

A Human Rights Perspective on Citizen Participation in the EU's Governance of New Technologies

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This article considers the EU's approach to citizen participation in the governance of new technologies from a human rights perspective. Noting that there is a dearth of insight on the interplay between citizen participation and human rights, the article sketches the essence of its own human rights perspective as being about empowerment. This perspective is brought to bear on EU discourse on citizen participation in the governance of new technologies. Analysis of the discourse—comprising law, citizen participation in EU governance and citizen/science relations, the 'public understanding of science and technology', risk and bioethics—reveals a disempowering 'deficit model' of citizens in need of education through their participation in governance. The analysis thus suggests that citizen participation in EU governance of new technologies is not truly informed by human rights, but is instead used as a legitimating technique.

1. Introduction

Human rights is the most emancipatory of the three broad ideological perspectives comprising the 'bioethical triangle' that governs new technologies. Apart from human rights, the 'bioethical triangle' is comprised of a largely restrictive, disempowering dignitarian ethic and a pragmatic, utilitarian one.¹ Each of the

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1 See, for example, Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies', in Murphy (ed), *New Technologies and Human Rights* (Oxford: Oxford University Press, 2009).

three has its own figuration of key terms, or ‘bioethical floaters’;² in the area of new technologies—such as harm, consent, precaution and, most relevantly for this article, ‘citizen participation’. The growth of new technologies has been accompanied by competition for regulatory relevance between the triangle’s three perspectives. The dignitarian approach in particular has been gaining traction as a way of coping with fears that science and technology are racing ahead of law and morality, ‘stripping out’ human dignity in the process. At the same time, there has been a considerable degree of conceptual and ideological vagueness *vis-à-vis* each of the three perspectives. So much so that dignitarians have, on occasions, appropriated ‘human rights’ to shore up age-old paternalism, undermining some of the hard-won rights, such as women’s reproductive choice, under the pretext of protecting their human rights.³

The human rights perspective in the ‘bioethical triangle’ thus lacks clear-cut boundaries—an uncertainty which is currently being explored by the burgeoning literature linking human rights to new technologies.⁴ This linkage raises the question: can citizens use human rights to connect with and help shape new technologies?⁵ Furthermore, what are the main challenges to using human rights in this way and how might they be addressed? What is quite clear though is that human rights helps to combat popular fears that new technologies move at a pace that law and morality find hard to match (the so-called problem of connection⁶ or of ‘the new’).⁷ Thankfully, human rights have helped to dispel this problem: law and morality eventually do catch up and contain science and technology because individuals, communities and institutions find new ways of connecting law and morality to these things.⁸

2 Ibid.

3 Murphy, ‘Taking Revolutions Seriously: Rights, Risk and New Technologies’, (2009) 16 *Maastricht Journal of European and Comparative Law* 15.

4 See, for example, Murphy, *supra* n. 1.

5 Cf. the questions raised in Jasanoff, ‘Biotechnology and Empire: The Global Power of Seeds and Science’, (2006) 21 *OSIRIS* 273 at 275.

6 Brownsword, ‘So What Does the World Need Now? Reflections on Regulating Technologies’, in Brownsword and Yeung (eds), *Regulating Technologies: Legal Futures, Regulatory Frames and Technological Fixes* (Oxford: Hart Publishing, 2008) at 26.

7 *Supra* n. 3.

8 For instance, the ‘geneticisation’ of rights reworks human rights enshrined in treaty or customary international law, giving us the ‘right to genetic identity’, the ‘right to genetic privacy’ and the ‘right to genetic confidentiality’: see Boussard, ‘Individual Human Rights in Genetic Research: Blurring the Line between Collective and Individual Interests’, in Murphy (ed), *supra* n. 1 at 6.

This possibility and practice is brought out by references to the 'politics of life itself',⁹ 'moral pioneers',¹⁰ 'genetic citizenship'¹¹ or 'biocitizenship'.¹²

Yet when it comes to 'citizen participation' in the governance of new technologies, there is not much guidance as to what a human rights perspective might mean.¹³ At the same time, ensuring the legitimacy and accountability of the governance of new technologies through citizen participation has been a hot topic in recent years.¹⁴ According to Jasanoff, citizen participation amounts to a 'technology of humility' in that it can contribute towards the governance or regulation of new technologies through framing, vulnerability, distribution and learning, and is therefore a practice that can help us to avoid 'hubris'¹⁵ through excessive reliance on science in areas of uncertainty. The proliferation of sites, spaces and fora at national, regional and international levels aimed at fostering citizen participation in the governance of science and technology demonstrates the increasing salience of citizen participation for enhancing accountability and legitimacy. In the European Union (EU), citizen participation in that governance forms part of a more general concern about tackling the 'democratic deficit' through measures that are aimed at reducing the distance between governance and citizens.¹⁶ This has prompted Jasanoff to highlight the EU as a site of great hope for the democratisation of the increasingly globalised governance of life by and through science and technology.¹⁷

9 Rose, *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the 21st Century* (Oxford: Princeton University Press, 2007). Cf. Webster, *Health, Technology and Society: A Sociological Critique* (Basingstoke: Palgrave Macmillan, 2007).

10 Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (London: Routledge, 2000).

11 Heath, Rapp and Taussig, 'Genetic Citizenship', in Night and Vincent (eds), *A Companion to the Anthropology of Politics* (Oxford: Blackwell, 2004).

12 Rose and Novas, 'Biological Citizenship', in Ong and Collier (eds), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems* (Oxford: Blackwell, 2005).

13 A similar point has been made in respect of citizen participation vis-à-vis a rights-based approach to health in, for example, Murphy, 'Technology, Tools and Toxic Expectations: Post-Publication Notes on New Technologies and Human Rights', (2009) 2 *Law, Innovation and Technology* 181.

14 For an overview, see Jasanoff, 'Technologies of Humility: Citizen Participation in Governing Science', (2003) 41 *Minerva* 223. For example, it has been queried whether design-based techniques impact negatively on constitutional values of accountability, transparency and participation and the conditions required for a moral community to flourish: see Brownsword and Yeung, 'Regulating Technologies: Tools, Targets and Thematics', in Brownsword and Yeung, *supra* n. 6 at 9.

15 *Ibid.*

16 The literature on the 'democratic deficit' is vast. For an overview of the debate surrounding agencies, see Scott, 'Accountability in the Regulatory State', (2000) 27 *Journal of Law and Society* 38; Scharpf, *Governing in Europe. Effective and Democratic?* (Oxford: Oxford University Press, 1999); and Arnall and Wincott, *Accountability and Legitimacy in the European Union* (Oxford: Oxford University Press, 2002). Cf. Joseph, 'Democratic Deficit, Participation and the WTO', in Joseph et al. (eds), *The World Trade Organization and Human Rights* (Cheltenham: Edward Elgar, 2009).

17 *Supra* n. 5.

However, this hope is in need of further exploration. In particular, there has been little consideration of whether citizen participation in the EU's governance of new technologies is oriented towards 'human rights', that is, whether it is really about empowerment. This article thus considers the main discourses constructing such citizen participation for their human rights, or empowerment, credentials. It interrogates the construction of citizen participation in the EU's governance of new technologies, and argues that it is deployed more as a legitimating technique than as a way to support citizen empowerment, and as such is not fully oriented towards human rights.

The next part of the article defines a human rights perspective as being concerned with empowering individuals and groups to contest the exercise of formally accountable power over life. The approach is brought to bear in Section 3, where it is used to analyse several key discourses—law, citizen participation in EU governance and citizen/science relations, the 'public understanding of science and technology' (PUST),¹⁸ risk and bioethics¹⁹—which construct citizens in a 'deficit model' as being in need of education through their participation in governance.²⁰ These discourses are not exhaustive, but they are representative of the wider picture. Undergirding them is the (neo)liberal view of delegating regulation to experts,²¹ in which public trust is construed as passive and granted without the need for two-way negotiation and ongoing renewal.

2. Human Rights

The article now turns to sketching the essence of a human rights perspective on citizen participation, which can be used to assess the construction of citizen participation in key EU discourses. It does not intend to establish exhaustive or comprehensive criteria for a human rights approach to citizen participation, nor does it intend to work out the mechanics of how such an approach can be instrumentalised to achieve certain ends. Our aim is more modest. Citizen empowerment is identified as the core of what human rights are about. This insight is used to tease out whether the construction of citizen participation in the EU's governance of new technologies is oriented towards empowerment and, therefore, human rights.

18 Often referred to as PUS, that is, 'public understanding of science' (without reference to technology), and so amended to PUST here.

19 Drawing on Flear, 'The EU's Biopolitical Governance of Advanced Therapy Medicinal Products', (2009) 16 *Maastricht Journal of European and Comparative Law* 113.

20 Cf. Galligan, 'Citizens' Rights and Participation in the Regulation of Biotechnology', in Francioni (ed), *Biotechnologies and International Human Rights* (Oxford: Hart Publishing, 2007).

21 Majone, 'The Credibility Crisis of Community Regulation', (2000) 38 *Journal of Common Market Studies* 273.

In talking about a human rights perspective, we take a non-doctrinal approach, paying close attention to critical theory and in particular Foucault-influenced ways of thinking about human rights, citizen participation and governance. We understand human rights to mean not just the body of law, but also the practices and projects, the 'movements or groupings of lawyers, non-governmental organizations, and others who seek to secure and defend a particular right, group of rights, or human rights in general'.²² As Yamin points out, 'the way in which we conceptualize the role of participation is closely linked to how we understand power and, in turn, the purpose and meaning of human rights themselves'.²³ We thus consider human rights, power and the role of participation together, concentrating on the 'discourses' figuring citizen participation.

Discourse 'transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it',²⁴ hence focusing on it is a vital step towards a rhetorical and operational 'way in', or platform, tackling the ways in which 'power' thwarts citizen participation. Power/knowledge is a term developed by Michel Foucault to denote the way in which changes in knowledge—here in science and technology—help to provide the basis for the production and exercise of governmental power and control. Furthermore, the various modes and techniques of governance in late modernity are fused with and ordered by neoliberal political rationality.²⁵ The latter uses technical reason and means–end, or instrumental, rationality to disseminate and enhance optimisation of life, so that citizens become 'complicit' in governance, what Foucault called 'governmentality'.²⁶ The accountability and legitimacy of power/knowledge becomes ever more crucial as formally accountable sites of power tighten their relations with science and technology—a phenomenon described as 'knowledge society'.²⁷

It is against this background that the essence of a human rights perspective needs to be sketched out. To begin with, human rights is a broad and universalising discourse, which has enjoyed remarkable success in terms of becoming a dominant ideology over the last couple of decades. Indeed, human rights is

22 Murphy, 'Repetition, Revolution, and Resonance', in Murphy (ed), *New Technologies and Human Rights* (Oxford: Oxford University Press, 2009), 1 at 7.

23 Yamin, 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health', (2009) 11 *Health and Human Rights* 5 at 7.

24 Foucault, *The History of Sexuality: Volume One, The Will to Knowledge* (London: Penguin, 1998) at 101 (emphasis added).

25 Rose et al. describe this as 'a way of doing things that...[is] oriented to specific objectives and that...[reflects] on itself in characteristic ways': see Rose, O'Malley and Valverde, 'Governmentality', (2006) 2 *Annual Review of Law Society and Science* 83 at 84.

26 Supra n. 5. On governmentality, see *ibid.*

27 Bell, *The Coming of Post-Industrial Society: A Venture in Social Forecasting* (Harmondsworth: Basic Books, 1976); Castells, *The Rise of the Network Society (The Information Age, Economy, Society and Culture Vol. 1)* (Oxford: Blackwell, 1996); Knorr Cetina, *Epistemic Cultures. How the Sciences Make Knowledge* (Cambridge, MA: Harvard University Press, 1999); and Stehr, *Knowledge Societies* (London: Sage, 1994).

now synonymous with law and justice themselves.²⁸ It is also widely accepted that human rights has become the quintessence of modernity, alongside other institutionalised discourses such as secularism, market freedom and democracy.²⁹ According to David Kennedy, '[e]ven within the liberal West, other useful emancipatory vocabularies (including the solidarities of socialism, Christianity, the labor movement, and so forth) are diminished by the consolidation of human rights as the international expression of *the* Western liberal tradition'.³⁰

Furthermore, the contemporary ascendancy of human rights involves a certain conflation between its local and international dimensions, which implies growing interpenetration of the different systems of legal norms and related discourses.³¹ Domestic rights frameworks increasingly embrace 'international standards', which is achieved not just through classic incorporation, but also through a range of innovative ways such as judges using international human rights law as a 'persuasive' authority.³² As the burgeoning literatures on law and globalisation and on the interaction between the local and global dimensions of human rights demonstrate, the interplay between the universal language of human rights and local belonging often proves key to the success of 'new' social movements.³³ Accordingly, we treat human rights as a discourse, without making rigid distinctions between the domestic and international dimensions of human rights in our analysis of citizen participation in the EU's governance of new technologies. However, some attention is required—and will be given—regarding the specifics of the 'EU's' human rights discourse.

28 It has, for example, been argued that law has come to be viewed 'as a system of rights which frames and contains government power': see Walker, 'Review of M. Loughlin, *Sword and Scales: An Examination of the Relationship Between Law and Politics*', [2001] *Public Law* 644 at 646.

29 See Asad, *Formations of the Secular: Christianity, Islam, Modernity* (Palo Alto CA: Stanford University Press, 2003) at 13. See also Asad, 'What Do Human Rights Do? An Anthropological Enquiry', (2000) 4 *Theory and Event* 4.

30 Kennedy, 'The International Human Rights Movement: Part of the Problem?', (2002) 15 *Harvard Human Rights Journal* 101 at 114.

31 See Knop, 'Here and There: International Law in Domestic Courts', (1999), 32 *New York University Journal of International Law and Politics* 501; Moran, 'Authority, Influence and Persuasion: Baker, Charter Values and the Puzzle of Method', in Dyzenhaus (ed), *The Unity of Public Law* (Oxford: Hart Publishing, 2004) 389. For more recent pieces along similar lines, see Moran, 'Inimical to Constitutional Values: Complex Migrations of Constitutional Rights', in Choudhry (ed), *The Migration of Constitutional Ideals* (Cambridge: Cambridge University Press, 2006) 233; and Kumm, 'Democratic Constitutionalism Encounters International Law: Terms of Engagement', in Choudhury (ed), *ibid.* at 256.

32 Moran, *ibid.*

33 On the issue of gay rights, see, for example, Stychin, 'We Want to Join Europe, not Sodom: Sexuality and European Union Accession in Romania', in Stychin, *Governing Sexuality: The Changing Politics of Citizenship and Law Reform* (Oxford: Hart Publishing, 2003); and Stychin, 'Same-Sex Sexualities and the Globalization of Human Rights Discourse', (2004) 49 *McGill Law Journal* 951.

It is a known observation that human rights discourse carries much potential for paradox and contradiction. According to Wendy Brown, for example, 'the paradox of rights' is found in its conflicting potential to be both liberating and constricting. On the one hand, universal rights operate on the assumption of the autonomous, rational, 'relentlessly self-interested subject of liberalism',³⁴ which discursively erases differences between citizens and their attendant disadvantages. On the other, rights as a tool refashioned for and by the 'particular' subject, as pertaining to a specific identity (be it women, blacks or gays—or perhaps most importantly in our context, in relation to new technologies—a genetic or biocitizen), further entrench what Brown calls the identity's constitutive 'injury' as well as the discourses and disadvantages that frame it in the first place.³⁵ In this way, human rights become inextricably linked with the markedly anti-emancipatory function of identity.

Human rights also tends to operate as a depoliticising discourse as it eschews power and history in the construction and representation of the subject (i.e. bearer of rights), which inevitably cements a certain 'ontological naturalness or essentialism'³⁶ in our understandings of the sources of deep political and social problems.³⁷ As depoliticisation makes extant discourses appear natural, it masks comprehension of human rights' historical emergence and production by them.³⁸ There is thus much potential for human rights' uncritical use by citizens to frame their claims to participation.

These concerns are extremely valid in the context of the EU, in which human rights has been underpinned by a clear 'common/internal market' ideology since its inception.³⁹ As the EU has historically been a political force driven by an explicit economic rationale, human rights developments in this context were originally linked to a principle of non-discrimination in European Community (EC) law. Thus, a human rights consciousness in the EC/EU grew out of a sense that discriminating Member States should not be permitted to gain an advantage in the competition with more conscientious ones. The European Court of Justice itself confirmed that avoiding distortions in competition is a key objective of EC sex equality law.⁴⁰ And as Stychin

34 Brown, 'Introduction: Freedom and the Plastic Cage', in Brown, *States of Injury: Power and Freedom in Late Modernity* (Oxford: Princeton University Press, 1995) at 25.

35 On the paradox of rights, see in particular Brown, 'Rights and Losses', *ibid.*; and Brown, 'Suffering Rights as Paradoxes', (2000) 7 *Constellations* 230.

36 Brown, *Regulating Aversion: Tolerance in the Age of Identity and Empire* (Princeton NJ: Princeton University Press, 2006) at 15.

37 Thus this understanding of 'politicisation' is much broader than the classic liberal understanding, which is largely confined to the democratic legislative process: see Brown (2000) *supra* n. 35 at 475.

38 *Supra* n. 34 at 15.

39 See Stychin, *supra* n. 33 at 78, contrasting the explicitness of the EU human rights ideology with the more implicit one based on the values of individual autonomy in the context of North America.

40 *Defrenne v SABENA* (No 2) Case 43/75 [1976] ECR 455.

notes, it is ‘universally acknowledged that economic factors were the motivating force behind Article 141 [which prescribed equal pay for men and women]’.⁴¹ Historically, the archetypal rights holder in the EU was the migrant worker: an economically mobile citizen of one of the EU Member States who relocates to work in another.⁴² Tellingly, the principle of non-discrimination based on nationality in the EC Treaty has been confined to ‘EU nationalities’,⁴³ excluding third countries’ nationals. Indeed, this exclusion is due to the very nature of the EU as an organisation concerned with the well-being of its own as part of a market integration project designed to make it competitive on the world stage. Such a situation inevitably creates one of the most compelling illustrations to the critique of human rights as a (neo)liberal ideology (as outlined above), in which pushing for more rights actually reinforces the parameters of the existing discourse.

Yet despite all these reservations and paradoxes, we stick to the basic position that human rights is still *the* most emancipatory discourse, and hence it can be of much use when it comes to citizen participation. The paradoxical nature of rights itself accounts for this; although discourses disempower, they also open up space and possibilities for refashioning elements for empowerment. While it is important to appreciate the pitfalls of human rights, this does not mean relinquishing its use altogether—only that human rights should not be fetishised or divorced from broader, underpinning currents that shape reality. Thus, our human rights perspective on citizen participation in the EU governance of new technologies implies a need for critical engagement with human rights—indeed, a human rights consciousness understood as being about empowerment. Yamin traces how tackling disempowerment, inequality and exclusion requires participation not just in regulatory decisions, but also in deciding ‘what gets decided’, and ultimately a critical self-consciousness and subjectivity that can help individuals to transform the terms of engagement.⁴⁴

Here is how human rights can be empowering in the EU context post the Treaty of Lisbon, which came into force on 1 December 2009 and provides a skeletal (and amended) Treaty on the European Union (TEU) which is fleshed out in the Treaty on the Functioning of the European Union (TFEU; replacing the EC Treaty). Albeit originating in the market integration project, human rights in the EU has long become an accepted and central discourse in its own right. Indeed, Article 2 of the TEU states that the EU is ‘founded on the values of respect for human dignity, freedom, democracy, equality, the rule of

41 Stychin (2003), *supra* n. 33 at 79.

42 See, for example, Hervey, *European Social Law and Policy* (London: Longman, 1998) at 106, with respect to social security hierarchies.

43 Article 12 EC Treaty, now Article 18 TFEU.

44 Yamin, *supra* n. 23.

law and respect for *human rights*.⁴⁵ Article 6(3) of the TEU makes 'fundamental freedoms', as guaranteed by the European Convention on Human Rights (ECHR)⁴⁶ and 'constitutional traditions common to the Member States', general principles of EU law. Furthermore, Article 6(1) of the TEU now gives the previously non-binding Charter of Fundamental Rights of the European Union (EU Charter) the same legal status as the Treaties.

Human rights discourse in the EU has been central to achieving a great many legal victories by previously disempowered individuals and social movements. One obvious example of a human rights victory is the rights of transsexuals in *P v S*⁴⁷—an issue which was very far off the minds of the original drafters of the EC Treaties. An even greater value lies perhaps in human rights' potential in *highlighting* these social struggles, bringing them to the public's attention and thus transforming attitudes to certain issues. This has happened, for example, in the context of sexual orientation in *Grant v South West Trains*.⁴⁸ Although the legal challenge by a lesbian employee of a company policy to provide travel concessions to heterosexual partners only was unsuccessful in this case, it succeeded in publicising the issue, and indeed contributed to the push for appropriate legislation post-Article 13 EC.⁴⁹ In this way, previously unpopular minorities have managed to mobilise human rights not only to achieve concrete legal and political gains, but also to redefine the very meaning of human in human rights, thus also reshaping the parameters of liberal citizenship.⁵⁰ It follows that, despite its (specifically EU) economic origins, its totalising and paradoxical nature, human rights remains an extremely useful way to channel social movements' causes, foster greater public awareness and engagement and thus foster democratisation.

In sum, we advocate a human rights perspective that fosters critical consciousness and thus is about empowerment. It is with these factors in mind that we can begin to move towards using that insight to interrogate the

45 Emphasis added.

46 European Convention for the Protection of Human Rights and Fundamental Freedoms 1950, ETS 5 (ECHR).

47 *P v S & Cornwall City Council Case C-13/94* [1998] ECR I-2143.

48 *Grant v South West Trains Case C-249/96* [1998] ECR I-621, in which the ECJ decided that the concept of 'sex' in Article 141 EC did not cover sexual orientation. The case was decided shortly after the adoption of the Treaty of Amsterdam, which introduced Article 13 EC (see below). On *Grant*, see Stychin (2003), supra n. 33.

49 Which provides that the Council may adopt legislative measures to combat discrimination in the fields of race, religion, disability, age and sexual orientation. Accordingly, Directive 2000/78/EC was adopted, which prohibits discrimination on the grounds of religion or belief, disability, age and sexual orientation in the sphere of employment and vocational training. The Racial Equality Directive (Directive 2000/43/EC) has a wider scope, prohibiting discrimination on the grounds of racial or ethnic origin in employment, vocational training, education, social protection, social advantages and access to goods and services (including housing).

50 Herman, 'Beyond the Rights Debate', (1993) 2 *Social & Legal Studies* 25 at 32. So that, in the case of sexual minorities, explicit arguments *against* their rights have been pushed out of the mainstream.

discourse constructing citizen participation in the EU's governance of new technologies.

3. Disempowering Citizens? EU Discourse on Citizen Participation in a Human Rights Perspective

A. Citizen Participation in EU Law

It is beyond the scope of this article to present a comprehensive analysis of the evolution of citizen participation in the context of the EU's constitutional legal order, in particular as it has developed pre- and post- the Treaty of Lisbon. As the law currently stands, Article 2 of the TEU states that the EU is 'founded on the values of respect for human dignity, freedom, *democracy*, equality, the rule of law and respect for *human rights*'.⁵¹ The principle of non-discrimination finds expression under Title II, 'Provisions on Democratic Principles', in Article 9 of the TEU which states that in 'all its activities, the Union shall observe the principle of the *equality of its citizens*, who shall receive *equal attention* from its institutions, bodies, offices and agencies'.⁵² Article 10(1) of the TEU highlights 'representative democracy' as the EU's foundation, and Article 10(2) notes 'direct' representation of citizens in the European Parliament, and the representation of the heads of state or government of the Member States in the European Council, and governments in the Council, 'themselves democratically accountable either to their national Parliaments, or to their citizens'. More pertinently, Article 10(3) of the TEU states that '[e]very citizen shall have the *right to participate* in the democratic life of the Union. Decisions shall be taken as openly and as closely as possible to the citizen'.⁵³ It highlights the importance of openness, transparency and subsidiarity, the latter essentially being about reducing the distance between governance and citizens.

Article 11 of the TEU elaborates on these foundations. Article 11(1) uses mandatory and rather cautious, half-hearted language when it states that '[t]he institutions *shall*, by *appropriate* means, give *citizens and representative associations* the *opportunity to make known and publicly exchange* their views in *all areas of Union action*'.⁵⁴ Article 11(2) of the TEU states that the 'institutions shall maintain an open, transparent and regular *dialogue with representative associations and civil society*'.⁵⁵ Article 11(3) of the TEU states that the EU's executive, the European Commission (Commission), 'shall carry out broad consultations with parties concerned in order to ensure that the Union's

51 Emphasis added.

52 Emphasis added. Citizens of the EU are, of course, defined as Member State nationals.

53 Emphasis added.

54 Emphasis added.

55 Emphasis added.

actions are coherent and transparent'. Finally, a novel innovation of the Treaty of Lisbon, and potentially useful platform for a citizen participation, is provided by the so-called European Citizens' Initiative in Article 11(4) of the TEU states that '[n]ot less than one million citizens who are nationals of a significant number of Member States may take the initiative of inviting the Commission, within the framework of its powers, to submit any appropriate proposal on matters where citizens consider that a legal act of the Union is required for the purpose of implementing the Treaties'.⁵⁶

Some of these points are elaborated in Part One, Title II on 'provisions having general application' of the TFEU. Article 15(1) states that '[i]n order to promote good governance and ensure the participation of civil society, the Union institutions, bodies, offices and agencies shall conduct their work as *openly as possible*'.⁵⁷ Article 17(1) of the TFEU notes how the EU 'respects and does not prejudice the status under national law of churches and religious associations or communities in the Member States', while Article 17(2) notes the EU 'equally respects the status under national law of philosophical and non-confessional organisations'. Participation enters in Article 17(3) where it states '[r]ecognising their identity and their specific contribution, the Union shall maintain an open, transparent and regular *dialogue* with these churches and organisations'.

As noted previously, Article 6(1) of the TEU recognises the EU Charter and gives it the same legal status as the Treaties. Yet, the EU Charter makes no reference to rights of citizen participation. Rather, in the EU Charter's preamble it is stated that 'the Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity; it is based on the principles of *democracy* and the rule of law. It places the *individual at the heart of its activities, by establishing the citizenship* of the Union. ...'.⁵⁸ It is arguable that participation is indirectly referenced by Article 6(3) of the TEU which makes 'fundamental freedoms', as guaranteed by the ECHR and 'constitutional traditions common to the Member States', general principles of EU law. These latter sources make references to participation.⁵⁹

When it comes to new 'technologies', there is a growing tendency for citizens to be explicitly referenced in the law specifically governing this area. One example is the Regulation on Advanced Therapies (ATR),⁶⁰ which is

56 For debate, see Kaufmann and Pilcher, *The European Citizens' Initiative: Into New Democratic Territory* (Brussels: Intersentia, 2010). There is a proposal for a regulation providing rules and procedures for the European Citizens' Initiative: see Proposal for a Regulation of the European Parliament and of the Council on the Citizens' Initiative, COM (2010) 119 Final. See further: <http://ec.europa.eu/dgs/secretariat-general/citizens.initiative/index.en.htm> [last accessed 1 October 2010].

57 Emphasis added.

58 Emphasis added.

59 Supra n. 20 at 344–8.

60 Regulation 1394/2007.

concerned with single marketing authorisations for advanced therapies based on gene-therapy, cell-therapy and tissue engineering.⁶¹ The ATR creates the Committee on Advanced Therapies (CAT), whose recommendations are passed up to the Committee for Medicinal Products for Human Use (CMPHU) for further consideration, and then up to the Commission for the final, formal decision.⁶²

The ATR procedures are designed to improve the adequacy and consistency of risk management strategies and surveillance after marketing.⁶³ Scientific expertise and justifications for authorisations are prioritised over participation.⁶⁴ That is, the CAT, being placed within the EMEA, is largely shielded from explicitly political processes by that institution's status as an agency. Yet, the CAT is biased towards scientific expertise, despite the inclusion of civil society. This valorisation and its effects are exemplified by the scientific justification the EMEA must provide if it does not follow the CAT's opinion. In terms of membership, the CAT is dominated by scientific expertise 'relevant to advanced therapies, including medical devices, tissue engineering, gene therapy, cell therapy, biotechnology, surgery, pharmacovigilance, risk management and ethics'.⁶⁵ Indeed, the requirement of scientific expertise is a 'precondition' for membership,⁶⁶ except for patients' associations and clinicians.⁶⁷ Moreover, patients' associations, although representing a measure of citizen participation, are not unproblematic either, as such collectivities do not necessarily represent the views of their members or ensure their participation within its structures.

To sum up the foregoing discussion, given the huge range of the CAT's tasks, concerned with 'the *quality, safety and efficacy* of each advanced therapy medicinal product',⁶⁸ it could be a hugely important site of engagement for citizens. However, citizens are disempowered by the bias towards scientific expertise. More generally, although EU 'law' provides a platform for citizen participation, it fails to ensure meaningful empowerment for citizens. There is a failure to

61 Cf. Farrell, 'The Politics of Risk and EU Governance of Human Material', (2009) 16 *Maastricht Journal of European and Comparative Law* 41.

62 In accordance with the principle of non-delegation established in *Meroni v High Authority* [1957-58] ECR 133. For an overview see: <http://www.ema.europa.eu/ema/index.jsp?curl=pages/contacts/2010/02/people.listing.0000008.jsp&murl=menus/about.us/about.us.jsp&mid=WC0b01ac05800292a6#PO> [last accessed 27 August 2010].

63 Roche, 'Advanced Therapies and the Outer Limits of DNA Regulation: New Horizons for Patents or a Scaffold Too Far?', (2008) 3 *Journal of Intellectual Property Law and Practice* 210 at 211.

64 For example, Article 8(4).

65 Emphasis added. Article 22(2)(2) states 'At least two members and two alternates of the Committee for Advanced Therapies shall have scientific expertise in medical devices'. Cf. Recital 11.

66 Article 21(2)(1).

67 Recital 11 (emphasis added). The two patients' associations are currently the European Genetic Alliances' Network and the European Organisation for Rare Diseases.

68 Emphasis added.

specify binding rights to participation, even if there is some attempt to provide the conditions of openness, transparency and accountability that foster participation. That is, references to dialogue are not conducive to providing a genuine and substantive input into governance. This is clearly unsatisfactory from a human rights approach that is interested in fostering empowerment. Of course, we need to interrogate other discourses in order to understand citizen participation's construction more fully—which is done in the rest of the article.

B. 'European Governance'

The weak commitment to citizen participation found in EU law is echoed in its policy documents. These documents are mostly produced and endorsed by the Commission, but also by formal institutional actors such as the Economic and Social Committee, politicians and scholars. The most important document is 'European Governance',⁶⁹ since it provides the EU's overarching approach to citizen participation. 'European Governance' arose in large part from the BSE crisis of the 1990s in which there was a 'collapse in consumer confidence caused by shortcomings in the institutionalisation of scientific knowledge'⁷⁰ in Member State and EU structures (but its ideas have since remained relevant in light of the controversy surrounding genetically modified organisms (so-called GMOs)).

'European Governance' calls for openness, transparency and enhanced participation by citizens throughout the process of science-based decision-making,⁷¹ a move affirmed and developed in subsequent documents.⁷² The main purpose of citizen participation is to engender (or restore) public trust and legitimacy, especially in areas of risk and scientific uncertainty, such as new technologies. Citizen participation is to be engendered by *inter alia* the establishment and publication of minimum standards for 'consultation' on EU law and policy-making, rationales for citizen and civil society inclusion, standards for their selection, as well as the conduct of included actors and

69 European Commission, *European Governance: A White Paper*, COM(2001) 428 final, 25 July 2001. For commentary, see Obradovic and Alonso Vizcaino, 'Good Governance Requirements Concerning the Participation of Interest Groups in EU Consultations', (2006) 43 *Common Market Law Review* 1049; and Armstrong, 'Rediscovering Civil Society: The European Union and the White Paper on Governance', (2002) 8 *European Law Journal* 102.

70 Everson and Vos, 'The Scientification of Politics and the Politicisation of Science', in Everson and Vos (eds), *Uncertain Risks Regulated* (Oxon: Routledge-Cavendish, 2009) 1 at 1.

71 *Supra* n. 69 at 8.

72 For an overview of initiatives, see Commission Staff Working Document, *Report on European Governance (2003-2004)*, SEC(2004) 1153, 22 September 2004. In the health sphere, one focus of new technologies, see European Commission, White Paper, *Together for Health: A Strategic Approach for the EU 2008-2013*, COM(2007) 630 final, 23 October 2007; and Commission Staff Working Document Accompanying White Paper, *Together for Health: A Strategic Approach for the EU 2008-2013*, SEC(2007) 1376, 23 October 2007.

the provision of up-to-date, online information on EU law and policy-making.⁷³ Together these documents frame the inclusion of citizens via supposedly representative collective or civil society actors.

Similar to rights and law, references to citizen participation here are paradoxical. On the one hand, they create a platform for the assertion of agency and sovereignty by citizens as they engage with governance. Indeed, consultation on new technologies creates the impression that the public constituted by the processes and techniques have ‘a certain decision making power over the adoption or shaping of the technology, that it has this power more generally (and non-consultation becomes suspicious), and that consultation is somehow preferable to other approaches to decision-formation’.⁷⁴ On the other hand, citizen participation is undermined through the techniques deployed and the construction of citizens within a ‘deficit model’. These latter disempowering aspects of ‘*European Governance*’ must be discerned if citizens are to be empowered.

Looking first at minimum standards, we can note Galligan’s view that focussing on ‘consultation’ rather than binding rights to participation is disempowering. ‘*European Governance*’ states that legally enforceable rights would produce ‘excessive rigidity and risk slowing the adoption of particular policies’.⁷⁵ This is revelatory because it suggests the focus is on supporting economic optimisation, and that citizen participation is deployed to promote that end. Another problem with minimum standards is that unlike rights to participation there is no binding way of promoting equity and fairness of access to the policy process by civil society groups. The absence of rights to participation is risky and problematic from a human rights perspective concerned with empowerment since *more* powerful groups (especially those backed by industry) are, as Galligan notes, likely to ‘form relationships with policy-makers that continue over time and... [provide] little room for more occasional or fragmented groups to be involved’.⁷⁶

In addition, the preference for minimum standards is determined without reference to the practices of other systems, particularly those of the EU’s Member States. The latter have tended to use sophisticated administrative law rights and mechanisms to foster citizen participation in relation to individuals, a point that seems to belie the Commission’s assertion that a legal approach is excessively rigid. As highlighted in the expert report ‘*Taking European Knowledge Society Seriously: Report of the Expert Group on Science and Governance*’ (‘*Taking European Knowledge Society Seriously*’), the assumption is

73 Butler, ‘Non-Governmental Organisation Participation in the EU Law-Making Process: The Example of Social Non-Governmental Organisations at the Commission, Parliament and Council’, (2008) 14 *European Law Journal* 558.

74 Ashcroft, ‘Constructing Empirical Bioethics: Foucauldian Reflections on the Empirical Turn in Bioethics Research’, (2003) 11 *Health Care Analysis* 3 at 9.

75 Supra n. 69 at 17.

76 Supra n. 20 at 351.

that law is simply too slow to ensure the 'the flexibility and responsiveness, not to mention anticipatory dynamism, "required" by modern science, technology, innovation and global competitiveness'.⁷⁷

The failure to seriously consider the experiences of other systems, particularly the need to augment legal approaches to fostering participation by groups, makes the EU's own deployment of citizen participation seem more about 'appearing' to enhance democracy than actually doing so. Indeed, reflecting back on the EU's weak legal commitment to citizen participation, it is worthwhile noting the observation made in *'Taking European Knowledge Society Seriously'*, that normative commitments to *inter alia* citizen participation are 'created under the name of "law" . . . [but] are not accountable to democratic control. . . Any loss of potential economic competitiveness is invoked as almost a "state of emergency", such that efficiency overrides the slower and more cumbersome application of democratic principles'.⁷⁸ In other words, constitutional values like democracy or human rights are put at risk by the need to ensure the neoliberal objective of economic optimisation, reflected and reinforced by the overarching architecture provided by the Lisbon Strategy, which has the goal of making the EU 'the most competitive and dynamic knowledge-based economy in the world, capable of sustainable economic growth with more and better jobs and greater social cohesion' by 2010,⁷⁹ a move reinforced by a refocus on growth and jobs.⁸⁰

Turning to the construction of citizens, civil society actors are deemed able to represent the interests of their members irrespective of sources of difference and discrimination such as socio-economic position, race, gender, sexuality and age.⁸¹ Yet, those who are given voice 'may be determined by what kind of position they are expected to take, and whether this coincides with or disrupts entrenched dominant frames'.⁸² This stymies the inclusion of those who might contest those frames. Moreover, since theories of collective action point to the difficulties involved for the 'excluded' or 'weakest' to organise even at the local and national levels,⁸³ it is clearly *more* difficult to organise at the EU level, where the distance between the centre and membership is greater.

77 *Taking European Knowledge Society Seriously: Report of the Expert Group on Science and Governance* (Luxembourg: European Commission, 2007) at 52.

78 *Ibid.* at 52.

79 Council of the European Union, *Presidency Conclusions – Lisbon European Council 23rd and 24th March* (Brussels: 2000) at para. 5. See Armstrong, 'Governance and Constitutionalism After Lisbon', (2008) 46 *Journal of Common Market Studies - JCMS Symposium: EU Governance After Lisbon* 413 at 413–14.

80 Kok, *Facing the Challenge: The Lisbon Strategy for Growth and Employment. Report from the High Level Group Chaired by Wim Kok* (Brussels: European Commission, 2004).

81 Warleigh, "Europeanising" Civil Society: NGOs as Agents of Political Socialisation', (2001) 39 *Journal of Common Market Studies* 619.

82 *Supra* n. 77 at 58.

83 Smismans, 'European Civil Society: Shaped by Discourses and Institutional Interests', (2003) 9 *European Law Journal* 482 at 499–503.

Moves to include citizens have come through, for instance, citizen panels or consensus conferences in the EU's *'The Meeting of Minds'*.⁸⁴ The 'open minded' citizen evoked in the latter is deemed to have not yet reached a fixed view on a particular issue, is not committed to any political movement, and is therefore able to be persuaded of a view. Such a citizen is therefore preferred over those with existing views, i.e. activists. That is because the 'open minded' citizen is supposed to be malleable and able to be convinced of a given position—educated—by experts. Such a citizen is not yet competent to truly participate in governance and take decisions. To summarise, the participation of civil society does not necessarily mean European integration will become more inclusive.⁸⁵

Bringing the foregoing together, as Walters and Haahr explain, citizen participation as consultation or a 'helping hand'⁸⁶ defines a public rationality that serves to disempower citizens. This is because involvement is less about reaching a decision through free and equal debate and '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*'.⁸⁷ As such, the stress on participation as consultation propounded in *'European Governance'* seems more like an education initiative.⁸⁸ The point of improved participation is distinctly functionalist in that it is used to engender greater confidence in the governance outputs produced by science and instrumental rationality⁸⁹ and, therefore, in 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'.⁹⁰ This public rationality finds corollary and support in the rationality of expertise. A distinction is made between experts and lay people or the public, with the latter being educated by the former. This is of course a well-known strategy for the distribution of power⁹¹—here working to disempower citizens. The consequence of the valorisation of science even in conditions of uncertainty is an undermining of the importance of participation.

So, although citizen participation is emphasised in *'European Governance'*, participation as consultation is not designed to guarantee a genuine, truly open and rigorous discussion with those members of civil society who are

84 See: <http://www.meetingmindseurope.org/europe.default.site.aspx?SGREF=14> [last accessed 27 August 2010].

85 Supra n. 83.

86 Cf. Burchell, 'A Helping Hand or a Servant Discipline?', (2009) 5 *Science, Technology and Innovation Studies* 49.

87 Walters and Haahr, *Governing Europe: Discourse, Governmentality and European Integration* (London: Routledge, 2005) at 83 (emphasis added).

88 Ibid. (emphasis added)

89 Bellamy et al. (eds), *Making European Citizens* (Basingstoke: Palgrave Macmillan, 2006).

90 Supra n. 87 at 83 (emphasis added).

91 Hervey and McHale, *Health Law and the European Union* (Cambridge: Cambridge University Press, 2004) at 317.

involved and consulted.⁹² The EU's public is implicitly constructed, represented and shaped in a 'deficit model'. The complementary public and expert rationalities demarcate the boundaries of citizen participation, which work to undermine popular control and contestation in EU governance. In particular, citizens are given little formal role in imagining new technologies and the EU's response to them, a move that limits the normative dimension of new technologies. Overall then it appears, as Smismans observes, citizen participation is really about 'contributing to EU *legitimacy* but *not* defined as a contribution to more active citizenship'.⁹³ It seems clear that this construction of citizen participation undermines empowerment and is, therefore, far from satisfactory from a human rights perspective that seeks to empower citizens.

C. *Elaborating on Citizen/Science Relations in the Governance of New Technologies*

Another series of documents focussed more specifically on new technologies helps to elaborate the EU's construction of citizen/science relations and the use of citizen participation in that context. Three documents are particularly illustrative: '*Life Sciences: A Strategy for Europe*' ('*Life Sciences*'),⁹⁴ '*Promoting the Competitive Environment for the Industrial Activities Based on Biotechnology within the Community*' ('*Competitive Environment for Biotechnology*'),⁹⁵ and '*Science and Society Action Plan*' ('*Science and Society*').⁹⁶ These extend and reinforce the rationalities and 'deficit model' found in '*European Governance*'.

'*Life Sciences*' provides the Commission's view on the approach for regulating biotechnology in the EU. The focus is on developing sustainable and responsible policies, and in particular winning the confidence and support of the EU's public. Citizen participation is not just linked to, but is actually framed by the neoliberal concern for optimisation. Ensuring that EU policy is centred on its citizens is a recurrent theme throughout the document, especially in exhortations that there is an 'open, collaborative, and sustained process to develop

92 In a different vein, see Fraser, 'Transnationalizing the Public Sphere: On the Legitimacy and Efficacy of Public Opinion in a PostWestphalian World', in Benhabib et al. (eds), *Identities, Affiliations and Allegiances* (Cambridge: Cambridge University Press, 2007).

93 Smismans, 'New Governance – The Solution for Active European Citizenship, or the End of Citizenship?', (2007) 13 *Columbia Journal of European Law* 595 at 604 (emphasis added).

94 Communication from the Commission, *Life Sciences and Biotechnology: A Strategy for Europe*, COM(2002) 27 final, 23 January 2002.

95 Communication from the Commission, *Promoting the Competitive Environment for the Industrial Activities Based on Biotechnology within the Community*, SEC(91) 629 final, 19 April 1991. See also Communication from the Commission, *Working Together for Growth and Jobs. A New Start for the Lisbon Strategy*, COM(2005) 24 final, 2 February 2005.

96 Communication from the Commission, *Science and Society Action Plan*, COM(2001) 714, 4 December 2001. See also Commission Staff Working Paper, *Science, Society and the Citizen in Europe*, SEC(2000) 1973, 14 November 2000; and Communication from the Commission, *Science and Technology, the Key to Europe's Future: Guidelines for Future European Union Policy to Support Research*, COM(2004) 353 final, 16 June 2004.

coherent and credible policies'.⁹⁷ The importance of public confidence in EU governance is emphasised in references to 'a structured dialogue' among scientists, industry and civil society through, for instance, the establishment of a Stakeholders' Forum, to be facilitated and administered by the Commission.

However, *'Life Sciences'* fails to define the precise role of civil society or rights to participation in the governance of new technologies. In a linked document reporting on progress, the Commission states that there 'is a need for commitments and actions from all private and public stakeholders involved in the Strategy'.⁹⁸ There is consideration of the merits of establishing a so-called 'multilateral consultative forum', the purposes of which are to facilitate open and balanced dialogue and 'a wide spectrum of interests, including scientists and a cross-section of civil society'.⁹⁹ Although a potential opening for participation, reliance on the 'stakeholder model' is problematic because it presumes that the issues 'at stake' are already agreed. Indeed, as noted in *'Taking European Knowledge Society Seriously'*, debate is foreclosed because agreement on what is at stake may not have been reached.¹⁰⁰

'Competitive Environment for Biotechnology' again highlights the promotion of innovation and the competitive environment for the EU's biotechnology industry. The focus seems very much on ensuring the public acceptability of EU governance, and for that purpose expert advice is emphasised as a way of legitimating decisions.¹⁰¹ *'Science and Society'* is, as the name suggests, more directly concerned with citizen/science relations in the EU context. In terms of what is being endorsed, the document is replete with references to the promotion of scientific education and culture, public awareness, science education and (interestingly) careers (which of course overlaps with the focus on innovation in the previous document), as well as a science policy closer to citizens, involving citizen society, and the use of expertise. The basic view seems to follow the pattern noted in *'European Governance'*. The document notes the 'acquisition of a basic grounding in science and technology by the European public and a regular flow of information to the public from experts are not in themselves enough to enable people to form an opinion'.¹⁰² Apparently direct engagement with expertise and a variety of fora is required (the following are noted: consensus conferences, citizens' juries, national and regional consultations and online forums¹⁰³). Indeed, it is 'not enough to keep them [citizens] informed. . . they must be given the opportunity to *express* their views in the

97 Supra n. 94 at 10.

98 Communication from the Commission, *Life Sciences and Biotechnology – A Strategy for Europe Progress Report and Future Orientations*, COM(2003) 96 final, 5 March 2003, at 21.

99 Ibid.

100 Supra n. 77 at 58.

101 Cf. supra n. 59.

102 Supra n. 96 at 12.

103 Ibid.

appropriate bodies'.¹⁰⁴ Of course, the mere expression of views does not guarantee they are taken into account in governance.

In addition, the main route for citizen participation is, following 'European Governance', through civil society, including organisations.¹⁰⁵ This might seem reasonable enough, but perhaps even more clearly than in 'European Governance' which it elaborates on, in 'Science and Society' citizens are figured within a 'deficit model', with the complementary public and expert rationalities again demarcating the boundaries of their participation. That is, citizen contestation of EU law and policy is deemed to arise from ignorance and to be resolvable by education which will promote understanding. The failure to see citizen contestation as sometimes produced by, say, alternative views and understandings of the science, suggests that education is the main purpose of citizen participation. Education is to be achieved through various means and involving various other actors, such as media, researchers, research institutions and universities, and even industry.¹⁰⁶ These actors help to demarcate the scope of citizen participation, for instance, because they help to define what citizens need to learn and could conceivably contribute to governance. This echoes 'European Governance' and serves to reinforce disempowerment. The focus on educating citizens limits the normative dimension of new technologies and implies that they have a limited role in imagining new technologies within EU governance and contesting the EU's response to them. Again it appears citizen participation is being deployed to shore-up the EU's governance of new technologies, instead of being about citizen empowerment.

D. Public Understanding of Science and Technology

Public Understanding of Science and Technology (PUST) supports the public and expert rationalities found in the above documents, especially 'Science and Society' and 'European Governance'. PUST is deployed as an instrument of EU governance, and as such it works to support the overarching agenda of producing economic optimisation.¹⁰⁷ PUST techniques include the *Eurobarometer* on attitudes to new technologies such as biotechnology,¹⁰⁸ reports, questionnaires and statistics. These conjure citizens, their understanding of science and

104 Ibid. at 14–15 (emphasis added).

105 Ibid.

106 Ibid. at 6.

107 Jasanoff, *Designs on Nature* (Oxford: Princeton University Press, 2005) at 251 (emphasis added).

108 See generally: <http://ec.europa.eu/public.opinion/index.en.htm> [last accessed 27 August 2010]; and <http://ec.europa.eu/public.opinion/index.en.htm>. [last accessed 27 August 2010]. On biotechnology, see Gaskell et al., *Europeans and Biotechnology in 2005: Patterns and Trends, Eurobarometer 64.3* (2006), available at: http://ec.europa.eu/research/press/2006/pdf/pr1906_eb.64.3.finalreport-may2006.en.pdf [last accessed 12 October 2010].

technology, and therefore the appropriate relationship between citizens and governance. So-called ‘absent presences’,¹⁰⁹ while citizens are not physically present in policy-making, they are represented and imagined by EU actors in order to provide a democratic basis for decisions. The techniques of PUST are established and interpreted by experts who educate citizens.¹¹⁰

Implicit in the use of such techniques is the definition of the ‘public’ by the researcher.¹¹¹ Given the inflection of PUST in the above documents, it is unsurprising that it implicitly constructs citizens, but so they are one-dimensional non-knowers in the ‘deficit model’. Such a prior framing of public understanding ensures issues are ‘marked off’ from the reach of popular control and contestation. As such, PUST ignores the potential for contestation and the normative dimension of new technologies, and underpins and elaborates on the expert and public rationalities found in ‘*European Governance*’.

Paradoxically, even as PUST constructs citizens in a ‘deficit model’ it also creates the conditions for the assertion of agency and sovereignty since agents can refashion PUST discourse for their own ends.¹¹² PUST can stimulate attitudes and preferences, and as such create a platform for participation. Nevertheless, in order to be empowered citizens must understand and outmanoeuvre the operation of PUST as an instrument of governance that, as with other discourses, does not merely reflect but also seeks to shape their identities and attitudes within the ‘deficit model’.

E. Cross-cutting Discourses: Risk and Bioethics

Underpinning and inflecting the substantive discourses on citizen participation are two main cross-cutting discourses: risk and bioethics. These circulate and work with the other discourses to underpin the expert and public rationalities and, as a corollary, the way in which citizens and the boundaries of their participation in governance are conceived for legitimating purposes. Looking first at risk, new technologies bring advances and benefits, but they also generate uncertainties and failures. Indeed, the risks associated with new technologies are endemic to ‘risk society’.¹¹³ EU governance of new technologies must therefore extend to analysing and managing the risks they generate.

109 Supra n. 77 at 58. A Report to the European Commission’s Directorate – General for Research.

110 Leach and Scoones, ‘Science and Citizenship in a Global Context’, in Leach et al. (eds), *Science and Citizens: Globalization and the Challenge of Engagement* (London: Zed Books, 2005) at 16.

111 Supra n. 74 at 10.

112 Cf. *ibid.*

113 Beck, *Risk Society: Towards a New Modernity* (London: Sage, 1986); Beck, *World at Risk* (Cambridge: Polity Press, 2009); and Giddens, ‘Risk Society: The Context of British Politics’, in Franklin (ed), *The Politics of Risk Society* (Cambridge: Polity Press, 1998).

For instance, risk is inflected throughout the ATR, noted above, as well as the other discourses figuring citizen participation.¹¹⁴ Indeed, separating out risk analysis and management functions is central to 'European Governance' as a response to the BSE crisis. To take 'Science and Society' as another example, risk governance¹¹⁵ is framed by the idea of placing 'responsible science at the heart of policy making'.¹¹⁶ Scientific expertise is used to cope with uncertainty¹¹⁷ and a sense of 'frustration and despair when experts fail to provide simple answers to apparently simple questions. The conclusion: 'Even the experts don't know what they're talking about!'. The document recognises this undermining of scientific authority generates 'a need to open up the process [of science-based decision making] by providing opportunities for the voicing of alternative views ('a competition of ideas'), for scrutiny and for constructive debate'.¹¹⁸ Nevertheless, although this again creates a platform for citizen participation, it can be thwarted by the techniques of, and constructions implicit in, risk governance.

One key concern is that the predominant focus remains on 'scientific definitions' of risk and the importance of *technical* expertise in interpreting data. Reliance on scientific rationality means regulatory priorities tend to be established by reference to technical criteria which are interpreted by experts.¹¹⁹ A consequence of this use of the power of objectivity and scientific rationality is a pre-emption of political discussion. Moving from this general observation, Farrell has noted how the EU governs new technologies such as advanced therapies in a way that removes issues from democratic contestation and citizen participation to a technocratic environment in which oversight is provided by those with the relevant scientific expertise.¹²⁰ The focus of the regime governing new technologies is on the promotion of innovation and the potential for economic optimisation. By contrast, the regime for blood, tissue/cells and organs is subject to political contestation and monitoring. An explanation for this bifurcation is provided by Andreasen and Hoeyer, who point out that citizens seem to be involved in governance for instrumental reasons, such as when their consumption of products based on new technologies makes it necessary.¹²¹ In other words, the EU's neoliberal orientation means citizen participation tends to be used to legitimate governance, but citizen participation

114 Reinforced by Committee for Medicinal Products for Human Use, [Draft] *Guideline on Safety and Efficacy Follow-Up – Risk Management of Advanced Therapy Medicinal Products* (London, 20 November 2008).

115 Supra n. 96 at 17–24.

116 Ibid. at 17.

117 Supra n. 96 at 22.

118 Ibid. (emphasis added).

119 Murphy and Whitty, 'Risk and Human Rights in UK Prison Governance', (2007) 47 *British Journal of Criminology* 798 at 802 (emphasis added).

120 Supra n. 61.

121 Andreasen and Hoeyer, 'DNA Patents and the Invisible Citizen: The Role of the General Public in Life Science Governance', (2009) 6 *SCRIPTed* 538.

becomes problematic in conditions where the promotion of innovation as a way of fostering economic optimisation through the consumption of products is the focus.

There is yet another way in which risk governance thwarts citizen participation. Power points out how accountability has become linked with organisation in a single logic through which democratic ideals 'are *increasingly positioned* within ideals for good governance of the risk analysis process. . .'.¹²² Consequently, techniques for accountability such as participation become part of a broader process of rendering organisations auditable and inspectable. They 'are *increasingly framed* as an organizational strategy to manage public expectations'.¹²³ Indeed, public perceptions are a source of risk, and so risk management is partly an exercise in governing 'unruly perceptions' and maintaining the 'production of legitimacy in the face of these perceptions'.¹²⁴ It is no surprise then that, as Black states, the rhetoric of risk is a 'useful legitimating device'.¹²⁵ In light of these insights, the EU's proclamations on inclusion of alternative voices seem rather disingenuous. Where participation is required as a technique for risk management it need not amount to substantive involvement.

At the same time, however, the logic of organisation and accountability also transforms 'human rights' into an institutional risk, that is, a risk for the institutions of risk governance. As Murphy and Whitty put it, '*managing risk means managing the risk of rights*'. Moreover, this risk is 'not limited to legal risk, that is, (potential) claims and litigation for violation of human rights obligations. . .'. There is also what they call 'legal risk+', encompassing for example 'the potential for human rights *consciousness* (e.g. as manifested in a public campaign) to disrupt the interests and overall standing of governments and organisations'.¹²⁶ Murphy and Whitty see this in a positive light, and this valence of 'rights as risk' is followed up below for the way in which it might enhance citizen participation as empowerment. For now another valence and implication is stressed. Citizen empowerment through explicit use of human rights techniques and consciousness are risks that must be dealt with by governance. The logic of organisation and accountability might transform and reduce techniques for participation and human rights to instrumental 'tick box' exercises that do not guarantee citizens a substantive input into governance. As such this operation of risk implicitly threatens to disempower citizens. Such a

122 Power, *Organized Uncertainty* (Oxford: Oxford University Press, 2007) at 20 (emphasis added). Cf. Rothstein, Huber and Gaskell, 'A Theory of Risk Colonization: The Spiralling Regulatory Logics of Societal and Institutional Risk', (2006) 35 *Economy and Society* 91.

123 Power, *ibid.* at 20–21 (emphasis added).

124 *Ibid.* at 21 (emphasis added).

125 Black, 'The Emergence of Risk-Based Regulation and the New Public Risk Management in the United Kingdom', [2005] *Public Law* 512 at 519.

126 Murphy and Whitty, 'Is Human Rights Prepared? Risk, Rights and Public Health Emergencies', (2009) 17 *Medical Law Review* 219 at 233 (emphasis added).

deployment of risk helps to buttress the 'deficit model' of citizen participation constructed by the discourses outlined above.

A further concern with risk governance is the way in which it works within neoliberalism's excessive freighting of individuals and groups with agency and responsibility. Individuals must self-manage their risk,¹²⁷ a tendency demonstrated in relation to, say, new diagnostic technologies, which make possible certain discourses on risk for those trying to determine their individual risk of cancer.¹²⁸ This move aids and abets depoliticisation in that it denies the socially constructed nature of risks, in other words, the way in which factors beyond individual control impact on personal risk. As a further consequence, there is also a denial of the potential of collective action to manage and control the social arrangements—such as the neoliberal orientation of EU governance—that help to generate individual risk.

Of course, those 'at risk' can share an identity and demonstrate 'biosociality'.¹²⁹ Yet it should be queried whether such groupings at least consider the potential of collective action to reorganise the social arrangements that construct risk. Linking back to 'rights as risk', another valence and implication of that framing is the way in which it renders risk useful to citizen participation oriented towards empowerment. This framing is useful since it creates space for human rights (understood as being about empowerment) to enter the logic of organisation and accountability and provide citizens with a way to shape governance. Citizen participation could also be enhanced by acknowledgement of uncertainty—and recognition of the possibility of failure—around new technologies and, therefore, the need for input from those who are affected by decision-making that cannot be based on science alone. Resort to the precautionary principle would help to provide such a 'way in' for citizens. The principle provides scope for citizen participation in conditions of uncertainty through explicit reference to societal concerns and norms.¹³⁰ One limitation on exploitation of the principle is that it is currently usually used in relation to green technologies.¹³¹ Nevertheless, the principle might be applied

127 Dean, *Governmentality: Power and Rule in Modern Society* 2nd edn (London: Sage, 2010); and Kemshall, 'Social Policy and Risk', in Mythen and Walklate (eds), *Beyond the Risk Society* (Maidenhead: Open University Press, 2006).

128 Robertson, 'Biotechnology, Political Rationality and Discourses on Health Risk', (2001) 5 *Health* 293.

129 Rabinow, *Essays on the Anthropology of Reason* (Princeton NJ: Princeton University Press, 1996); and Gibbon and Novas (eds), *Biosocialities, Genetics and the Social Sciences* (London: Routledge, 2007).

130 That is, 'the determination of a tolerable risk level generally requires the involvement of the public in one way or another', see de Chazournes, 'New Technologies, the Precautionary Principle, and Public Participation', in Murphy, *supra* n. 1 at 179.

131 Typically genetically modified organisms (GMOs). For an overview, see Pollack and Schaffer, *When Cooperation Fails, The International Law and Politics of Genetically Modified Foods* (Oxford: Oxford University Press, 2009).

to red technologies,¹³² generating potential for citizen participation in that governance.

Having considered risk, the discussion now turns to discuss the implications of bioethics for citizen participation. Human rights is referenced in several international declarations on the topic, for instance, the Universal Declaration on Bioethics and Human Rights (2005), and in the European context there is interaction between bioethics and human rights in, for instance, the Convention on Human Rights and Biomedicine (the Oviedo Convention) and its Protocols.¹³³ Within the EU bioethics has gained prominence through the introduction of ethics committees in the Member States by the Clinical Trials Directive,¹³⁴ and at the EU level, through the creation of the Group of Advisers on the Ethical Implications of Biotechnology (GAEIB),¹³⁵ appointed in 1991, and which became the European Group on Ethics (EGE) in 1997. The EGE's mandate was renewed in 2001 and 2005, and on the last occasion 'to cover all areas of the application of science and technology'.¹³⁶

The EGE lacks a firm constitutional basis in EU law,¹³⁷ but it has a great deal of influence through the advice it provides the Commission on the ethical aspects of new technologies. It is composed of experts, whose opinions are published immediately after adoption.¹³⁸ The former chair of the EGE has said that several of the opinions have been based on a 'human rights oriented approach'.¹³⁹ As bioethics has been institutionalised in policy-making through the opinions¹⁴⁰ of the GAEIB/EGE, it has been transformed into a form of normativity beyond law or 'grey governance',¹⁴¹ generating various exhortatory, persuasive and binding consequences. These support EU funding of controversial research¹⁴² and legislation¹⁴³ on new technologies.

132 These intervene in human biology. For this argument, see Brownsword, *supra* n. 1 at 76.

133 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine 1997, ETS No 164 ('the Oviedo Convention'). As of March 2009, four additional protocols to the Convention have been adopted: on the Prohibition of Cloning Human Beings, adopted 12 January 1998, ETS No 168; on Transplantation of Organs and Tissues of Human Origin, adopted 24 January 2002, ETS No 186; on Biomedical Research, adopted 25 January 2004, CETS No 195; and on Genetic Testing for Health Purposes, adopted 27 November 2008, CETS No. 203.

134 Directive 2001/20/EC.

135 *Supra* n. 95.

136 Decision 2005/383/EC.

137 Busby, Hervey and Mohr, 'Ethical EU Law: The Influence of the European Group on Ethics in Science and New Technologies', (2008) 33 *European Law Review* 803.

138 For an overview, see: <http://ec.europa.eu/european.group.ethics/avis/index.en.htm> [last accessed 27 August 2010].

139 Hermerén, 'Accountability, Democracy, and Ethics Committees', (2009) 2 *Law, Innovation and Technology* 153.

140 See: <http://ec.europa.eu/european.group.ethics/avis/index.en.htm> [last accessed 27 August 2010].

141 *Supra* n. 137.

142 Opinion 10 – 11/12/1997 – Ethical aspects of the 5th Research Framework Programme and Opinion 22 – 13/07/2007 – The Ethics Review of hESC FP7 Research Projects.

143 For an overview, see *supra* n. 137.

It could be argued that the comprehensiveness of the EGE's opinions, which range from synthetic biology,¹⁴⁴ to animal cloning for food supply,¹⁴⁵ prenatal diagnosis¹⁴⁶ and products derived from human blood or human plasma,¹⁴⁷ suggests that the group is, to quote Jasanoff, 'conceived in instrumental terms, to neutralize the potentially divisive consequences of Community [now EU] policy regarding the life sciences'.¹⁴⁸ This view is supported by Busby, Hervey and Mohr, who point out that, like EU agencies such as the EMEA, the EGE supplies 'authoritative normative endorsement to legislation that supports the activities of market actors within the biotechnology industry'.¹⁴⁹ Such legislation, like the ATR noted above, usually includes a 'Whereas' endorsement by the EGE in the recitals,¹⁵⁰ rendering bioethics a procedural requirement. In other words, bioethics is conceived in instrumental terms to support the establishment, functioning and optimisation of the internal market.

To elaborate, before the GAEIB was created, public discussion of the ethical dimension of what was then EC governance of new technologies was eschewed in favour of the criteria of safety, quality and efficacy. It was 'imperative' to 'avoid a situation creating uncertainty (which) could result in a diversion of investment and could act as a disincentive for innovation and technological development by industry'.¹⁵¹ Bioethics was linked to the avoidance of regulatory uncertainty and potentially harmful confused public debate: 'This is important for industry as such confusion can adversely influence the whole climate for industrial development of biotechnology'.¹⁵² Moreover, it appears bioethics was actually constructed as being about education in that its purpose was 'to ensure that the general public is kept properly informed'.¹⁵³ In other words EU citizens were aggregated into a single public constructed in the 'deficit model' as being in need of education so as to underpin economic optimisation. As such, bioethics implicitly disempowered citizens as it was used to pacify controversy and public contestation.

After the inception of the GAEIB, now EGE, bioethics became linked more closely to the project of integration, an integral component or precursor of which is the fostering of EU citizenship. Bioethics is now more about providing a democratic basis for governance through the representation of the values of EU citizens: 'European integration *must mean more* than establishing a single market; progress in science and technology must be given a *human, social and*

144 Opinion 25 – 17/11/2009 – Ethics of Synthetic Biology.

145 Opinion 23 – 16/01/2008 – Ethical Aspects of Animal Cloning for Food Supply.

146 Opinion 6 – 20/02/1996 – Ethical Aspects of Prenatal Diagnosis.

147 Opinion 2 – 12/03/1993 – Products Derived from Human Blood or Human Plasma.

148 Supra n. 107 at 90.

149 Supra n. 137 at 842.

150 Recital 28, Regulation 1394/2007.

151 Supra n. 95 at 8.

152 Ibid. at 11.

153 See: <http://ec.europa.eu/european.group.ethics/archive/1991.1997/organisation.en.htm> [last accessed 27 August 2010].

*ethical dimension, otherwise European citizenship cannot be established.*¹⁵⁴ Indeed, through the EGE the ‘Commission aims to promote responsible research in Europe and to keep the rapidly advancing progress in science in harmony with the *ethical values of all Europeans*’.¹⁵⁵ As such, bioethics has underpinned an intensification of talk of dialogue between science and society.¹⁵⁶ However, while the latter evokes society, there is no attempt to involve it. Reinforcing the complementary public and expert rationalities present in the documents analysed above, there is no pretence of participation as consultation, but rather representing the supposed views of citizens in expert discourse, a move that reinforces the limited boundaries of participation.¹⁵⁷

More broadly, citizen participation in bioethics is also undermined by the principle of subsidiarity, found in Article 5 TEU. The latter operates to determine when the EU can act on competences it shares with the Member States, such as in the area of the internal market. The principle is ordinarily conceived as being about limiting occasions when the EU legislates in place of the Member States and, therefore, reducing the distance between governance and citizens. Nevertheless, in the EU, bioethics is to be determined by Member State ‘governments’ rather than their citizens.¹⁵⁸ Furthermore, when the legislation adopted by the EU legislature impinges on bioethics, such as the Human Tissue and Cells Directive¹⁵⁹ and the ATR, its ethical content is removed from citizen contestation to be determined by committees and the Member States.¹⁶⁰

Overall, the impression is that the EU is ‘*de facto engaged in unaccountable forms of biopolitics*’. Ethics is represented as if it is naturally *a matter of expert judgment only*, though this very framing has markedly shaped, and continues to shape, which ethics and whose values count in European politics’.¹⁶¹ In these various ways the public and expert rationalities identified above are reinforced, and citizens are disempowered as experts are valorised. Bioethics operates to support the ‘deficit model’, demarcating the boundaries of conceivable citizen participation, and limiting citizen input into the normative dimension of new technologies to representation of their values in expert discourse.

154 See: <http://ec.europa.eu/european.group.ethics/archive/1991.1997/bilan.en.htm> [last accessed 27 August 2010] (emphasis added).

155 Supra n. 77 at 49 (emphasis added).

156 More generally, see Jecker et al., *Bioethics. An Introduction to the History, Methods, and Practice* (Sudbury MA: Jones and Bartlett Publishers, 1997); and Stevens, *Bioethics in America. Origins and Cultural Politics* (Baltimore MD: Johns Hopkins University Press, 2000).

157 Supra n. 77 at 49.

158 Tallacchini, ‘Governing by Values. EU Ethics: Soft Tool, Hard Effects’, (2009) 47 *Minerva* 281 at 293, citing <http://web.archive.org/web/20030418165425/http://europa.eu.int/comm/research/science-society/ethics/research-e-legislation.en.html> [last accessed 27 August 2010].

159 Directive 2004/23/EC.

160 Supra n. 160 at 293–5.

161 Supra n. 77 at 47 (emphasis added). Indeed, ‘bioethics has always been a biopolitics and the political dimension is only now coming into relief for bioethicists’, see Bishop and Jotterand, ‘Bioethics as Biopolitics’, (2006) 31 *Journal of Medicine and Philosophy* 205 at 205.

However, even as bioethics as practised by the EGE operates to depoliticise and thwart citizen participation, paradoxically it can be seen to open up a space for democratic contestation and participation.¹⁶² In making pronouncements on new technologies, the EGE is opening up knowledge domains and patterns of thought, which make possible contestation and attempts at citizen participation in imagining new technologies. At a general level, such practices or 'biosocialities' were noted above.¹⁶³ These hold out at least the potential for citizens to refashion bioethical discourses so as to shape governance.

4. Concluding Remarks

This article analysed several key documents taken to be indicative and representative of the discourses constructing citizen participation in the EU's neo-liberal governance of new technologies. It argued that citizen participation appears to be deployed as a legitimating technique rather than as a substantive input into governance. As such, citizen participation is not fully oriented towards a human rights perspective, which is focused on engendering empowerment. In particular, the analysis has shown how the framing and shaping of new technologies in that governance is 'marked off' from popular control and contestation. The boundaries of citizen participation are indicated in EU law, but its contours are drawn more clearly through the overarching approach to citizen/science relations provided in *'European Governance'*, and a number of documents that operationalise its content in the specific context of the governance of new technologies.

The limited boundaries of citizen participation are set and buttressed by the implicit construction of citizens within a 'deficit model', which is underpinned by expert and public rationalities. In this mould, citizens are deemed to be in need of education through their participation in governance. As such the model presumes that issues are framed and settled prior to citizen involvement. PUST supports the 'deficit model' by providing the data that confirms the need for citizen education. The cross-cutting discourses of risk and bioethics aid and abet the 'deficit model'. Despite the uncertainty around new technologies, the governance of the risks they generate relies on the power of scientific rationality and objectivity to reinforce the 'deficit model'. Bioethics is supposed to represent the views of EU citizens in governance, and therefore provide a democratic basis, but it is actually an expert-generated discourse deployed to calm contestation around new technologies. This operation of bioethics supports the idea that citizens have little to contribute given the 'deficit' in their understanding. As a corollary of the 'deficit model', citizens are supposed to

162 Supra n. 74.

163 Supra nn. 9 and 129.

tend to their own interests and self-manage—and they are deemed incapable of sharing power with fellow citizens in order to organise their options and change governance.

Although the EU's use and deployment of citizen participation is deeply problematic from a human rights perspective concerned with empowerment, integral to a Foucauldian analysis is the double-edged or paradoxical nature of power. Such an understanding provides hope for an approach to citizen participation that is about empowerment, and which supports a similar understanding of human rights as it competes against the other points in the 'bioethical triangle'. As indicated in several places throughout the article, the discourses constructing citizen participation also create a platform for citizens, a rhetorical way into governance and a space in which citizens can demand and contest the exercise of the EU's power over life. Examples of the assertion of agency also include patient movements (say HIV/AIDS activists in the United States¹⁶⁴ or cancer activists in the EU¹⁶⁵) that have become involved in governance as 'experts of the soma'¹⁶⁶ who work to expand the range of credible framings and perspectives on their conditions. In short, citizens must remain critically engaged with the discourses that construct their participation in EU governance if they are to combat the 'deficit model' and shape new technologies.

164 Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (London: California University Press, 1996); and Cooper, *Life as Surplus* (London: Washington University Press, 2008), particularly 'On Pharmaceutical Empire: AIDS, Security, and Exorcism'. Also see Rabeharisoa and Callon, 'Patients and Scientists in French Muscular Dystrophy Research', in Jasanoff (ed), *State of Knowledge* (London: Routledge, 2004).

165 Trubek, Nance and Hervey, 'The Construction of a Healthier Europe: Lessons from the Fight Against Cancer', (2008) 26 *Wisconsin International Law Journal* 804.

166 *Supra* n. 9 at 27–31.