise not usually seen as related to power and governance. The use of scientific discourse and researchers (including academics) in particular (and as also exemplified in the use of medical discourse in the jurisprudence) creates a field for consideration of, and also often reinforces the arguments for, EU interventions. Thus, as Brown notes, speaking of governmentality more generally, it “draws upon without unifying, centralizing, or rendering systematic or even consistent, a range of powers and knowledges dispersed across modern societies.”

Further general points about the scope for and texturing of activism by EU governance discourse can be made by reference to comments on the White Paper entitled “European Governance,” since this frames the strategy for civil society involvement in “Together for Health.” In relation to “European Governance,” William Walters and Jens Hendrik Haahr note how there is an emphasis on openness and transparency, but:

[In the same breath this document calls for strengthening of involvement. Reforms are called for which will facilitate the participation of citizens, organizations of “civil society” . . . in the processes of European policy formulation and implementation. These reforms include the provision of up-to-date, online information on the state of policies as they process through different decision making stages; and the establishment and publication of minimum standards for consultation on EU policy . . .]

Walter and Haahr highlight how techniques for enhancing consultation and strengthened involvement of citizens and “civil society” are technologies of agency (about which more is said shortly) that point to public rationality. However, the stress on involvement and consultation initiated in “European Governance:”

[Appears not as much as the result of a quest to establish a firmer basis of information and argumentation for policies, as of a desire to increase popular support and understanding for these policies. Involvement and consultation appear as educational initiatives rather than as instruments for the pursuit and testing of valid arguments.]

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143 Brown, Power, supra note 21 at 74.
144 WALTERS & HAAHR, supra note 21, at 76.
145 Id. at 83 (emphasis added).
In support of this point, Walter and Haahr note how, as the Commission states, the point of improved participation is that it is likely to engender greater confidence in governance outputs and, therefore, in the system of governance and the institutions that dominate it. In other words, the point of increased participation is “not that improved participation will provide a more convincing and therefore a more rational basis for policy.”

The same point was made in “Together for Health:”

[A] core value is Citizens’ Empowerment. Health care is becoming increasingly patient centered and individualized, with the patient becoming an active subject rather than a mere object of health care. Building on the work on the Citizen’s Agenda, Community health policy must take citizens’ and patients’ rights as a key starting point. This includes participation in and influence on decision making...

On the central mechanism for potential activism, the Health Policy Forum’s purpose is:

[T]o bring together umbrella organizations representing stakeholders in the health sector to ensure that the EU’s health strategy is open, transparent and responds to the public concerns. The intention is to provide an opportunity to organize consultations, to exchange views and experience on a wide range of topics, and to assist in implementation and follow-up of specific initiatives.

Similarly, the Open Forum’s main activity seems to be that of:

[A]n annual conference and exhibition event. The objective of the Open Forum is to provide a platform for networking and exchange of ideas and views of different stakeholders of the European health community (health professionals’ organizations, public health NGOs, patient groups, and service providers and funders).

So, although the active patient is emphasized in “Together for Health” (a point that will be returned to shortly), the central mechanism for activism reveals a continuation of the public rationality inaugurated in “European Governance,” in which references to involvement and con-

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146 Id. (emphasis added).
147 Together for Health, supra note 13, at 4 (original emphasis for ‘Citizens’ Empowerment’, otherwise emphasis added).
149 Open Forum 2005, supra note 122 (emphasis added).
sultation do not guarantee a genuine and truly open and rigorous discussion with those members of civil society who are involved and consulted. The EPHA itself highlights how EU governance, such as through the HLPR in 2003, has hitherto not promoted participation by patients and their groups since it was “confidential and lacking [in] transparency.” This does not bode well for the strategy adopted in “Together for Health,” particularly given the dearth of details for what involvement and consultation with patients’ groups will entail and how it will be carried out.

All this is hardly surprising. In a reflection on the governance debate Stijn Smismans notes how the main focus in “European Governance,” and, as suggested, in “Together for Health,” “is not direct citizen participation but functional representation, i.e., representation via associations and interest groups. The language is one of civil society . . . concerned interests, interested parties, and stakeholders.” Participation of these actors is about “contributing to EU legitimacy but not defined as a contribution to more active citizenship.” Thus, as Walters and Haahr explain, this rationality “at least partially emerges in a paternalistic version.” This is because:

\[\text{Involvement is not first and foremost a vehicle for the achievement of rational agreement on the basis of the free and equal exchange of arguments oriented towards understanding. It is more a vehicle for persuasion, for rhetorical action in which the point is to convince the objects of rhetoric of certain given beliefs, preferences and identities.}\]

This point is only reemphasized below, when the implications of the norm of expertise are considered further, and it is queried how much influence the EPF and the EPHA might have when faced with those who have traditionally been privileged in the Community system of govern-

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\[\text{150 Cf. Nancy Fraser, Transnationalizing the Public Sphere: On the Legitimacy and Efficacy of Public Opinion in a PostWestphalian World, in IDENTITIES, AFFILIATIONS AND ALLEGIANCES 45, 60-66 (Seyla Benhabib, Ian Shapiro & Danilo Petranovic eds., 2007) (discussing political legitimacy and the concept of shared citizenship in the Westphalian and postWestphalian era).}\]

\[\text{151 European Public Health Alliance, Patient Mobility Report Published-December 2003, http://www.epha.org/a/964?var_recherche=kohll (last visited Nov. 9, 2008) OR ALTERNATIVELY}\]

\[\text{See EUROPEAN PUBLIC HEALTH ALLIANCE, PATIENT MOBILITY REPORT PUBLISHED (2002), http://www.epha.org/a/964?var_recherche=kohll.}\]


\[\text{153 Walters & Haahr, supra note 21, at 83 (emphasis added).}\]
nance, such as Commission officials and experts. There is clearly a lot to unpack about civil society involvement in EU health governance. For instance, the stakeholders involved and sometimes sponsored by the Commission (such as state actors, professionals, and patients), their roles, and relative positions. Yet, instead of providing an empirical analysis of such issues, this article focuses on the discourse shaping, organizing, and conditioning civil society involvement and actors’ positioning within EU governance as an effect of the norm of expertise.

Having made some general points, this paper now moves to the examples of the EPF and the EPHA, in order to critique and extract some further problematic elements of EU health governance discourse for activism. A first point is that the EU, in fostering civil society engagement with its system of governance through techniques of governing, such as providing funding and putting out “calls” for the aggregation of national level organizations into EU umbrella organizations, is populating and texturing the discursive space opened by Community law rights. This creates a field of power/knowledge and new frameworks for thought and action in a process of exchange and dialogue. Public power seeps into civil society, which becomes a target of EU governance.

Second, the dialogue is developing a new relationship between civil society and the EU’s system of governance in the area of health. The dialogue signals the colonization of the emancipatory and democratizing potential of human rights discourse by depoliticizing governance discourse. This colonization also signals the growing importance of neoliberal political rationalities of optimization in the governance of health, which has otherwise tended to rely on welfare discourse and rationalities, particularly at the national level. The neoliberal rationalities find their most prominent articulation through EU governmental technologies for selecting civil society actors with which to engage, requirements for “professionalism,” which squeeze out groups that are deemed unprofessional, and which are perhaps less well-resourced and organized collec-

154 Special thanks are due here to Jean McHale for suggestions and to John Morison for further inspiration.

155 Cf. Tamara K. Hervey, EU Governance of Health Care and the Welfare Modernization Agenda, 2 REG & GOVERNANCE 103 (2008)(discusses how new governance processes are being used by both EU member states and the EU to help promote efficiency in health care policy).

tivities, as well as others that determine the role and activities of those actors “embedded” in EU governance as about involvement and consultation. In other words, EU governmentality is mobilizing, organizing, selecting, and conditioning civil society actors through knowledges and techniques that regulate the conduct of their conduct.

For instance, the EPF and the EPHA highlight how the organization of actors stimulated and required by EU governance creates two different types of patient groups: those that are “officially” recognized and/or established and encouraged by the EU and those who are not. Social movements, while not of the same kind as patient groups, are nascent forms of social activism, and, as this paper would suggest, have much in common with the second type of patient groups in that they too are not recognized. Recognition is important because the privileging of the EPF and the EPHA creates a hierarchy of access levels to the actors and structures of EU governance. Further, the EPF, for instance, seeks to enhance its representativeness and legitimacy by contrasting itself with unnamed “others,” “groups who tended to express patients’ views without prior consultation with the interested parties.”

The EPF “also provides support to patient groups from the new EU Member States through education, empowerment, and training,” as well as seeking to exchange best practice on “Strengthening Patient Groups in the EU.” This highlights the hierarchy between more and less included groups, and indeed highlights a hierarchy of expertise, with the EPF seeking to forward an epistemic advantage vis-à-vis less “included” actors. This hierarchy of civil society actors is likely to generate different dialogues between “recognized” or “official” civil society actors and actors and structures of EU governance and groups or movements without such recognition. EU generation of power/knowledge through the research it funds is also important because although it is widely accessible and might be used by individuals, it is the EPF and the EPHA that have the greatest access to the system of governance and source of knowledge. The EPF and the EPHA’s proximity to this source can only enhance their position vis-à-vis non-included actors, especially in light of the “outreach” projects it undertakes with non-included groups.

157 See New Governance, supra note 152.
158 What is the European Patients’ Forum?, supra note 85.
159 Id.
Third, we must question how effective “recognized” or “official” civil society actors actually are when they engage with EU governance actors and structures. “Together for Health” highlights the importance of getting various stakeholders involved in EU governance, not just patients (represented by the EPF), but also others, such as providers and funders (represented by the EPHA, which also represents patients). EU discourse configures power/knowledge relations between actors because it valorizes and privileges science and professionalized expertise over other knowledges, such as day-to-day dealings with illness. As Foucault observes these latter “subjugated knowledges” have been “disqualified as non-conceptual knowledges: as insufficiently elaborated knowledges, naive knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity.”\(^{161}\) The point of this observation is not to query the content or methods of science or other forms of expertise privileged in EU governance, but rather to highlight the power effects of establishing expertise, particular that of science, as the norm and truth.

One effect is that the EPF and the EPHA might be better termed “lay members” of EU governance structures since they are not selected for involvement by virtue of some sort of scientific expertise. Indeed, in light of the privileging of expert and scientific knowledges in the discourse, and the way in which such knowledges operate as truth, depoliticizing debate, it is to be questioned how much influence the EPF and the EPHA have, compared to health care professionals, representatives of national government, and Commission officials, those who have traditionally wielded power in EU governance and who have an epistemic advantage. “Voice” does not guarantee influence, since others might not listen or take the input seriously, or the input might be implicitly disqualified or downgraded as failing adequately to meet the norm of expertise. Consequently, the dialogue between the EPF and the EPHA on the one hand and the experts entrenched in EU governance on the other, is likely to be limited and undermined. This is quite unlike the discursive democ-

\(^{161}\) FOUCAULT, SOCIETY, supra note 21, at 7 (emphasis added).
racy theorized by Habermas and noted as a prescriptive and descriptive model for EU governance. In this regard, Joerges notes how the:

[A]uthority of expertise threatens the realm of practical reasoning, the claim to equal participation by all concerned in decision making, and the accountability of elected political representatives to their constituencies . . . Laymen and experts might have comparable intelligence and virtue, but they boast different types of knowledge. The expert’s knowledge cannot simply be substituted or ‘overruled’ by the problem perceptions and preferences of the layman.

Clearly, patients require a strategy to tackle the power-effects of expertise if they are to be truly active. This article suggests a strategy in the final section of this paper, but for now the point is to highlight the effects. Consonant with this point, Tamara Hervey and Bart Vanhercke highlight the importance of the Commission’s expertise in organizing EU governance. The Commission has managed to set the terms of the EU health governance debate, particularly in relation to so-called “soft” processes on patient mobility and the OMC, by building on its epistemic advantage as initiator of “hard” Community legislation. In a form of “path dependency” it appears the Commission’s hegemony and independent agency as the lynch pin of Community law and policymaking is not undermined by governance talk of participation, involvement and consultation of civil society. Yet, as noted above, the EPF and the EPHA also have access to EU funded research results, which renders it amenable to exploitation by them in acting against the power effects of other actors’ expertise, reinforcing the hierarchy vis-à-vis non-included patients’ groups.

Although there is scope for the EPF and the EPHA to challenge expertise, a fourth point can be made querying their representativeness of patients in the first place. Since the EPHA represents several constituen-
cies, and not just patients, it is questionable how effectively patients’ are represented. The EPF in particular makes a point about being “truly representative of European patient associations” since it “reaches the grassroots of the European patient associations and thus represents the views of an estimated 150 millions of European patients across the twenty-seven Member States, disregarding their disease, social status, or gender.” As Smismans points out, the involvement of civil society does not necessarily mean European integration will become more inclusive.

Participation in the EPF, the EPHA and, to a lesser extent, social movement activism, presupposes and requires that individuals are willing and able to participate. The discursive space for active citizenship presupposes and requires citizen awareness of health care needs and their entitlements. Patients’ ability to assert those entitlements is also important. It is usually those with the time and money to participate (i.e., older people from the middle classes) who are able to make use of rights and rights rhetoric, and who participate in actors like the EPF and the EPHA.

Indeed, as Smismans notes, theories of collective action point to the difficulties involved for the “excluded” or “weakest” to organize even at the local and national levels. A fortiori the problems can only be magnified when organizing at the EU level, where distance between the center and membership is notably exacerbated. Determining whether or not this is actually the case for the EPF and the EPHA is beyond the scope of this paper, but it is worth noting Alex Warleigh’s evidence that individual members or supporters of NGOs are not allowed to engage directly with policymaking. The NGOs also provide few or no means through which individual members or supporters can get actively engaged, whether through opportunities for learning or influence. Others point to the under representation of groups from Eastern and Southern

167 What is the European Patients’ Forum?, supra note 85.
169 European Civil Society, supra note 168, at 491.
Member States. A rejoinder to this point might be that, as the EPF asserts, efforts are made, for instance, to ensure those who are unable to articulate their claims because of their medical condition have an opportunity to do so through their caretakers. Yet, it is to be questioned whether and to what extent caretakers are able to speak for those with little or no voice, especially where the caretakers’ own views and interpretations mediate the slightest articulations.

Furthermore, the Internet and other modern communications might mitigate the problems of distance. Indeed, as noted above, digitization is recognized for its ability to facilitate aggregation and organization of interests, although as noted above, the extent to which this is the case in EU health governance remains to be seen. The discourse of participation in EU governance remains problematic. Heterogeneity of patient experiences seems to be overlooked. Equality of agency between patients is often assumed. The conditions that might shape and undermine their agency, in addition to the sources of inequality that might undermine their ability to articulate and participate in civil society, seem to be disregarded. Sources of inequality, differences in experiences, and consequent disparities in agency imply that civil society actors and processes are of varying strategic importance for differently situated patients in articulating their particular claims.

As a connected point, the selection and vetting processes for members of the EPF are particularly interesting, because of the influence of capital (industry), which raises the question of whether the EPF is always representing patients’ interests, or whether capital’s interests sometimes take precedence. The EPHA’s membership apparently does not raise similar concerns. Medical treatments implicate biovalue, which is exploitable, for instance, by pharmaceutical companies. According to Health Action International, pharmaceutical companies sometimes use patients to lobby health authorities for their products, sometimes providing the funding and assisting organization. Such companies are, by the EPF’s own admission, funding its members. In this way, corporate interests might be able to “capture” civil society actors and, through their

171 Greer, Mobilizing Bias, supra note 5, at 416-17.
172 What is the European Patients’ Forum?, supra note 85.
input into decision making, exert further influence on EU regulators. This is problematic for the ways in which it might, for example, generate supplier induced demand, raise health care costs, and misdirect resources.\textsuperscript{175} As a result, collective actors might be stimulated by human rights discourse, but their actual activities are controlled by forces circulating around the sites of interaction with the national and EU levels, here, those arising out of capital.\textsuperscript{176}

This leads to a fifth closely connected point about the developing subjectivities of biocitizens. Just as it was pointed out in relation to the subjectivities of biocitizens as bearers of Community law rights, the depoliticizing discourses of liberalism, optimization, the market, and especially neoliberalism that imbricate EU governance discourse undermine the scope for activism, in part because of the sort of agency that is envisaged. Within EU governance discourse biocitizenship entails a limited form of activism in which the citizen acts as an entrepreneurial actor, as highlighted by Trubek et al.\textsuperscript{177} This article argues that this weakens the body politic, which is constituted by actors who are the converse of publicly minded. This subjectivity is only reinforced by the public rationality that was traced earlier in this section. Public rationality also links to expert rationality. For, if the public’s role in EU health governance is limited, and the norm of expertise is established, there arises the matter of highlighting the experts who are privileged and dominate EU governance discourse, and the subjectivities this norm creates or reinforces. As Walter and Haahr explain, expert rationality assumes a subject with preferences, desires and wishes that need to be addressed by expertise. However, this “is not . . . a subject who requires convincing, who has a desire to understand.” Having much in common with public rationality, the relationship between this expert rationality and the subjectivities it establishes is paternalistic:

\begin{quote}
[A] relation where expertise applies its capacities towards the fulfillment of certain needs which are presumed to be important for citizens, producers, or consumers, but where these subjects are at the same time implicitly constructed as incapable of understanding, unin-
\end{quote}


\textsuperscript{176} See ONG, \textit{supra} note 21, at 195-219.

\textsuperscript{177} Trubek, Nance & Hervey, \textit{supra} note 7; \textit{The Changing World of European Health Lobbies, supra} note 5. See also Flear, \textit{supra} note 1, (for norm entrepreneurs and more from the Europeanization literature). \textit{Cf. Mobilizing Bias in Europe, supra} note 5 (discussing the role of different interest groups in the EU).
Sixth, the foregoing analysis of the discourse reveals how the role of the EPF and the EPHA within the Health Forum, and EU governance more widely, through other public consultations—such as after the ECJ’s jurisprudence on the Community law rights (through, for instance, the electronic reflection process in 2004 on the Commission’s new EU health strategy)—are partly used as a Commission tool to legitimize further initiatives in health governance. Consonant with the analysis in this paper, Hervey and Vanhercke note how these consultations help to depoliticize debates, keeping issues “under the radar,” partly as a consequence of a sense of ownership amongst stakeholders generated by their involvement. Hervey and Vanhercke use the example of the Pharmaceutical Forum and pharmaceutical governance, in which the involvement of various stakeholders assisted speedy progress of issues that had previously been rejected in the Pharmaceutical Review, which, as the name suggests, involved a review of EU governance of the regulation of pharmaceuticals. Hervey and Vanhercke also identify a key problem with the EU’s developing governance of health, with repercussions for activism. The OMC is becoming central to the development of EU health governance, but it remains largely closed off to civil society interests at the EU level. Membership is comprised of high-level civil servants, EU officials, and experts. This provides another example of civil society actors being encouraged, selected, organized, and conditioned by EU health governance. Civil society involvement helps to provide the image of input legitimacy for EU health governance, thereby abetting the dispersal and operation of neoliberal rationalities. This “governing through freedom” represents the expansion of governing by and for the EU, which, paradoxically, is made possible by the nominally emancipatory discursive space leveraged open by Community law rights.

178 WALTERS & HAAHR, supra note 21, at 83.
179 Hervey & Vanhercke, supra note 10.
180 Id.
CONCLUSION: TOWARDS A STRATEGY FOR RENEWING ACTIVISM

This paper explored the potential for active European biological citizenship in the discursive space opened by Community law rights to treatment abroad in some circumstances to suggest that EU health governance discourse undermines activism. It has been suggested in this article that the Community law rights might be exploited by patients. They might use the rhetoric of human rights and health to challenge and democratize the provision of publicly funded health care in the Member States. In addition, this article also analyzed the few key representative examples of the discourse on civil society in the health arena and used the examples of the EPF and the EPHA to suggest that the discursive space opened by Community law rights is being colonized by EU governance discourse to foster a neutered or passive form of activism.

A governmentality perspective reveals how the active biological citizenship being fostered by the EU is the contrary of what it says it wants: a basis for generating input legitimacy. Analysis of the discourse of EU health governance reveals the input as tokenistic, a fig leaf that hardly belies the continued absence of a deeper input by citizens, as well as the EU’s failure to use and engage in discourse and democratic practices that truly take its subjects seriously as participants in governance, rather than mere targets. While the EU has sought to foster civil society, its governance discourse produces entrepreneurs and eviscerates the public sphere, and therefore undermines the capacity to build a basis in society that is capable of generating substantial input legitimacy.

Nevertheless, there is always, as Foucault stresses, the potential for individual and collective actors in civil society to shape EU governmentality through their very engagement, such as in the case of cancer noted elsewhere in this collection. While it appears that patient activists have been fairly active in initiating interaction with EU governance in cancer, patient activists seem to be more reactive in the newer context of the discursive space opened by the Community law rights to receive treatment abroad. This only affirms their passivity in practice. Yet,

182 See Mobilizing Bias in Europe, supra note 5; The Changing World of European Health Lobby, supra note 5.
cancer activists are noted as behaving like entrepreneurs, which of course affirms the organizing potential of neo-liberal EU governance discourse, with all that implies about the neutering of activism.

How might patients challenge their construction and limitation as entrepreneurs to become more truly active biocitizens? A discursive strategy could involve renewed exploitation of the rhetorical aspect of human rights as well as use of the notion of participation underpinning republican citizenship discourse.\textsuperscript{183} In deploying these discursive strategies individual and collective activists must actively \textit{sic} and continually discern and work against the way(s) in which human rights and other aspects of EU governance regulate the conduct of their conduct and undermine their activism. In particular, activists must seek to enhance their representation through actors like the EPF and the EPHA. Yet, being wary of the potential for elite disengagement and depoliticization in the latter, activists must also seek to engage with actors throughout the network of relations constituting EU health governance. Activists must also work against the power effects of expertise in EU governance discourse (and, for that matter, within collectivities like the EPF and the EPHA), and they might productively do so through critical observation and a quest for counter-expertise.\textsuperscript{184} These can be used to highlight \textit{inter alia} occasions when experts are “captured” by powerful economic interests, a lack of reflection, the \textit{lacunae} of knowledge, and ever present normative and ethical issues.\textsuperscript{185} This paper is a contribution towards enhancing awareness and transparency of EU health governance, rendering it more transparent and amenable to proactive engagement by patients, should they deem it necessary, and wish to engage with and seek to change it.

\textsuperscript{183} In a different vein, constitutionalism might be seen as a discourse that has strategic potential for activism. \textit{See} Oliver Gerstenberg, \textit{Expanding the Constitution Beyond the Court: The Case of Euro-Constitutionalism}, 8 EUR. L. J. 172 (2002). However, its structuring and neutering of civil society might be deemed too strong. \textit{See} Emilios Christodoulidis, \textit{Constitutional Irresolution: Law and the Framing of Civil Society}, 9 EUR. L. J. 401 (2003).

\textsuperscript{184} E.g., DIPEx Charity, \textit{http://www.dipex.org.uk/} (last visited Mar. 9, 2009).

\textsuperscript{185} Joerges, \textit{supra} note 164, at 24.