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Democratizing Bioethics. Online Participation and the Life Sciences

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DEMOCRATIZING BIOETHICS

Online participation and the Life Sciences

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Acknowledgments

It is commonplace to start academic books with an explicit acknowledgment of all of the people that contributed—in fashions that usually range from institutional and financial support, to intellectual debt, up to the more generic, but still fundamental, provision of emotional buttress—to the making of the work that follows. This is typically accompanied by a disclaimer in which the author acknowledges his own full responsibility for any of the mistakes that might be contained in the work itself.

Though this is not a book, I will subscribe to this rule. I am responsible for all mistakes that might be contained in this dissertation, but am also indebted to numerous people, without whom the work itself would not have been possible. Four years is a really long time and listing all of them might take a while. I will try and keep it as brief as possible.

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Introduction

When my supervisor and I started discussing the opportunity of writing this dissertation, which happened relatively late into my PhD, we shared one bold idea: public bioethics in Italy was in dire straits. In a number of respects this situation looked unsatisfactory both from a scholarly point of view and to us as Italian citizens. Formal institutions such as the National Committee for Bioethics (CNB) had proven inadequate in more than one circumstance and had been doing so in ‘creative’ ways, mainstream politics did not seem to have much of a clue as to how to go about legislating morally controversial issues in a way that was perceived as legitimate by the population, the academic debate had hardly any recognizable impact onto the actual policy-making, and the population had, in more than one occasion, fallen prey of sensationalist media coverage, mustering around scientifically and morally dubious causes.

We clearly saw some space for improvement and set out to try and foster a participatory initiative, ideally a long-term platform for the discussion of bioethically controversial topics that might have had some recognizable and longed for impact onto the Italian public sphere. It was meant to combine features we believed to be quite uncontroversially desirable in institutions supposed to support public choices: (i) that decisions relied on mechanisms of inclusion, i.e. allowing for bottom up input, and (ii) that incompetent participation did not derail the process. After all, popular control is a fundamental kernel of most democratic theories and it was unclear why responsiveness to the popular will ought not to extend to the domain of bioethics in a democratic society. Essentially, we were convinced that bioethics deserved to be democratized and we were relatively clear about how that needed to be practically done.

However, this initial intuition sparked a similarly intuitive question: what, in our efforts, would have made the resulting decisions more legitimate? It was a fairly simple question. As it often happens, though, it turned out to require asking a number of related questions, which prompted articulate and long answers. Why would the solution of essentially moral issues require the application of a political conception of legitimacy? And what makes political resolutions legitimate in the face of moral disagreement? How can we ground the compelling power of those resolutions vis-à-vis the fact of moral pluralism? If there exists any acceptable definition of legitimacy, how do we measure the legitimacy of our processes and that of our decisions? Also, why ought we to prescribe competent

participation in bioethics when competence requirements do not apply to political participation in general? What is the relationship between political theory and institutional practice? And what happens if our theoretically grounded prescriptions turn out not to yield the empirical results we expected of them?

The dissertation I am introducing is the winding road that answering these questions led to. It can therefore be seen as one—fairly long—argument trying to ground the claim that indeed it makes sense to try and democratize public bioethics in Italy (but there are no substantial reason why this conclusion should not be extended to other political communities, sharing a similar set of political problems, which most advanced democracies seem to be facing). Trying to develop this argument required tackling both a series of rather tough theoretical issues in political theory and dealing with an array of practical constraints to properly empirical experimentation. I did my best to take up both challenges in ways that make sense. I am aware of the ambitious nature of the overall project. Hopefully what follows will prove that the project was not overly ambitious.

A brief glossary

This dissertation tries to grapple with the political predicament of public bioethics. What the political predicament amounts to will be made clear below. For the purposes of this paragraph I mean to simply provide a commonsensical definition of what public bioethics is and somewhat stipulatively assume that definition.

Public bioethics is the domain within which claims to collectively binding decisions concerning morally sensitive issues arising from biomedical progress are adjudicated. In a sense public bioethics (which will at times be referred to via the shorthand of bioethics) encompasses both the domains of research ethics, clinical ethics and medical ethics to the extent that, within these domains, claims are meant to be laid as to how, as a community, we ought to act with respect to specific moral problems.

I will assume a definition of what counts as public that I borrow from Habermas. In his classic, *The structural transformation of the public sphere*, he provides a thorough historical reconstruction of how the very idea of nowadays public sphere has come to mean what we now take it to mean.

“In a rescript of Frederick II from 1784 one reads: “A private person has no right to pass public and perhaps even disapproving judgment on the

actions, procedures, laws, regulations, and ordinances of sovereigns and courts, their officials, assemblies, and courts of law, or to promulgate or publish in print pertinent reports that he manages to obtain. For a private person is not at all capable of making such judgment, because he lacks complete knowledge of circumstances and motive.”¹ A few years before the French Revolution, the conditions in Prussia looked like a static model of a situation that in France and especially in Great Britain had become fluid at the beginning of the century. The inhibited judgments were called “public” in view of a public sphere that without question had counted as a sphere of public authority, but was now casting itself loose as a forum in which the private people, come together to form a public, readied themselves to compel public authority to legitimate itself before public opinion” (Habermas 1991, 25).

According to this later and decidedly modern definition, the public sphere is the sphere of public authority, where people come together—in countless ways, and in a wide array of venues—to collaboratively, and to some degree disorderly, construe the notion of legitimacy and to ask that public authority complies with that notion of legitimacy. Institutions are meant to provide some order to the public sphere and most of this dissertation is concerned with the way we structure institutions to host the political adjudication of moral claims in bioethics. A definition of the term is therefore in order.

The term institution is generally used whenever three conditions obtain: an institution is “*a*) a norm (a rule) or a *class* of formal and/or informal norms, *b*) that results in a *regularity* of behaviors, compliant with the norm or norms, *c*) and that is endowed with some *sanctionatory* mechanism.” (Panebianco 2009, 97). This is a fairly broad definition of institution that might be taken as coextensive with any historically crystallized set of social practices. I will mostly use the term in this loose sense. However, at times I will refer to institutions, institutional setting, institutional architectures, to denote a subset of these practices, specifically the class of formally recognized practices embedded in democratic procedures.

¹ “W. Schone, *Zeitungsvesen und Statistik* (Jena 1924), 77” (Habermas 1991, 256).

There are no other recurring terms whose meaning is taken for granted from here on. Whenever terms are used, which may raise some definitional perplexity, I made my best efforts to introduce them explicitly.

In what follows I summarize the content of the thesis and pinpoint the most relevant joints of its structure.

Structure of the thesis

Democratizing Bioethics concerns the relation between science and democracy in two separate and distinctive ways: on the one hand it is about the role that science plays in democratic societies, and exactly how democratic institutions can fit the governance of a specific scientific domain—the Life Sciences; on the other it is about the role that (some understanding of) science can play as a blueprint for the design of democratic institutions for public bioethics.

The work provides a theoretical framework in which proper democratic participation is defined throughout a continuously revisable and progressive endeavor that is argued to resemble in significant respects scientific progress. This framework is subsequently deployed in order to lay out a normative proposal as to the values that ought to inform a compelling institutional design for the democratization of bioethics. Finally, this institutional design, i.e. an ICT instrument for bioethical deliberation, is built and preliminarily tested, and I report on the results of this preliminary test.

The dissertation is divided in three parts. In introducing the work I summarize some aspects of the now notorious Stamina case, highlighting three of the features of the story that, I contend, are central to the understanding of current and unresolved issues concerning the management of moral disagreement in science (in democratic societies). The very first section of the first part lays out the reasons why public bioethics is to be regarded as an inherently political endeavor and, therefore, why a political theory of public bioethics is in order. Given the fairly recent ‘deliberative democratic turn’ in bioethics and science policy-making, I then tackle foundational issues of contemporary democratic theory arguing that these foundational issues are consistently overlooked in the literature concerning practical applications of deliberative democratic tools for bioethical policy-making and that they need to be foregrounded if there is any hope of using empirical literature on democratic innovations to feedback onto normative theories of political legitimacy and, subsequently, onto institutional design. I

will claim that, unless these issues are discussed and solved, any appeal to the democratization of institutions that deal with moral disagreement rests on some axiomatic definition of political legitimacy, whose measure cannot but be construed as a function of the axiomatic normative theory on which the definition depends. This results in normative theories that act as unrevisable models of political legitimacy and thereby favor some institutional design over some others simply *by definition*. Hence, I focus on the promise that some understanding of Habermas' approach to law, what I call *moderate political realism*, can lead democratic theory beyond the "political moralism" vs. "political realism" divide, rejoining descriptive and normative conceptions of political legitimacy.

In the second part, building upon this moderately realist approach I specify the features of a normative theory of political legitimacy for bioethics: an *online moderate epistocracy* grounded in a republican definition of freedom as non-domination and in a Deweyan conception of democracy as education. I defend the institutional arrangement that is deduced from this theory from objections raised against existing attempts at participatory governance summarized in Part I.

Finally, in Part III, I rough in an empirical test of the institutional arrangement informed by my normative theory, illustrating an exploratory pilot experiment we conducted in Italy on the online participatory governance of direct-to-consumer (DTC) genetic testing.

Part I

A theoretical framework for democratic innovations

Moral disagreement and the Life Sciences

Moral pluralism challenges democratic life in ways that at times threaten the very existence of advanced democracies. People are bound by norms they sometimes genuinely disagree with and feel are at odds with their deeply held moral beliefs. Democracy cannot avoid wronging citizens altogether in this respect. Still, societies need to rely on some sets of norms and institutions and intuitively, there seem to be better and worse ways of tackling *politically* moral quandaries, ways that result in more and less ‘legitimate’ norms.

In the paragraph that follows I reconstruct a case of ethical disagreement that was prompted by recent and controversial developments in the Life Sciences, i.e. cell therapies and the prospects they open up. This case well summarizes the reasons of concern for the political theory that underlies the way in which bioethical issues are currently handled in democratic polities.

The Stamina case: or the national broadcasting of moral disagreement

February 17th 2013. *Italia 1*, one of the several TV channels part of the network owned by Mediaset S.p.A., the largest privately held commercial television network in Italy, is broadcasting in prime time *Le Iene*. More than 3 million people are watching, summing up to a share of more than 14% of the population watching television that night². *Le Iene*³ is a long-standing TV program (it has been running since 1997), which hybridizes investigative journalism with entertainment. Giulio Golia is introducing a story whose title eloquently summarizes the point the authors are making: “Stem cells: Is there hope for Gioele?”⁴. Gioele, the one-and-a-half year-old child of a couple from Palermo, Sicily, is affected since birth by Spinal Muscular Atrophy type 1 (SMA1), the most severe form of SMA which leads to death usually before two years of age due to fatal respiratory failure (Su et al. 2011). SMA is an autosomal recessive neurodegenerative disease. It has, especially as compared to its severity, a fairly high carrier frequency (between 1 in 35 and 1 in 50 (Su et al. 2011)). There was not, and there still is not, to date, any treatment available for any form of SMA (Roe and Shur 2006). Gioele, when the TV program was shot, could barely move and only artificially breathe. His parents had been trying to arrange to have him treated with stem cells prepared using a method allegedly discovered by Davide

² Original data by Auditel are available upon payment. Source: <http://www.davidemaggio.it/archives/70827/ascolti-tv-di-domenica-17-febbraio-2013> (last access April 16th 2014).

³ A proper translation would turn the title Italian into *Reservoir dogs*. That is because reporters wear suits and sunglasses that make explicit reference to Quentin Tarantino’s main characters dress code in the movie that goes by the same name.

⁴ Original title in Italian “Staminali: Una speranza per Gioele?”. <http://www.iene.mediaset.it/puntate/2013/02/17/golia-staminali-una-speranza-per-gioele-7610.shtml> (last access April 16th 2014).

Vannoni's research group. Davide Vannoni at the time was a tenured professor of cognitive ergonomics and psychology of communication at the University of Udine⁵. In 2009 he founded and became president of the Stamina Foundation, a non-profit organization whose explicit mission is to spread knowledge on adult stem cells beyond the scientific community (and specifically to the 'civil society') and to promote research on stem cells acting also as an institutional bridge towards the clinical application of regenerative medicine⁶. At no point in the program, nor anywhere in the Stamina Foundation website, was it officially claimed that what has since then come to be known as Vannoni's (or Stamina) method is an effective treatment for any disease. However it is extensively suggested that regenerative medicine—the Stamina method being an instantiation of some kind of such a medicine—might be used in the treatment of a wide array of diseases ranging from cardiac problems, to Parkinson's disease, to type I diabetes. At the time when the piece is broadcast on national television, the issue is essentially judicial in nature. A public hospital, the Spedali Civili in Brescia, had been administering mesenchymal stem cells derived using Vannoni's protocol to a number of patients with untreatable diseases (one of these patients, Celeste, affected by SMA1, features in the televised story). An inspection injunctioned by district attorney Raffaele Guariniello in late 2012 and subsequently received and endorsed by the Agenzia Italiana del Farmaco (AIFA), had resulted in the immediate discontinuation of the administration at the hospital in Brescia⁷. However some of the patients whose treatment had been interrupted had successfully appealed to their local court. The courts had upheld their requests apparently⁸ on the grounds that (i) there was a clear threat to the life of the children and (ii) the treatment did qualify for compassionate use⁹, i.e. it could legitimately be administered without

⁵ He has since then lost his position in Udine and presently has tenure at the Università Niccolò Cusano, an online university based in Rome.

⁶ In Italian "Diffondere la conoscenza sulle cellule staminali adulte. [...] La nostra Fondazione vuole contribuire a rendere queste conoscenze patrimonio di tutti: sia del mondo scientifico, sia della società civile in tutte le sue forme" and "Sostenere la ricerca sulle cellule staminali adulte. [...] la Fondazione che si pone anche da soggetto intermediario tra le conoscenze biologiche prodotte da altri centri europei ed extraeuropei, presso i quali finanzia programmi di ricerca, e le applicazioni mediche, producendo convenzioni con centri trapianto o strutture ospedaliere pubbliche e private in diversi paesi." From <http://www.staminafoundation.org/section/mission-staminali-adulte> (last access April 16th 2014).

⁷ The official document by the AIFA: http://www.agenziafarmaco.gov.it/sites/default/files/ordinanza_1-2012.pdf (last access April 16th 2014).

⁸ I was unable to retrieve the actual pronouncements of what in Italian are called "Tribunali del lavoro" (roughly labour courts). The information about the justification for the sentence has however been referred to in a number of Italian newspapers such as Corriere della Sera (http://www.corriere.it/salute/12_agosto_23/giudice-ordina-staminali-alla-bimba-marco-pappagallo_a0e00210-ec7-11e1-89a9-06b6db5cd36c.shtml last access April 16th 2014) or L'Unità (<http://cerca.unita.it/ARCHIVE/xml/2455000/2450111.xml?key=Pino+Stoppon&first=101&orderby=0&f=fir> last access April 16th 2014).

⁹ The compassionate use of drugs (notice that cell therapies are normed as drugs in Italy, and part of the controversy, as I will show below, lies precisely in this identification) is regulated by a decree issued by the Ministry of Health on May 8th 2003 (and revised in 2008). It can be found here: <http://www.agenziafarmaco.gov.it/sites/default/files/DOC230113.pdf> last access April 16th 2014. The decree prescribes that clinical trials beyond phase 2 provide evidence as to the promises held by the treatment in order for the definition of compassionate use to apply.

the administration being part of an ongoing clinical trial. The hospital was therefore compelled to provide those patients with further infusions as soon as possible. Gioele's parents in the meantime had put forward a formal request to the hospital but had been denied any reply, presumably as a result of the development of the legal controversy. Following the intervention of the TV program, Gioele's parents eventually managed to get their child the treatment they wanted him to be administered. The piece would end up with Gioele's mother claiming that some results (she attributed to the therapy) were already visible after few days since the first infusion. The interviewer, in closing, asked her whether she knew that the hospital and Vannoni himself were under investigation for the administration of potentially harmful medications, adding that the Ministry of Health had deemed the method 'unorthodox'. This is how she replied.

“Frankly, I mean, what collateral effects can affect a baby who is totally paralyzed, unable to eat, speak or breathe? What can make him worse off than he already is? [...] If there's even the slightest of chances that we can give him a longer and decent life, I believe it is my duty, as a mother, as a parent, to try. [...] I think he has a right to a decent life. [...] On our lives, we decide. No one else.”¹⁰

That was the first time I personally encountered the story. I have followed quite closely the long winding political and judicial road of the so-called Stamina case since. This took place at a 'strange' time in Italian political history. Renato Balduzzi, minister of health during the months in which the story unfolded, left his office when the Monti cabinet was dismissed in the early Spring of 2013. A new Parliament was elected, giving way to a new government led by Enrico Letta who took over Pierluigi Bersani's (the then secretary of *Partito Democratico* (Democratic Party)) unsuccessful attempt at securing a government without the support of the *Popolo della Libertà* (The People of Freedom). Enrico Letta's Parliamentary majority embraced parts of the centre-right (e.g. Mario Monti's *Scelta Civica* (Civic Choice), the Christian democratic *Unione di Centro* (Union of the Centre) which both received appointments to some ministry in return) and, more significantly, arranged what have been called *larghe*

¹⁰ “Sinceramente io penso che su un bambino che è paralizzato totalmente, che non mangia, non parla, non respira...quali effetti collaterali ci possono essere? Di più di quanto lui già ne ha addosso? Cosa gli può succedere di più? [...] Se io posso dare a mio figlio una speranza in più di allungare la vita a mio figlio e di dargli una vita dignitosa, io devo provare da madre, io devo provare da genitore. [...] Penso che è un diritto suo soprattutto. [...] Sulla vita nostra decidiamo noi, non decidono gli altri.” Translation is mine. <http://www.iene.mediaset.it/puntate/2013/02/17/golia-staminali-una-speranza-per-gioele-7610.shtml> 10' 15" (last access April 17th 2014).

intese, a coalition lumping together representatives from the elected both for the *Partito Democratico* (PD) and Silvio Berlusconi's *Popolo della Libertà* (Pdl). This resulted in the appointment of people from the Pdl to five ministries and to the vice-presidency of the cabinet. Beatrice Lorenzin from the Pdl was nominated minister of health. She managed to retain her position after February 2014 along the surprisingly untumultuous shift from the Letta to the Renzi cabinet, when the PD withdrew its support to their own Prime Minister Enrico Letta. One of the tasks Beatrice Lorenzin inherited from Renato Balduzzi's mandate was the management of the increasingly intricate and increasingly advertised Stamina case. The issue of how to settle the case is still ongoing at the time of the discussion of this thesis. However, I will not delve into all of the details here. Some of these, though interesting as a matter of historical record, are irrelevant to the point I am making and to the topic I will be covering in the thesis. I will particularly disregard journalistically enticing backstories and will instead cherry pick and highlight some moments that will help me pinpoint the reasons why this and similar stories¹¹ recapitulate fundamental issues in the current relationship between science and democracy (or politics more in general).

The technocratic governance of stem cell treatments

In November 2012, once the results of the inspections led by the AIFA and the *Nucleo Antisofisticazioni* (NAS an Anti-Adulteration group of the *Carabinieri*, one of the Italian Police forces) had been acquired by the Ministry of Health, the then minister Renato Balduzzi set up a board of 5 scientific experts ("Board di saggi"¹², one of whom did not actually attend the meeting). They were summoned to draft recommendations as to the governance of stem cell treatments in Italy. This fairly small group of people was also specifically asked to report about the inspections conducted in Brescia and advise as to the discontinuation of the treatments being administered at the hospital relying on Vannoni's method. They recommended: (i) that local and national institutions collaborate to the compilation of a formal record of all stem cell treatments (excluding hematopoietic stem cell treatments—excluded for reasons

¹¹ Probably the most recent example is the #savejosh case. Josh being a 7-year-old boy who had defeated cancer several times since the age of 9 months and was now, due to a weakened immune system, facing a life-threatening viral infection. After a fairly big public outcry, Chymerix, a company producing an unapproved anti-adenoviral infection drug apparently capable of curing Josh's medical condition was pressured into giving him this experimental treatment. They did so resorting to some kind of legal workaround: instead of granting the kid the compassionate use of the drug, they had the FDA immediately green-light a new clinical trial for which he was eligible.

The case was reported in the Washington Post: http://www.washingtonpost.com/national/health-science/crowdsourcing-medical-decisions-ethicists-worry-josh-hardy-case-may-set-bad-precedent/2014/03/23/f8591446-ab81-11e3-adbc-888c8010c799_story.html?hpid=z1 last access April 17th 2014.

¹² <http://www.salute.gov.it/dettaglio/dettaglioNews.jsp?id=2306&tipo=new> last access April 17th 2014.

that will be touched upon below) being performed both in public and private hospitals; (ii) that all cell therapies make use of products manufactured in AIFA-certified cell factories (this holding for both approved clinical trials and for compassionate use); and (iii) that the Ministry of Health insist on presenting patients undergoing treatments using the Stamina method with the opportunity of switching to any other, more scientifically validated, alternative. This latter recommendation was formulated on the grounds that, according to the laboratory analyses performed by the *Istituto Superiore di Sanità* and in Massimo Dominici's lab (Massimo Dominici being a member of the board himself) and relying on the review of two patent requests describing the method, the protocol was scientifically unsound, the administration of the therapy could be linked to severe harms and unacceptable biological risks and, most importantly, patients might be undergoing treatments as a result of false hopes, potentially fraudulently fostered by the proponents of the method.

In introducing one of his latest works Josiah Ober recalls William J. Clinton's motto summarizing his strategy for national health care policy-making: "*Gather the experts. Close the door. Design a policy. Roll it out. Reject criticism.*" (Ober 2008, para. Introduction). Ober contends that some Athenian time-traveling democrat would despise such an approach due to its underlying willful ignorance of dispersed knowledge¹³. What is interesting here is not so much the epistemic advantage of democracy over other forms of government, but rather the similarity between how Clinton describes the way toward the streamlining of decision-making in healthcare policy and the way the Italian Ministry of Health decided to set up the governance of stem cell treatments. We can dub this strategy *technocratic*. Technocracy can be defined as "a system of governance in which technically trained experts rule by virtue of their specialized knowledge and positions in dominant and political and economic institutions" (Fischer 1990, 17; cited in Evans 2006, 217). This approach to governance, according to Evans (2006) can be said to rely on at least two main kernels: these we will call the *anti-politics kernel* and the *value-neutrality kernel*. According to the former, the idea that complex issues can be tackled asking to a representative professional politician or the person on the street is preposterous. In a sense, technocracy demands that at least some decisions (namely the most complex ones¹⁴) be removed from the sphere of the

¹³ Further on I delve more in depth in the epistemic desirability of democratic arrangements.

¹⁴ Notice that given the increasing complexity of the sciences and the highly articulated division of cognitive labor behind most of the decisions communities have to take, a fairly unproblematic extension of the argument would require that almost every decision is 'contracted' to experts in the specific field at hand, therefore reducing politics to the domain of mere endorsement and/or enactment of decisions taken elsewhere.

political and that experts be left to decide on behalf of society. The *anti-politics kernel* therefore relies on a pessimistic assumption about the epistemic capabilities of the public to understand and decide on complex issues (and on a fairly optimistic assumption about the epistemic capabilities of the ‘experts’): the public is not endowed with the skills or the knowledge to make sensible decisions about what a society ought to be doing concerning some issue someone has deemed ‘complex’. This first assumption can be taken to entail that, given the need for public support to technocratically made decisions and the wide-spread ignorance and misinformation of the public opinion, fuelled by sensationalist media coverage of technoscientific issues, “medium- and long term initiatives should be devised to narrow the knowledge gap between experts and the general public” (Bucchi 2009, 2) in the hope that reducing the knowledge gap will reduce the public’s hostility towards science and its activities. However, this kernel alone would hardly make any case for the technocratic governance of issues that raise significant moral disagreement, as bioethical issues do. In fact, one could easily reply to the mere anti-politics technocrat that if moral values are involved in the decision, there is hardly any chance that anyone but the person in the street holding his/her values, knows those values (or knows them better than him/her). The *value-neutrality kernel* serves the purpose of sterilizing such objections. Decisions are put in the hands of experts, or better experts contribute essentially to shaping the way in which public decisions are made, because these decisions are not (or are not presented as) essentially about values. They are (or are presented as) exclusively meant to adjudicate facts.

Technocracy, so characterized, lumps together two distinct forms of removal: (i) the removal of decisions from the domain of politics and (ii) the removal of judgments of values from those decisions.

Against this backdrop, the way decision-making was handled by the Ministry appears patently technocratic: few appointed experts were called upon to solve an issue that was (i) deemed complex (and implicitly more complex than politicians could handle, let alone the people themselves) and (ii) uncoupled, through the very workings of the advisory board, from issues of value. The removal of values in this case, as compared to other cases of policy-making concerning controversial technoscientific issues, was also apparent in the perplexing absence of any of the usual professional bioethicists, with all members of the board being medical doctors or molecular biologists¹⁵. Although

¹⁵ Some space will be devoted further on to the exploration of the role that the Italian National Bioethics Committee (CNB) might have played, but did not play, in this and similar occasions.

the technocratic stance was apparent in the decision that the ministry made, the effort was presented as an instantiation of governance. Interestingly, in fact, the term ‘governance’ features, in its English form, in the Italian title of the board itself. This suggests the existence of a deliberate attempt at mustering the values attached to the “new human technology of governance” (Nowotny and Testa 2010, 74–83), thus trying to somehow ‘proceduralize’ conflict. The term governance has progressively and historically replaced the term government, with the former (as opposed to the kind of centralized hierarchical state regime with which the latter can be identified) implying a form of “regulation in which the participants voluntarily submit to a common goal” (Nowotny and Testa 2010, 75) whose regime operates under conditions of transparency and radical decentralization. One of the defining traits of the human technology of governance is the almost exclusive focus on problem-solving which is accompanied by a deliberate eclipse of social conflicts and power relations.

“[T]he emerging tendency is to shift potential solutions of existing conflicts to the procedural level as much as possible (proceduralization). This leads to a situation in which contents regarded as intractable and difficult to deal with are tacitly presupposed in favour of rendering the procedure transparent.” (Nowotny and Testa 2010, 75)

This is however only one of the several defining features of governance as it came to be characterized since the 1990s (Mayntz 1999). According to Nowotny and Testa there are six other features that contributed to the historical success of governance. I will briefly summarize these and argue that the attempt at governance by the Ministry of Health has systematically disregarded or overlooked all of these issues.

- i. Heterogeneity of participants to the governance is taken to enhance the quality of decisions.
- ii. The openness of the decision-making process to iterative revisions is central to the system of governance.
- iii. Arenas of governance are often (problematically) uncoupled from representative institutions.
This is the case because:
- iv. Deliberation and negotiation, i.e. arguing and bargaining, are regarded as fundamentally more important than majoritarian resolutions.
- v. The identification of common moral grounds is seen as an essential part of the process of governing controversial issues.

- vi. A system of governance requires the creation of some public forum for every willing participant to convene as a stakeholder. (Nowotny and Testa 2010, 77–9)

First, the board of experts tasked by the Ministry of Health with setting up the governance of stem cell treatments was made of only 5 scientists (of which only 4 did contribute to the decision). Whatever specification of the concept of diversity one might be willing to subscribe to, it is hard to argue that the board would be acting upon the recognition of the value of diversity here. Second, although the advisory role of the board makes it hard to establish whether their decision was meant to be seen as open to revision, it is a fact that the decision itself, in the form it was published, had been radically impervious to upstream public input and was not immediately up for grabs to the general public. Third, even though the arena in which the board operated was indeed uncoupled from representative institutions, the homogeneity and dearth of participants made it a peculiarly unlikely locus for negotiation and deliberation. Which allows for at least the suspicion that, fourth, reason-giving and bargaining were not seen as central values in the construction of the project of governance. Fifth, no ethics discourse was ever foregrounded in the decision (this probably also as a result of the common scientific background of board members), resulting in a substantial lack of effort at singling out common moral grounds for the decision to be taken. Sixth, and finally, the board was not only closed to bottom-up stakeholder participation, but also utterly blind to input from the general public, which was neither elicited, nor picked up.

Despite the direct reference to the term “governance”, then, the recruitment of the board of experts by the Ministry of Health looks like a strategic attempt at mobilizing the concept without acting upon the entire array of values and principles that the concept entails. The idea of governance is clearly not unproblematic, and there are a number of ways in which one could define the desirability of a democratic governance of science. I do not assume that democratic governance would be desirable in this case, and am instead criticizing the kind of—suspicious—use of a ‘lexicon’ of governance on the part of the institutional actors involved.

In a sense, then, in conclusion, the attempt put forth by the Ministry was technocratic on at least three different and interesting levels: (i) the Ministry itself had previously been depoliticized (in this case meaning made up of unelected ‘professionals’) as a result of the dire Italian economic situation which had led to the resignation of Berlusconi and the appointment of the Monti cabinet by the Italian

President Giorgio Napolitano, (ii) the board was composed of professional scientists appointed according to their expertise in the field of stem cell research and excluded the opportunity of both recruiting from the general population and feeding the public opinion into the process of policy-making, (iii) the set up of the policy itself made superficial, strategic, and somewhat paradoxical use of the rhetoric of governance, deployed as a technology of control, or management, of moral disagreement rather than as a (more or less desirable) technology of inclusion and non-hierarchical coordination.

Contestation in the public sphere: communicative rationality and legitimacy

“Political communication, circulating from the bottom up and to the top down throughout a multilevel system (from everyday talk in civil society, through public discourse and mediated communication in weak publics, to the institutionalized discourses at the center of the political system), takes on quite different forms in different arenas” (Habermas 2006, 415). Indeed, not every discourse does happen or has to happen, for that matter, in proper institutional arenas. In fact, the public sphere—conceived here along Habermas’ definition “as the sphere of private people come together as a public” (Habermas 1991, 27)—extends well beyond the boundaries of institutions into what Jane Mansbridge calls an all-encompassing “deliberative system”, a system¹⁶ in which:

“Through talk among formal and informal representatives in designated public forums, talk back and forth between constituents and elected representatives or other representatives in politically oriented organizations, talk in the media, talk among political activists, and everyday talk in formally private spaces about things the public ought to discuss [...] people come to understand better what they want and need, individually as well as collectively.” (Mansbridge 1999, 211)

Endorsing an inclusive stance as to what counts as happening within the public sphere, however, does not entail the outright acceptance of just about any claim as to what is a *properly functioning* public sphere. Habermas famously constructed his ideal speech situation as a ““domination-free communication” in

¹⁶ Mansbridge specifies that her use of the term system differs from its technical characterization as a relation between properties of the parts and (emergent) properties of the sum of the parts (Mansbridge 1999, 228).

the sense of the formation of a consensus through the unconstrained constraint of argument in discourse” (Apel 1990, 35). This is even more explicitly stated in the following passage:

"Discourse can be understood as that form of communication that is removed from contexts of experience and action and whose structure assures us: that the bracketed validity claims of assertions, recommendations, or warnings are the exclusive object of discussion; that participants, themes and contributions are not restricted except with reference to the goal of testing the validity claims in questions; that no force except that of the better argument is exercised; and that, as a result, all motives except that of the cooperative search for truth are excluded."

(Habermas 1992, 107–8)

In the remainder of this paragraph I mean to show that the degree of dispersion and the lack of proper mutual challenges to central claims made by the opposing factions can be interpreted as symptoms of the worrying lack of a platform for “domination-free communication”, i.e. both a common set of principles that guide interactions towards mutually binding decisions and a shared space for the definition of those principles and those decisions, for the collaborative construction of a common language of political legitimacy in the Stamina case and in bioethics more generally. Further below I will argue, *contra* Mansbridge, that this consideration does not afford the imposition of what we might call ‘deliberative requirements’ for the whole public sphere, showing however that it makes sense to have deliberative standards proportionate to the degree of bindingness of the output of the specific subset of the public sphere one is engaging with. An explicit proviso is in order concerning the argument presented shortly in this paragraph: I will make instrumental and apparently ideological use of Habermas’ theory of legitimacy here. I do not subscribe to this theory *in toto*, though. This will become apparent as I argue, later on, that the theory itself, though valuable and roughly consistent with the one I will develop for a democratization of bioethics, requires some foundational work that, in Habermas and in theories of democratic legitimacy that followed falling in the tradition he set up, e.g. most notably Gutmann and Thompson’s (Gutmann and Thompson 2004; Gutmann and Thompson 1996), is missing. For the purposes of this paragraph, however, I take Habermas’ view to provide an insightful point of access to highlight the obvious problems that underlie the issue I am

describing, namely that communicative rationality stands in some intuitive and important relation to the legitimacy of mutually binding decisions. Since Habermas' and my normative stance substantially overlap in this respect, the kind of problems that are highlighted are relevant to the overall project of the dissertation.

During the months that followed the broadcasting of the piece summarized above, the debate concerning the alleged Vannoni method and whether it was fair that some patients (most notably vulnerable children) were not being given a chance to get the treatment got increasingly public. This led a number of noted personalities to take sides on the issue. On March 6th, 2013 Adriano Celentano, a popular Italian singer wrote an open letter¹⁷ to one the most widely read newspapers in Italy, the *Corriere della Sera*, voicing his discontent at the management of Sofia and Gioele's cases by minister Balduzzi. Ending his letter on an ironic note he asked, rhetorically, if cases of bureaucratic inertia and institutional deafness such as this one could not be the reason that had granted Beppe Grillo's *Movimento 5 Stelle* (5 Stars Movement, M5S) an unexpected electoral success¹⁸. Astonishingly, on March 10th the Ministry issued a prompt reply¹⁹ in which Balduzzi addressed directly Celentano's concerns. Highlighting the fact that the method had been recognized as non-compliant with existing regulations, he however granted a waiver to Sofia and Gioele—along with any other patient who had already been given their first infusion—allowing for the continuation of the treatment. This was presented as a measure of fairness. Inconsistent rulings by different courts had in fact contributed to creating a situation in which some people had obtained to have the hospital in Brescia legally mandated to administer the treatment, whilst other people were being prevented from getting the same treatment, in the same hospital, with cells prepared in the same lab and supposed to cure the same disease for the sole reason that they appealed to a different court that has ruled otherwise. Recently Balduzzi claimed this decision had been severely constrained by the chaotic situation created by an extensive media

¹⁷ The letter is accessible, in Italian, on the newspaper's website at: http://archiviostorico.corriere.it/2013/marzo/06/Ecco_Perche_Grillo_Vinto_co_0_20130306_4f11b004-8626-11e2-8dc4-8b60e31f7e35.shtml (last access April 29th, 2014).

¹⁸ The M5S won almost the 25% of votes in both chambers of the Parliament at the political elections held on February 24th and 25th 2013. (see: <http://elezioni.interno.it/camera/scrutini/20130224/C000000000.htm> and <http://elezionistorico.interno.it/index.php?tpel=S&dtel=24/02/2013&tpa=I&tpe=A&lev0=0&levsut0=0&es0=S&ms=S> last access April 29th, 2014)

¹⁹ http://www.salute.gov.it/portale/news/p3_2_4_1_1.jsp?lingua=italiano&menu=salastampa&p=comunicatistampa&cid=3882 last access May 6th, 2014.

campaign, which had resulted in undue pressures on the government to act urgently²⁰. This decision quickly elicited the response of various groups that can be very roughly lumped together under the heading of ‘scientific community’. On March 15th a group of nine Italian scientists (medical doctors and molecular biologists) and three ‘advocates of science’ (a philosopher of science, an historian of medicine and a lawyer) published an open letter to Balduzzi on *La Stampa*²¹. They pointed out how the ministerial decision to issue a waiver for presumed cell therapies that had no scientific evidence in their support would unduly grant some credibility to those treatments, consequently feeding misplaced hopes on the part of the patients. The signatories directly addressed the issue of a citizen’s freedom to choose whether and how to be cured and argued that that freedom does not entail any recognition or avail of those alleged therapeutic methods by the state. They also remarked how the choice of the Ministry apparently excluded the scientific and medical community from making valuable contributions to the evaluation of the merits of the proposed treatment, thereby impeding the deployment of the technical, social, educational and moral role proper of scientific knowledge. This, they concluded, appeared as a disquieting relaxation of standards of vigilance on the exercise of medicine that had “so far been confined to regions of the world characterized by the weakness of their democracies”²². The online version of the letter has received only two comments: the first of these comments voices suspicions of conflict of interest and, though articulated in highly emotional terms, it provides an accurate estimation of how far from the actual moral target of the issue this letter was. Similarly to what Gioele’s mother claimed, when parents are faced with their child’s incurable disease, a disease whose progression deprives the child of some of the hallmarks of human dignity, parents seem to have a duty to attempt whatever is in their powers to make the child’s life better. The end of the comment reads: “Clearly you don’t have dying children, for whom you would readily give a shot at snake juice [sic], if someone told you it worked”²³.

²⁰ <http://www.sanita.ilsole24ore.com/art/in-parlamento/2014-03-12/caso-stamina-nato-caos-143113.php> last access May 5th, 2014.

²¹ <http://www.lastampa.it/2013/03/15/cultura/opinioni/lettere-al-direttore/staminali-lettera-aperta-al-ministro-della-sanita-26fUz0SvvJLtlulJCWZzYN/pagina.html> last access May 6th, 2014.

²² “[...] confinate a regioni del mondo nelle quali debole è la democrazia.” http://www.salute.gov.it/portale/news/p3_2_4_1_1.jsp?lingua=italiano&menu=salastampa&p=comunicatistampa&cid=3882 last access May 6th 2014. My translation.

²³ “Chiaramente voi non avete figli che stiano per morire, per i quali provereste subito il succo di serpente, se qualcuno vi dicesse che serve a qualcosa” <http://www.lastampa.it/2013/03/15/cultura/opinioni/lettere-al-direttore/staminali-lettera-aperta-al-ministro-della-sanita-26fUz0SvvJLtlulJCWZzYN/commenti.html> last access May 7th 2014.

Although having granted access to the therapies to patients who had already been undergoing the treatment as a *una tantum* matter of last resort, the Italian Ministry of Health had been working on a decree to settle the issue of stem cell treatments in Italy more than provisionally. The decree would translate into law more or less precisely the recommendations of the abovementioned board of experts, thus ruling stem cell treatments in a fashion identical to that of medicines. This would entail, once (and whether) the law had passed, the injunction, to the Spedali Civili in Brescia, to have cells prepared in good manufacturing practice (GMP) facilities certified by AIFA and no dispensation for in human clinical trials that had no scientific merit. This proposed decree therefore soon came to be known among its opponents as the “Anti Stamina decree”²⁴ and vocal groups coalesced around the cause of preventing the decree from being turned into a binding law.

The picture below is just one instantiation of the online content used to garner people around the cause and organize a public demonstration on March 23rd in order to halt Balduzzi’s Anti Stamina decree and unlock the test and further development of Vannoni’s method.



Figure 1 A picture posted on the Facebook page “Ministro Balduzzi aiuti La Piccola Sofia”, advertising the public demonstration to be held in piazzale Ostiense, Rome, on March 23rd, 2013.

The demonstration did take place and, along with a continued media campaign, turned out to be quite influential. The decree 24, March 25th 2013, regulating the “[u]se of medicinal products prepared on a non-recurring basis for advanced therapies and the therapeutic use of medicinal products undergoing

²⁴ <https://www.facebook.com/509951612381361/photos/pb.509951612381361-2207520000.1399559967./517842711592251/?type=3&theater> last access May 8th 2014.

clinical experimentation”²⁵ approved, in this version, on March 27th, contained a number of overt concessions to the Pro-Stamina party. In particular, clauses 2 and 3 of article 2 of the decree claimed respectively that: (i) public hospitals were allowed to complete treatments that had already started using mesenchymal stem cells, even though these had been prepared in laboratories that did not comply with the existing regulations, and (ii) treatments were regarded as “started” even in those cases in which tissues had only been drawn from the donor or some authority had commanded the treatment. The most relevant provision of the decree was however the characterization of the treatments thereby regulated, as transplantations and not as medicines. This decision was conflicting with EU regulations regarding stem cell treatments, which fall into the category of advanced therapy medicinal products. Defining stem cells as medicinal products entails subjecting the use of cell therapies to the usual tight protocol of subsequent phases of clinical trials. The prospective decision to rule differently—with regulation for transplantations being way looser—mesenchymal stem cell treatments in Italy caused international outrage. The very next day the decree was approved by the Italian Senate, *Nature* weighed in on the issue, summarizing what had happened and was still happening and pretty straightforwardly taking sides against the Stamina Foundation, mostly highlighting the shaky scientific grounding of the ‘method’ (Abbott 2013). On April 8th²⁶, the International Society for Stem Cell Research (ISSCR) issued a press release in which the president of the Society and Nobel prize winner (for his research on induced pluripotency of stem cells) Shinya Yamanaka voiced his concerns about the decision upheld by Italy’s health minister saying that the ISSCR “sympathize with patients with incurable diseases. However, there is little objective reason to believe that these patients have the possibility of benefitting from a mesenchymal stem cell therapy and treatment decisions should not be made outside of a controlled clinical trial without data on safety and efficacy.”²⁷ On April 16th *Nature* published a very explicit editorial in which the journal (the published editorial has no author) cautioned the Italian Parliament “to heed independent expert advice before voting to deregulate stem-cell therapies” claiming that “[m]any scientists around the world were appalled by the events in Rome, and rightly so” and adding that it was “wrong to exploit the desperation of the disabled and the terminally ill and to

²⁵ “Impiego di medicinali per terapie avanzate preparati su base non ripetitiva e impiego terapeutico dei medicinali sottoposti a sperimentazione clinica.” My translation.

<http://www.normattiva.it/uri-res/N2Ls?urn:nir:stato:decreto-legge:2013-03-25:24> last access May 9th 2014.

²⁶ <http://www.isscr.org/home/about-us/news-press-releases/2013/2013/04/10/isscr-voices-concern-as-italian-government-authorizes-unproven-stem-cell-therapy> last access May 14th, 2014.

²⁷ *Ibidem*.

raise false hopes of quick fixes” (“Smoke and Mirrors” 2013, 270). A few weeks later Beatrice Lorenzin took office as the new health minister. This succession led the ‘negotiation’ to an entirely new stage: having heard the old cabinet, Renato Balduzzi, representatives of AIFA, *Centro Nazionale Trapianti* (CNT, National Transplant Center) and *Istituto Superiore di Sanità* (ISS, the Italian National Institute of Health), the new ministry proposed and had the Chamber of Deputies approve a set of amendments to the decree according to which the ‘non-compliance with GMP’ clause was dropped and a publicly funded clinical trial had to be conducted (or better, coordinated) by the ISS to ascertain the safety and effectiveness of the method²⁸. AIFA and ISS would jointly assess the trial, which was envisaged to get conclusive results within 18 months from July 1st, 2013. To this purpose a total of €3 million were allocated from the National Health Budget (*Fondo Sanitario Nazionale*). On May 23rd 2013, the decree, in this final version was approved and converted into law 57. During the months that followed²⁹ the Ministry tried to progressively lay out the details of a so-called Decreto Ministeriale (an administrative act containing detailed regulations for the deployment of policies and the like) that would lead up to the kick-off of the trial in July. These actions included the set up of (i) a scientific committee tasked with deciding on firm scientific grounds what diseases the treatment would be tested for, what protocol ought to be followed in administering the method and, most importantly whether or not the trial was worth conducting in the first place and (ii) a third-party committee that would assess the results of the trial. Vannoni and the Stamina Foundation, in exchange for unusual (and partly unexplainable given the ‘non-patentedness’ of the protocol and the non-commercial purpose of the foundation) guarantees that the method would be kept highly confidential, agreed to disclose it to the scientific committee and to have cells prepared following GMP in AIFA-certified cell factories. The committee was subsequently nominated, with one of its members representing the interests of EURORDIS, a “non-governmental patient-driven alliance of patient organisations representing 624 rare disease patient organisations in 58 countries”³⁰. On August 1st, after a series of deferments apparently due to Vannoni’s reticence to provide the committee with documents describing the method, the method accompanied by motives and rationales for picking three specific diseases for the

²⁸ <http://www.normattiva.it/atto/caricaDettaglioAtto?atto.dataPubblicazioneGazzetta=2013-05-25&atto.codiceRedazionale=13G00102¤tPage=1> last access May 14th 2014.

²⁹ The events orderly laid out can be found at http://www.salute.gov.it/portale/news/p3_2_1_1_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=1315 last access May 14th 2014.

³⁰ EURORDIS “About” page. <http://www.eurordis.org/about-eurordis> last access May 14th 2014.

trial (i.e. bulbar amyotrophic lateral sclerosis, cerebral palsy and Kennedy's disease) was handed in to the scientific committee. On October 10th the Ministry issued a document³¹ in which, having taken cognizance of the report by the scientific committee recommending—unanimously—not to proceed any further with the experimentation, the general director of the Ministry resolved to halt the clinical trial. This decision was however legally challenged by the Stamina Foundation on the grounds that some members of the committee had already publicly expressed their opposition to the method, prior to their appointment in the committee. The *Tribunale Amministrativo Regionale* (TAR) of Lazio, on December 4th, ruled upholding Stamina's legal case and forcing the Ministry to issue, in the first months of 2014, new appointments to the committee. The presidency, at first entrusted to prof. Mauro Ferrari, was contested by the scientific community, with a number of eminent academic and scientific personalities publishing two letters to *Nature* (Garattini et al. 2014; Bianco et al. 2014) expressing perplexities at his impartiality, in light of one interview broadcast by the TV program *Le Iene*. To date, the jury is, in a fairly non-metaphorical sense, still out on the issue.

Habermas says that, in relation to the threat of the disruption of social coordination due to disagreement, “[n]ormally, only a few options are available: carrying out straightforward “repair work”; putting aside the controversial claims, with the result that the ground of shared assumptions shrinks; moving into costly discourses of uncertain outcome and open to unsettling questions; breaking off communication and withdrawing; and, finally, shifting over to strategic action” (Habermas 1996, 21). Each of these four solutions, as shown from the rough reconstruction above, has been unsystematically attempted in the handling of the Stamina case by the Ministry and, oddly enough, no attempt at actual communicative action, understood as “the use of language oriented to mutual understanding” (Habermas 1996, 18) took place. The timid attempt to recruit stakeholders represented by the request to have one representative of EURORDIS sitting on the committee can be seen as an attempt at “carrying out straightforward “repair work””. This attempt however did not result in any visible improvement. First, the association was perceived as unrepresentative of the interests of those patients who had vocally made their case for the method. Secondly, the highly formalized context in which a representative of the association took part did not in fact allow for genuine moral arguments. And indeed even making institutions available for contributions by stakeholders more substantially

³¹ <http://www.trovanorme.salute.gov.it/norme/renderNormsanPdf;jsessionid=XVIjUX3LDh9WwjMxHvVCnw...sgc4-prd-sal?anno=0&codI.eg=47244&parte=1%20&serie=> last access May 14th 2014.

may not have sufficed to rendering decisions politically legitimate. This is unsurprising, though, and it might be explained by making intuitive appeal to positions such as Julia Black's, according to whom "simply focusing on the structural dimension, providing the structures in which different actors can participate, will not lead to a negotiated agreement" and therefore "regulation needs to facilitate communication by taking on the role of interpreter or translator: putting the views of each participants into a language that the others can understand" (Black 1998, 623). However, this was not the kind of role that the institutions trying to regulate took up in this case. Quite the contrary, very similarly to the route consistently taken in these attempts at tackling ethical issues at a formalized institutional level, in this case the issue was stripped of its inherent moral nature, it got progressively proceduralized and finally transfigured into an issue of scientific adjudication in which the problematic core was not so much how to translate claims and views, but rather how to transfer claims of scientific integrity to the general population. The Ministry decided to put "aside the controversial claims, with the result that the ground of shared assumptions" shrank. The morally charged question "Do people suffering from incurable and deadly diseases have a moral claim to just any treatment?" was turned into the morally neutral question "Does the method have any scientific merit whatsoever?" This is consistent with what is known about ethics boards and committees whose members describe being confronted with what some call a 'consensus' culture and with the systematic downplay of genuinely ethical issues. Poort, Holmberg and Ideland report how, in two paradigmatic cases from Switzerland and the Netherlands, "[d]espite their [explicit] task, the ethical issues were not the main focus; instead the committees merely standardized practical and technical matters" (2013, 8). These steps led more or less directly towards a strategic approach of the parties, both trying to gather as much consensus as they could to leverage their respective sheer political power: on the one hand the Ministry, supported by the entirety of the scientific community, on the other the Foundation, supported by a number (hard to quantify even approximately) of vocal 'lay citizens'. As I said, this can be taken to depend on the scarce availability of institutional forums or with the proper—'translating'—function carried out by institutional actors within those forums. However there is a further reason why the series of attempts at managing moral disagreement failed. Hendriks (2006) associated the emergence of issues of mismanagement of moral disagreement with the lack of institutions located at the right level in the public sphere. She characterized the literature on deliberative democracy as affected by a sharp divide between what she calls 'micro' and 'macro' theories of deliberation.

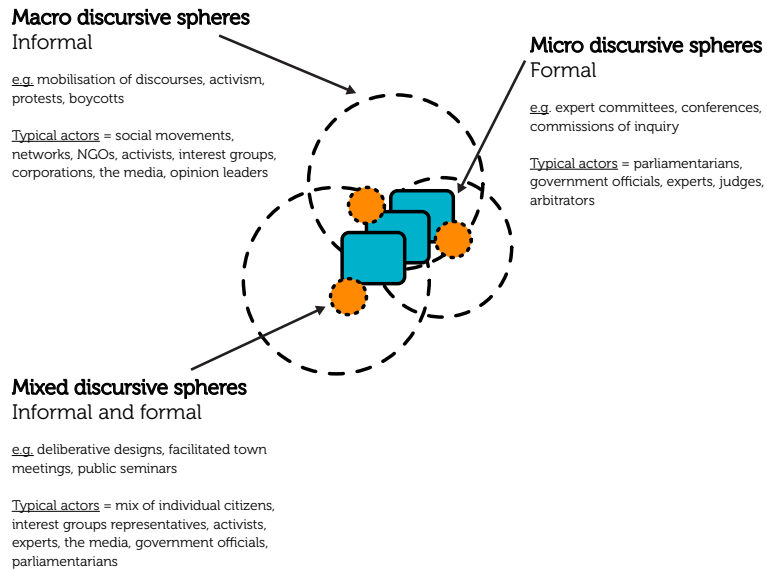


Figure 2 Macro, micro and mixed discursive spheres. Adapted from (Hendriks 2006, 500)

As shown in Figure 2, whereas the former focus on ideal conditions for deliberative processes in institutional loci, e.g. existing institutional forums, the latter see the whole of the public sphere as a relevant locus of deliberation. Both of the approaches, she contends, have problems. Namely, ‘micro’ approaches unduly discount the ways in which the civil society acts around institutions and framing issues within micro-spheres, while ‘macro’ approaches fail to account for the unequal distribution of resources that clearly disrupts deliberation in the public sphere. More importance ought to be given to this last hybrid kind of sphere because—at least this is Hendriks’ contention—“these procedures are more likely to reflect the constellation of discourses surrounding a problem than the kinds of deliberative enclaves found in state institutions and in the public sphere” (Hendriks 2006, 502) and can effectively take up the translating role that only affords authentic communicative action, thus granting normative legitimacy to political decisions.

As we have seen, the Stamina case displays vividly the utter lack of such mixed spheres in the Italian public sphere. The debate on the governance of stem cell treatments was first removed from a properly political context and restricted to a micro discursive sphere (with the issue being clearly divested of its moral nature). This somehow allowed for (or simply caused) the outburst of vocal complaints within the fairly unregulated macro discursive sphere, in which adjudication has had, at least in this case, very little to do with information and consideration. Moore (2010) building upon Hendriks’ structure of the public sphere, argued that public bioethics organizations could be seen as a mixed discursive sphere, therefore suggesting that what Dodds and Thomson (2006) called National

Bioethics Organizations (NBOs) ought to deploy the translating and participatory role that might trigger genuine communicative action thus affording higher normative legitimacy of the decisions being taken. Further below I will present the Italian National Bioethics Committee (*Comitato Nazionale di Bioetica*, CNB), showing that that was the institutional body that might have successfully and fruitfully fulfilled that role. In this last introductory paragraph I will venture to show how the progressive proceduralization of the moral case ended up transforming the problem into a sophisticated case of scientific adjudication between two competing bio-objectifications of stem cell treatments.

Competing identities of stem cell treatments

Stem cell treatments have long challenged “conventional cultural, scientific, and institutional orderings and classifications” (Holmberg, Schwennesen, and Webster 2011, 740). Though it is a fact that cell therapies make use of cells that are manipulated outside of the body, the degree of manipulation to which the biological material extracted from a donor is subject can vary significantly (e.g. induced pluripotency requires a process much longer than, say, the Stamina method, which supposedly relies on adult mesenchymal stem cells then allegedly induced to differentiate into neural stem cells³², which still implies way more manipulation than autologous peripheral stem cell transplantations). This variety must be said to afford a number of sensible characterizations of the object that are stem cells when prepared for therapeutic use: most notably they might be characterized both as transplants and as medicinal products. The European Medicines Agency (EMA) defines cell therapies “as medicinal products *when there is more than minimal manipulation* of any cell type destined for clinical application or where the intended use of the cells is different to their normal function in the body”³³. More analytically stated:

“Cells or tissues shall be considered ‘engineered’ if they fulfill at least one of the following conditions:

³² The method, as described in the patent application originally submitted to the U.S. patent office with this ID US2013065304 can be found here: http://worldwide.espacenet.com/publicationDetails/originalDocument?FT=D&date=20130314&DB=worldwide.espacenet.com&locale=en_EP&CC=US&NR=2013065304A1&KC=A1&ND=5 last access May 19th, 2014.

³³ European Medicines Agency (EMA) website. My emphasis. http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2013/04/news_detail_001769.jsp&mid=W_C0b01ac058004d5c1 last access May 19th, 2014.

— the cells or tissues have been subject to substantial manipulation, so that biological characteristics, physiological functions or structural properties relevant for the intended regeneration, repair or replacement are achieved. The manipulations listed in Annex I, in particular, shall not be considered as substantial manipulations,

— the cells or tissues are not intended to be used for the same essential function or functions in the recipient as in the donor.” (Antunes and Pottering 2007, article 2, clause 1, item (c))

Annex 1 lists explicitly procedures, mostly mechanical (with the notable exclusion of soaking in antibiotic and antimicrobial solution), that count as minimal. It can be inferred from the taxonomical nature of the list that the amount of manipulation that counts as “more than minimal” cannot be singled out sharply. Therefore the so-called biomaterial affordances of cell therapies do not adjudicate, on their own, one identity of stem cell treatments over another, namely that of medicines over that of transplants. The regulatory efforts undertaken by European institutions therefore fell very much in the same epic narrative of heroic regulators who try and “tame the unruly object” (Holmberg, Schwennesen, and Webster 2011, 741): in this case deciding, simply via legislative fiat, to create a new category, that of *advanced therapy medicinal products*, to fit the hybrid status of cell therapies and other treatments (Antunes and Pottering 2007).

The decision to identify stem cell therapies as medicinal products according to the degree of manipulation they undergo, though tracking a relevant difference between transplantation procedures and stem cell administrations, might have followed different paths. Some tissues that are transplanted do undergo some manipulation, part of which resembles, if only ‘quantitatively’, that used for stem cell treatments. For instance, both autologous and allogenic peripheral stem cell transplantation for the treatment of side effects of some types cancer, most notably the myelotoxicity of some treatments for leukemia, involve manipulation of the blood inside the body of the donor: colony stimulating factors, i.e. G-CSF proteins, are used to stimulate the production of stem cells and to allow their mobilization into the blood of the donor (Welte et al. 1996). Hence one might have suggested that the difference between transplants and advanced therapies medicinal products be identified with the inside/outside of the body of the donor boundary rather than in the amount or kind of manipulation of the cell. Of course, stimulating the body of the donor is a fairly indirect sort of manipulation of the tissue, and

importantly the manipulation does not affect the cell type nor their function, but still this is in no way one of the procedures listed in Regulation (EC) No 1394/2007 and it seems to essentially modify, or engineer, the tissue for the sole purpose of its clinical use. The definition therefore clearly has merits and highlights existing differences without openly fabricating them, but, as any legal or regulatory provision, it features some degree of arbitrariness. It is interesting to notice, in this regard, how, in one editorial published in the EMBO (Bianco et al. 2013), the authors first emphasize that the “best current example of a stem cell therapy” (Bianco et al. 2013, 1489) bone marrow transplant, was first tested in human and failed. They recall it took more than a decade of research for bone marrow transplant to “become the standard of care for many hematological conditions” (Bianco et al. 2013, 1490). Then they go on to argue that the kind of *ex-vivo* manipulation entailed by mesenchymal stem cell infusions introduces specific risks, which demand that they be regulated as medicines. The case of bone marrow transplantation shows however that there were peculiar and specific risks in treating diseases with methods for which robust mechanistic evidence suggested a sensible way forward (in the face of clinical failures). The authors in fact claim further on that the mere existence of a clinical trial should not be taken as evidence of the promises held by some treatment. If this is true, though, it is also true that the mere existence of a regulation that distinguishes bio-objects is no good reason to assume that there is a relevant difference there, whereby relevant I mean a difference that deserves being differently regulated. Just as robust evidence does not consistently predict clinical success (and clinical failure ought not to be taken as a direct disconfirmation of established mechanistic knowledge), so the absence of such a robust knowledge ought not to be taken to be predictive of increased risks of a prospective clinical trial. It is true, and it makes sense that, in the name of patients’ safety, society enforces strict regulations for the use of potentially harmful products. However the degree of strictness of regulations cannot be straightforwardly linked to the novelty introduced in the making of the product at issue: the mere existence of differences between two classes of products is not a good argument to regulate one more tightly than another.

By now it should be clear that the regulation of advanced therapy medicinal products underlies ontological intricacies concerning the degree of naturalness of the product to be administered. Intricacies that cannot be reduced to the comparison of risks involved in transplantations and stem cell treatments and in which societal values and private interests loom way larger than they appear at first.

These values and interests have been deliberately marginalized in the Stamina case, suggesting that the demand for a looser regulation simply was incompatible with inherent features of stem cell treatments, which makes them more ‘artificial’ and therefore more risky and potentially more harmful than transplantations. This entailed flattening most, if not all, of the morally relevant features of the issue, onto a—relatively less controversial—judgment of fact: the Stamina method is a stem cell treatment; stem cell treatments are medicinal products, therefore the request to loosen regulation does not make sense.

To sum up, I highlighted three specific, but interrelated issues in the Stamina case. First, I showed that the mode of governance of choice for the issue was only superficially (or rhetorically) ‘post-modern’ (governance being the ruling strategy of post-modernity). For it was presented as an attempt at governance, while displaying essential features of exclusionary technocracy. This first issue links to the second issue both chronologically and theoretically: the lack of proper upstream engagement of stakeholders in the issue led to outraged reactions by a public opinion mostly informed via sensationalist media coverage. I showed how contestations in the public sphere were peculiarly devoid of attempts at mutual understanding of the actors. Mutual understanding ought, according to Habermasian theories of democracy, to characterize properly normative efforts at attaining political legitimacy. In fact, whereas the ‘public opinion’ was making an ethical case for last resort or compassionate use of whatever was available (some knowingly disregarding the scientific worth of the methods), mobilizing concepts such as an alleged right to life, the ‘scientific community’ would reply with integrity of research talk, scientific certification of knowledge, hardly ever tackling directly the issue from the perspective of individual rights to self-chosen healthcare. This failure to recruit proper mutual engagement in communicative action, I showed, resulted in the institutional proceduralization of the issue (a phenomenon that, as shown further on, is part and parcel of the latest developments of bioethics in the Western world), which progressively became an issue of scientific adjudication rather than an issue of genuine moral disagreement. Specifically, the issue became one of competing identities of the object at stake: whether stem cell therapies could and ought to count as transplantations or medicines.

These three interconnected issues speak forcefully to the absence of some available institutional platform capable of structuring the public sphere by means of a common language, i.e. the language of

bioethics. But how do we want this language to be? And who would be allowed to legitimately speak in that language?

I have suggested that more democratic (however defined) participation to the governance of regenerative medicine (and to the management of moral disagreement in the life sciences more generally) is desirable. However it is unclear, so far, why it would be so, what reasons ground the claim that a more democratic bioethics would be better. In short it is unclear why we should democratize bioethics. Is it in the hope that this will result in less social conflict, in a more ordered public sphere? If so, is it empirically true that more participation leads to lowered social tensions? And even if it were true, do we regard the reduction of social conflict as an overarching value? Why is democracy the political theory for bioethics? And why does bioethics need a political theory in the first place? To these issues I devote the next section.

Bioethics as politics

Democratizing Bioethics, as the direct object in the title suggests, is a work about bioethics. However, if one parses through the table of content of this dissertation, he/she might be struck by the fact that the vast majority of the topics covered in the thesis are not immediately recognizable as falling within the standard disciplinary scope of bioethics. Instead, at a first blush and quite counterintuitively, most of these clearly concern political theory in general and democratic theory more specifically.

In this paragraph I set out to argue that public bioethics commands explicit reference to its underlying political theory. Currently, as we have glimpsed at, some of the political theories informing efforts at tackling bioethical issues are objectionable in a number of respects. Here I argue that, no matter how it became academically established and societally recognized, bioethics is intrinsically a political endeavor. This inherence of politics in bioethics, I contend, cannot be disregarded or underplayed. I identify the main political theory—more or less explicitly referenced—in bioethics and argue that it is problematic to accept *any* political theory as *the* political theory with which to handle moral disagreement in the life sciences without provisos and that even well-grounded attempts at providing articulate democratic political theories for bioethics tend to foreground normative (most of the times stipulative and moral) conceptions of political legitimacy overlooking or straightforwardly neglecting unsettled foundational issues. Attending explicitly at these foundational issues I will propose a middle ground between deductive essentialist political theories and radically antifoundational political theories, i.e. what I call a moderately realist political theory. Upon this middle ground I suggest constructing a *democratic experimentalist framework* within which new institutional arrangements for the political management of bioethical issues are conceived as hypotheses on how to attain higher legitimacy.

A proper definition of legitimacy, and a description of the role this multifaceted concept plays in this framework is the topic to which I devote the next section.

A short history of the establishment of bioethics

Though I clearly could not have—for biographical reasons—directly witnessed the years of the dawn of bioethics, the institution at which I have been spending the last four years is somehow prototypical of what bioethics, as a discipline, had grown into, in the late 1990s worldwide. The FOLSATEC PhD program, founded in 2007 and established at the European School for Molecular Medicine, therefore

offers a direct view to judge the role and standing of bioethics today in Italy and displays some of the distinguishing features of bioethics institutions created in the U.S. around the end of the 1960s. In this paragraph I trace back the origins of the enterprise of public bioethics, defined here, following Moore, as “the whole range of bodies and procedures such as national ethics councils, parliamentary ethics commissions or public consultations on ‘ethical issues’ that are meant to inform and guide political decision making with respect to ethical considerations” (Moore 2010, 716), in the academic establishment of bioethics interdisciplinary working groups, emerged alongside the need for a medical ethics articulated in the language of ethics rather than the language of medicine.

Albert Jonsen recalls how, in 1967, he himself got introduced to bioethics. In doing so he quotes Dr. F. Patrick McKegney, back then director of the psychiatric liaison facility at the Yale-New Haven Hospital, as having told him over lunch: “You've been reading and writing all this theoretical stuff about ethics. Why not come down to the hospital and I'll show you what an ethical problem really looks like” (Jonsen 1998, ix). A similar sort of need for a reality check of abstract ethical theories must have grounded the establishment—at a medical institution—of a research group deliberately supposed to tackle ethical issues forty years later. With quite some substantial lag, the FOLSATEC group set out to become just the institutional and systematic version of this practical and *impromptu* interest in the actual import of ethics as to biomedical progresses.

Bioethics indubitably branched from medical ethics, which, in 1947, the date with which we are told the discipline ‘was born’, already had a long history. This history was very much the history of codes of conduct subscribed to by medical doctors, or ‘healers’—a broader term denoting medical practitioners without cultures with some established western-like medical science. The questions that this orthodox medical ethics was supposed to tackle were essentially those concerning the right actions that healers ought to perform: right actions that is, both correct, i.e. resorting to the remedies that are known to treat the conditions (which over time entailed the moral duty on the part of the doctor to be competent and updated), and good, i.e. compliant with the community’s “rules, customs and beliefs that constitute the meaning of life for the society” (Jonsen 1998, 6). This led, in the U.S, to the successive revisions of the American Medical Association’s (AMA) principles of medical ethics which turned ethics in medicine into “rules for professional cohesion and respectability” (Jonsen 1998, 8). Only physicians contributed to the literature covering these issues and the way they did so was

basically devoid of explanation. Detailed ethical reasoning was very much the exception rather than the rule, to the point that contributions to this literature tended overwhelmingly to be shaped in the form of exhortations rather than full-fledged arguments.

The decades that followed World War II saw a decided leap forward in the machinery and techniques used by physicians and, subsequently, spurred a new course in medical ethics itself. These unexpected and unprecedented developments were the spark that brought philosophers, theologians, lawyers and physicians together, to face the new challenges that were disfiguring the normal life of the biomedical community: a radical restructuring of training necessitated by the rise of a vast array of specialties with the related dusk of the family doctor, the shortage of trained workforce, the rising costs of medical procedures and the prospective reform of the financial scheme supporting biomedicine. The enlargement of the community concerned with these issues essentially created, after then 1960s, bioethics as a new domain ideally capable of supporting the troubled consciences of medical professionals³⁴. The role played by the nascent bioethics community was to flesh out apparently unproblematic issues in order to expose their inherent ethical problematicity. This was a work in fact best accomplished by those trained in what Abraham Kaplan cites Bertrand Russell as having claimed are the two main tasks of philosophy: “first, to make complicated things simple and, second, to make simple things complicated” (Kaplan 1968, 153).

After this initial phase of informal ‘cross-pollination’ and mutual enrichment of the disciplines involved at these conferences and events, calls for bioethics to stand out as a discipline in its own merits started to be voiced. James Gustafson, one of the founding fathers of American bioethics, in 1968 identified a need for “interdisciplinary work within universities or centers that have personnel and resources for the arduous tasks of intensive and long-term work” (Gustafson 1968, 27; cited in Jonsen 1998, 20). It was not long before this piece of advice turned into reality and a host of centers explicitly devoted to this sort of interdisciplinary study were launched. In 1969 the Society for Health and Human Values, currently consolidated in the American Society for Bioethics and Humanities³⁵, was founded with the explicit purpose of “developing change in both professional attitudes and public

³⁴ Jonsen speaks of a “Decade of Conferences” (Jonsen 1998, 13–19), the 60s, through which the biomedical community started making exercises of self-reflexivity asking the hard questions that bothered them and asking them out loud at conferences. At these conferences, for the first time lawyers and philosophers were making explicit and relevant contributions.

³⁵ <http://www.asbh.org/about/history/index.html> (last access August 11th 2014).

awareness” in relation to human problems arising from advances in biomedicine (D. M. Fox 1985, 334). In the same year the Hastings Center is founded “*to address fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities, and societies*”³⁶. In 1971 the Kennedy Institute of Ethics opens at Georgetown University to “bring expertise to the new and growing ethical problems in medicine today”³⁷.

Bosk and Frader, trying to make sense of the existence and performance of institutional ethics committees (IECs) at healthcare facilities, traced a fine but sharp line between IECs and institutional review boards (IRBs). From the late 60s onwards, “responding to the memory of Nazi medical experiments and the more recent scandalous behavior of researchers in the United States” (Bosk and Frader 1998, 95), the U.S. federal government had established this new kind of institutions, IRBs, meant to provide a sort of third-party oversight to experimental practices, i.e. scientists were no more left to review their own protocols scanning for ethical issues. These bodies had a clear political mandate, their composition was fixed and, regardless of what that entails for the actual practice, they supposedly were endowed with the means to make sure that biomedical and behavioral experimental practices fell squarely within the boundaries of moral acceptability. IECs, in contrast, arose out of no politically mandated need and therefore had no clearly defined sets of procedures, no precise scope or composition (Cransford and Doudera 1984). They were established as a result of the historically critical relevance of what Renée Fox famously dubbed the “bioethics movement” (R. Fox 1989). Bosk and Frader mention three early landmark cases that brought to the institutionalization of ethics committees: (i) citizens’ committees in Seattle trying to settle, on a case-by-case basis, the allocation of kidneys to be transplanted; (ii) the controversies over neonatal non-treatment raised by two MDs’ report published in the *New England Journal of Medicine*—Raymond Duff and A. G. M. Campbell (Duff and Campbell 1973). The MDs voiced their concerns about excruciatingly painful life and death decisions that they essentially did not know how to take. And (iii) the Supreme Court of New Jersey’s ruling on the Quinlan case (a young woman in persistent vegetative state whose family were asking to discontinue artificial ventilation), in which the court called for ethics committees to be formed at hospitals so as to have issues such as the one they were ruling, left out of the court rooms. In spite of this early legal blow, the formal status of IECs remained substantially unsettled.

³⁶ <http://www.thehastingscenter.org/About/Default.aspx?id=5009> (last access August 11th 2014).

³⁷ <https://kennedyinstitute.georgetown.edu/about/history.cfm.html> (last access August 11th 2014).

However, the creation of IECs resident in healthcare institutions might be seen as having played a role towards the subsequent rise of public bioethics. In fact, the swelling of IECs and the birth of independent and academic institutions purposely addressing bioethical issues were already signs of the diminishing control that the scientific community was capable of exerting over the most morally controversial parts of their activities. These could be seen, in a sense, as attempts at self-regulation of the scientific and biomedical community, via the recruitment of new specialized (cognitive) forces. In the 1970s, the same forces started being recruited, in the U.S., both at federal and state level, to provide input into policy-making, “mandated to examine and provide guidance or recommend regulations concerning the ethics of specified research activities or outcomes” (Kelly 2003, 342).

The progressive entrenchment of academe and medical institutions described above therefore might have misleadingly conveyed some sense in which bioethics, as a discipline, could have translated directly into a policy-making device. Its authority and legitimacy within the boundaries of academia and institutions deliberately deciding to rely on their oversight, somehow managed to spill over and extend to the public domain. And indeed, irrespective of the extent to which they successfully did so (in most of the cases their mandate ended up with reports no one took political action upon, e.g. the Ethics Advisory Board established within the Department of Health, Education, and Welfare in 1977 whose most relevant opinion on the federal support of research using human in vitro fertilization was never mentioned after publication and whose formal status was sterilized in September 1980 (Jonsen 1998, 107)) most of these institutions conceived of input into policy-making proper as falling clearly within their scope.

In the next paragraph I rely on John Evans’ work to show how public bioethics bodies contributed to the establishment of a peculiarly non-political bioethical discourse, thus obfuscating even further the already foggy and odd sort of political authority they were and still are endowed with.

Formal and substantive rationality in bioethics

Using Human Genetic Engineering (HGE) as a case in point, John Evans (Evans 2002) highlighted a pattern characterizing the development of the discourse in bioethics. Relying on Weberian insights (Weber 2004), he argued that the style of bioethical discourse on HGE has progressively shifted from ‘thickness’ to ‘thinness’, from substantive rationality (i.e. rationality allowing for discussion of both ultimate ends and means) to formal rationality (i.e. rationality focusing solely on the best means

towards given ends), culminating in the kind of professional debate hosted within new institutional loci, namely government advisory commissions. Such expansive tendency of formal rationality clearly extends well beyond the boundaries of HGE and can be said to apply to issues in bioethics more generally (Powers 2005).

Historically, bioethics has thus turned, via the formalization of its rationality, into a public arena, a platform for (i) the adjudication of claims of moral permissibility and (ii) science policy-making in the Life Sciences. The more entrenched with the day-to-day life of political institutions in democratic societies bioethics became, meaning the more bioethics historically became embedded in the process of institutional policy-making, the less substantive the arguments allowed—and as a matter of fact presented—got. It became progressively clear that such a liberal role—commonly grounded in the Rawlsian ideal of an ‘overlapping consensus’ concerning specific issues (Rawls 2005)—for bioethics commissions would not suffice in that it systematically discredited substantive or thick views of the good and the right, views hardly ever effectively overlapping and intrinsically proper to pluralist societies. This was even more worrying given that, “[t]hrough the bioethicists of the 1970s began the process of secularizing bioethics, Jonsen argues, they were strongly influenced by its moralistic origins and so still needed to work from some set of principles” (Wolpe 1998, 49) and that therefore, some thick conception of morality was, at least historically, behind the formal rationality of those commissions.

Evans contends that “[n]ot all issues have changed—only some have been “civilized” by the bioethical form of argumentation—and the debate over those that have changed has purposely been moved to government advisory commission” (Evans 2002, 175), thus suggesting that the shift towards the non-political address of the community of bioethics is not something that needs to happen for science policy-making to make its due course. In fact, the American debate on abortion offers, according to Evans, a clear-cut example of how discourses can resist the assimilation by the formal language of bioethicists. Interestingly, in the case of abortion, the “debate ha[d] retained the public as the ultimate decision-maker” and therefore, “the thinning of the HGE debate might have been prevented if actors at various points had been able to keep decision making in the hands of the public” (Evans 2002, 178). In 2006, Evans himself would go on to claim that “public bioethics—at least in the dominant forms—is implicitly designed for and tries to use technocratic authority” (Evans 2006, 213). This attempt at

unveiling the hidden political theory behind public bioethics is especially important in light of what just shown about the historical establishment of the bioethics community: bioethicists had come to hold specific decision-making (even via the influential range of their opinions) positions without any explicit political mandate other than that of the representatives in charge of the appointments, either academic or institutional (but hardly ever democratic). In the face of such public responsibilities, bioethicists had hardly ever self-reflexively attended at their own public role asking questions such as “How is it that I am in a position to address these particular kind of questions in the forms and approaches I do, and to the audience and with the authority and sponsor I have”? (Belkin 2004, 378). This politico-theoretical naïveté progressively faded out, and the debate about bioethics has since then turned wildly politico-philosophical, i.e. it has come to concern the politics of bioethics, the means and modes of political management of moral disagreement in the Life Sciences. To the point that currently the chair of Obama's Presidential Commission for the Study of Bioethical Issues is the renown political philosopher Amy Gutmann. An impressive number of publications have so far attempted to face the social and political reality of moral disagreement and some effort has been put into fostering new forms of democratic handling of policy-making in bioethics. The political theory that goes under the name of deliberative democracy strongly influenced such practical attempts. In fact, deliberative theories of democracy seem precisely one of the ways out of the dichotomy between purely procedural and purely substantive political management of moral disagreement. As Walzer alerted us to both dimensions are still inherently intertwined and “[n]o procedural arrangement can be defended except by some substantive argument, and every substantive argument (in political philosophy) issues also in some procedural arrangement” (Walzer 1981, 386). Gutmann and Thompson, when laying the foundations for their political theory, were not shy about the substantive principles on which deliberative democracy relies: reciprocity, publicity and accountability (Gutmann and Thompson 1996; Gutmann and Thompson 2004) are principles whose grounding must be taken as somewhat axiomatic. More importantly, however, the role of these principles’ cannot be dispensed with for the entire theory to be theoretically sound. Below I will explore more in depth the relationship that these principles entertain with the political legitimacy of the decisions that are taken in institutions that rely upon them. To my purposes here it is not important to investigate how political theorists went about justifying their own preferred political theory, but rather to stress the very fact that bioethicists have started to feel compelled to see their activity as political. This entails that the activity of bioethics must be

performed with the modes and means of politics. Essentially, the community of bioethics has progressively been led to the recognition of one unequivocal fact about bioethics, that is that if politics is the means by which people's views inform their own government, then bioethics, and *a fortiori* public bioethics, is a political endeavor throughout. As Michael Parker put it, “[b]ioethics is political because in all its manifestations it is constituted by clusters of normative, value-driven activities with implications for people's lives and their environment” (Parker 2007, 185). Foregrounding the political theory that informs one's bioethical contentions is therefore not just a matter of clarity, but rather one of intellectual honesty.

If bioethics is indeed political throughout, then it is reasonable to ask what political theory does or ought to apply to it. The community of bioethics has been asking this question relatively little and seems to have instead decidedly turned to a serious commitment to deliberative democratic tools for the handling of moral disagreement in the life sciences. This has informed the so-called ‘deliberative turn’ in bioethics and healthcare ethics (Abelson et al. 2013). Probably as an unintended consequence of the decision to recruit ‘cognitive workforce’ outside of their community to assess the ethical issues arising from their own work, MDs’ and scientists’ authority in judging “on behalf of society the moral legitimacy of scientific inquiry is argued to have diminished significantly” (Kelly 2003, 341). As a result of such unwanted damaged legitimacy of the scientific community, public bioethics has had more and more to shift towards forms of direct recruitment of the public³⁸. For dubious reasons that will be delved into below, deliberative democracy emerged as the theory of choice. For now, suffice it to say that this was probably because deliberative democracy—at least as articulated by Gutmann and Thompson—takes the intermingling between the procedural and the substantive tenets of their theory as a fact and suggests going beyond what their proponents present as otiose foundational issues, to instead practice deliberative democratic politics in a way that is compatible with genuine pluralism about values.

Amy Gutmann said that “[w]hether or not foundational claims are metaphysically possible is a moot point as far as the ideal of deliberative democratic politics is concerned. The alternative is not antifoundationalism, but fairly conducted collected deliberations that yield provisionally justified

³⁸ Even though, as I will notice below, there might have been other, more controversial, forces playing a role to move the field in this participatory direction.

practices and policies” (Gutmann 1996, 345). I partly agree with this statement and believe that democratic practice is central to the endeavor of justification of provisional solutions to moral quandaries in bioethics. However, I contend that the foundational question cannot be dismissed this quickly. In particular, I will try and show, a fair consideration of that very question entails giving up completely on the idea that some specific political theory is ‘really’ (or ‘objectively’) superior to others and rather embrace a democratic experimentalist framework within which normative political theories serve as sensible justifications to ask that a specific institutional arrangement be tested in practice.

What political theory for bioethics?

Once granted the role that political theory has for discussions in bioethics, it still remains unclear what political theory—if any—ought to be subscribed to by politically aware bioethicists. This is a relevant question to the extent that bioethics is meant to be—more or less directly—productive of collectively binding decisions. These decisions are always supposed to be authoritative, and a successful political theory of bioethics can only be worked out in case one specifies the criteria that make those decisions *legitimately* authoritative. The problem of what counts as a legitimately authoritative political decision is long-standing in political philosophy, and I would go so far as to claim that it is *the* problem of political philosophy. Different answers to the question “What makes a political authority legitimate?” clearly gave rise to different and competing political philosophies. These politico-philosophical answers do not generally cross-talk and the very fact that a plurality of answers to this question obtains suggests that some common grounds for legitimately authoritative decisions have not been found yet.

Further on I will attempt an analytical reconstruction of the concept of legitimacy that I believe can help in the development of a more compelling ground for democratic experiments in bioethics. In this paragraph, instead, I present what I call the problem of normativity in politics. I subsequently dismiss Huemer’s argument that political authority is simply an illusion and that therefore there is no hope of solution to the problem of normativity in politics. Then I review two examples of attempts at solving the problem of normativity in bioethics in more or less political ways. I take these examples as lying, at different points, on a spectrum along which one can order attitudes towards political theorization—the spectrum that goes from foundationalism to antifoundationalism. Convincing criticisms can be raised against the institutional arrangements or the straightforward solutions that are called for from foundational standpoints. These criticisms do have a bite: I will present an alternative to

foundationalism in politics, i.e. political realism, and argue that, however compelling, this different approach, taken at face value, seems to offer little guidance in developing new and better institutions. Therefore I will proceed to outline my own experimentalist democratic framework for bioethics, one that is, so to say, ‘moderately realist’ and which, I will argue, pushes forward Williams’ realism and Dewey’s democratic ideal.

The problem of normativity

The relation between philosophy and democracy is a specific instantiation of that between philosophy and politics. How we define such a relation, hence, hinges on the definition of political philosophy one is willing to endorse. Michael Walzer, in his 1981 fundamental paper about philosophy and democracy (Walzer 1981), discusses the authoritarian (and in some intuitive sense anti-democratic) vocation of most heroic³⁹ philosophical foundations of politics. Whenever the highly theoretical speculations of the philosopher get the chance of transforming practice into some approximation of the truth of his thought, he does not do so ‘politically’, he does not bargain or negotiate, he limits himself to advising the execution of his truth, to recommending the conversion of that truth “of speculation into the utility of practice” (Hobbes 1651, 227). This kind of top-down approach can be dubbed, following Raymond Geuss, “ethics-first” (Geuss 2008, 9): political philosophy being some applied ethics, specifically ethics as applied to politics. David Estlund’s (Estlund 2009) philosophical framework of democratic authority is a recent instantiation (one of the most prominent⁴⁰) of precisely this kind of widespread philosophical attitude towards politics in general and democracy more specifically, but, as I will show below following Waldron, this deductive hierarchical attitude can be detected in most politico-philosophical contributions.

For their normative constructions are built upon assumptions about some inescapable and shared set of principles, values and ideals, any of these attempts has to grapple with essentially metaphysical issues about the nature of normativity. Specifically any radically foundational approach to the definition of political ideals has, sooner or later, to come clean about the reasons why the kind of

³⁹ Following Wittgenstein, Walzer tries to make sense of the claim that a philosopher should not be “citizen of any community of ideas” (Wittgenstein, 1970 no.455). This kind of radical detachment can take two main forms, he says, for what concerns political philosophy: the first is contemplative, the second heroic. The contemplative political philosopher has no interest in actually changing the community he studies. The heroic political philosopher withdraws from his community and then gets back to it “in order to found it again” (Walzer 1981, 380). It is this second form with which both Walzer and my thesis are concerned here.

⁴⁰ Rawls among many other liberal political philosophers is a clear example of this kind of approach (Rawls 2005; Rawls 1993).

political authority they construe would be legitimate, meaning why such and such kind of political authority would command assent to its decisions. In order to do so, these theorists must single out the ultimate source of normativity, that which makes politically binding whatever is supposed to be politically binding. On the one hand, a theory could go full-blown metaphysical, fixing axiomatically a set of principles from which to derive the specifics of one's theory. This approach looks however ill fated. Say we built our political theory upon the concept of reciprocity, defined as the willingness to mutually justify collectively binding decisions with reasons in principle acceptable by all those bound by them. The question remains why one would be compelled to act reciprocally. And in case one came up with some other principle justifying reciprocity, the why question would apply to that as the ultimate justificatory ground for normativity. Essentially, this will inevitably lead to either an infinite regress, or to issues linked to the voluntary submission, i.e. actual consent, to those ultimate assumptions. The first is an inescapable theoretical problem, while the second is a serious empirical challenge.

On the other hand, attempts that do *not* rely on metaphysics, can be challenged on the grounds that, apparently, “answers to questions about the source and authority of norms traffic in sociological concepts” (Turner 2010, 6) such as community, rules or intentions. Unfortunately, the regress towards a non-metaphysical justification of the normative cannot possibly end in sociological concepts or meanings because concepts and meanings must rely in turn on the existence of some normativity, independent, and actually implied, by those sociological concepts. As Turner alerts us to, this is a standard *tu quoque* argument, whereby non-metaphysical justifications make use of meanings that cannot be made to work without a pre-existing firm normative ground (Turner 2010, 11). And if normativity exists on its own, then there is no need to ground it in something else.

This is, in a nutshell, the problem of normativity in politics—one clearly dilemmatic in kind. A problem which is ever more pressing due to (i) the all-pervading nature of normativity in political life and (ii) the wild degree of disagreement about the actual nature of normativity even outside academia. In introducing a volume in which Christine Korsgaard addresses—and defends her solution to—the problem of normativity, Onora O’Neill claims that:

We not merely have beliefs: we claim that we and others ought to hold certain beliefs. We not merely have desires: we claim that we and others

ought to act on some of them, but not on others. We assume that what somebody believes or does may be judged reasonable or unreasonable, right or wrong, good or bad, that it is answerable to standards or norms. (O'Neill 2010, xi)

She claims further that, no matter how pervasive normativity is in our lives, “there is huge disagreement about the source and the authority of norms on which we all constantly rely” (O'Neill 2010, xi).

Normativity, in a sense, can then be loosely taken to be the what Habermas called “the obligatory orientation of action” (Habermas 1996, 5), the ‘power’ that compels one to do/not do something, which makes, as I just said, the *problem* of normativity the quintessential problem of political theory. For bioethics is one (political) arena for the adjudication of authoritative norms, it cannot escape the question of what makes those norms authoritative and a proper political theory of bioethics must satisfactorily address the problem of normativity.

There are indeed a number of threats to a theoretically viable and empirically acceptable solution to the problem of normativity in bioethics. I will first tackle the most alarming one, which comes from those voices that claim that simply no legitimate political authority can exist, and therefore implies no acceptable solution to the problem is available for *any* political theory of bioethics. A recent reconstruction of this attempt at dismissing the existence of political authority can be found in Michael Huemer’s *The Problem of Political Authority*. In the following paragraph I object to the *pars destruens* of his book to subsequently try and counterargue more constructive attempts specifically trying to address the issue of the normative grounds of political authority in bioethics. Finally, I will approach a solution to the issue, i.e. political realism. A solution I find more promising and that I will adjust to my own purposes.

Dismissing the illusion of political authority

Michael Huemer has recently published a volume in which the very issue of normativity in politics is tackled head on: the author systematically reviews attempts at grounding political authority, i.e. attempts that try and distinguish between legitimate and illegitimate compelling powers, and ends up showing that none of these succeeds, thereby suggesting political authority is just an illusion we ought

to dispense with. I find most of the arguments he puts forward shaky: in particular there are two interdependent points he makes that are peculiarly unconvincing. The first one concerns the distinction Huemer traces between agents and actions and the bearing this supposedly has on the definition of political authority. The second one concerns the distinction between merely political obligations and other kinds of obligations: the former being obligations whose force depends on there being an authoritative agent such as the State.

These distinctions apparently try and tell apart genuinely political from other forms of authority, but they do so in a way that is, as I will show, ineffectual. To argue for the first claim, i.e. that a difference in agency, rather than in actions, distinguishes political authority, he resorts to an example⁴¹: he asks the reader to imagine a mundane scenario in which a band of vandals is damaging monuments, gardens, houses and other private and communal properties. In the neighborhood, given that nobody seems to be doing anything about the problem, you and your family decide to take it very seriously and start looking for these vandals. When you find them, you confine them in your basement. Then, after a couple of weeks, you knock at your neighbor's door asking for a cash contribution to the "crime prevention fund" (Huemer 2013, par. A political parable). After all, you have successfully reduced the crime rate. Your neighbor, unfortunately, seems to have no intention to refund you for your efforts, therefore forcing you to make your case more convincingly by pointing at the gun in your holster and reminding him that were he to decide not to contribute, you would be compelled to convict him along with other felons. In all probability, Huemer says, your neighbors would not be content at receiving these requests—nor the threats they come with.

This 'parable', as I said, is meant to be suggestive of two distinguishing features of political authority: (i) at the bottom of the exercise of *any* compelling power of the sort governments have, is violent coercion (as a last resort were the threat of violent coercion not be enough to convince the defiant) and (ii) there is something inherent in the agent that threatens to use violence that makes his/her actions intuitively objectionable. The former point is straightforward: any cooperative scheme (and institutions are such kind of scheme) needs some mechanism to effectively enforce cooperation onto those who refuse to abide. The latter point is instead both unclear and unconvincing. The reason why

⁴¹ This is his explicit methodology throughout the book: reasoning "on the basis of what seem to me common sense ethical judgments" (Huemer 2013, par. Preface) to reach very controversial conclusions on uncontroversial premises. Oddly enough the book makes hardly any effort at referencing to whom would subscribe to Huemer's own common sense ethical judgments.

you acting as a vigilante asking for taxes look more objectionable to your neighbor than, say, policemen paid with state taxes, intuitively has to do with the system of guarantees that is supposed to make sure that certain rules are observed when ‘fighting the crime’, e.g. that the accused are given a chance for a fair trial or that we implicitly or explicitly submitted to the laws of the state. These rules do not seem to apply to the actions of vigilantes simply because the story assumes this to be the case. And in fact the example becomes even more puzzling when Huemer goes on to say that “[o]ne can modify the example so as to remove any difference that might be thought relevant, and provided one does not convert the vigilante into a government, most people will still intuitively judge the vigilante much more harshly than government agents who act analogously” (Huemer 2013, par. Actions versus agents: the need for authority). It is unclear why and how the author can simply assume that people will judge the two cases as he claims people would: first, some neighbors might well be willing to pay the vigilante the money on the grounds that it was ‘high time someone did something about the vandals issue’. I would not exclude this possibility—nor would I take this to be a minoritarian option for that matter. More importantly, however, the proviso that one ought not to turn the vigilante into a government is dubious: all of the features characterizing the two agents are essentially actions they do/do not perform and the very fact that one can hypothetically reduce the actions of a vigilante to those of a government suggests that the State or the Government is no natural kind, and that actually vigilantes are a form of government, one peculiarly lacking legitimacy according to some set of procedural standards.

Taking this shaky distinction for granted, Huemer further claims that “[p]olitical authority [...] is the hypothesized moral property in virtue of which governments may coerce people in certain ways not permitted to anyone else and in virtue of which citizens must obey governments in situations in which they would not be obligated to obey anyone else” (Huemer 2013, par. The concept of authority: a first pass). This definition implies that political authority is a moral property of a distinctive agent, the State or the Government, which is essentially different from other forms of moral obligation. To press this point Huemer says that a duty not to murder, even if enshrined in the law, is not a genuine political obligation because “we would be morally obligated not to murder even if there were no laws against it” (Huemer 2013, par. The concept of authority: a first pass). Then he proceeds to present income tax as the clearest case of political obligation, again failing to identify the moral difference-maker,

conveniently presenting killing as a non-political obligation but overlooking the justification that politically mandated violence would still require in case somebody did kill regardless of our shared intuition that we ought not to do so.

The endeavor of identifying the moral grounds of political authority is meant precisely to single out obligations whose political enforcement is required because we tend to agree that those obligations exist. And in fact Huemer's methodology, i.e. relying on a presumed common-sense ethics to debunk any justification of political authority, reveals a fatal flaw: it is unlikely that his solution plays out as he plans, in that the "common sense ethical judgments" upon which the analysis rests range wildly even within specific communities, and this very wild variety is precisely the result of the so-called fact of moral pluralism, which in turn is the quandary that politics is meant to solve. Appealing to the uncontroversial existence of some finite and defined class of common ethical judgments simply assumes that there is no need for political authority, thus rendering any other argument pointless *petitiones principii*.

This is of course not to say that just any political authority is legitimate, but rather that political theories need some account of legitimacy that does not rely on unquestioned ethical and moral premises. Questioning the ethical premises of political theories is what most political philosophers have done throughout the history of the discipline, coming up with different definitions of what makes—or would theoretically make—some political authority legitimate. These differences clearly translate onto bioethics as a political issue. In the next paragraph I review two interesting attempts at solving the problem of normativity in bioethics. They peculiarly recommend similar institutional features, but lie very far from one another on the spectrum that goes from foundationalism to antifoundationalism. For different clusters of reasons, both these approaches can be convincingly criticized. I will oppose to these attempts an antifoundational, essentially *more* political approach to bioethics that, I believe, can still provide a satisfactory solution to the problem of normativity in bioethics and in political theory more generally.

Daniels' constitutionally explicit fair procedure

Norman Daniels' *Just Health Care*, published in 1985 (Daniels 1985), is probably the most notable attempt at developing a full-fledged ethical framework for healthcare reforms. The work contributed as well to paving the way for work that tried to bridge the gap between theoretical speculations on how to

define justice and the implications such definitions have when it comes to the distribution of healthcare resources. In introducing his later work, *Just Health* (Daniels 2008), Daniels describes the 20-year long journey that helped him highlight strengths and limitations of his previous account of justice and healthcare. In particular, he acknowledged the narrow focus he kept on the distribution of healthcare resources, vis-à-vis epidemiological findings suggesting a high degree of correlation between the distribution of other kinds of goods and their impact on health⁴², but he also pointed to the feeble impact that his account had onto the actual practice of healthcare priority setting and resource allocation decisions more generally. In pointing this out, Daniels recognized that part of his new work, would revolve around an issue of legitimacy, i.e. “given moral disagreement about how to meet health needs, how can priority- or limit-setting decisions come to be accepted as fair and legitimate?” (Daniels 2008, 4). His answer to this question, in *Just Health* is essentially (and explicitly) devolved to the domain of the political. His now well-known principle of *accountability for reasonableness* requires the application of deliberative democratic machinery to reach controversial priority-setting decisions in the most legitimate way possible. Interestingly, though, Daniels refuses to explain, in the book, why principled and democratic actual deliberation is not the way to go in order to get to a definition of the more general principles of justice in health he spent a hundred pages laying out. In note, he refers readers back to an older contribution of his, saying that “[w]ere this book about the theory of justice in general, I would have to explain why I am opposed to using a democratic deliberative process to derive all aspects of justice (Daniels 1999); instead, in this account of justice and health, I am simply invoking it to supplement the problems left unaddressed by the principled account developed thus far in Part I.” (Daniels 2008, 103). In that contribution, a chapter he wrote for the *Deliberative Politics* volume (Daniels 1999), Daniels tries to supplement Gutmann and Thompson’s *Democracy and Disagreement* (Gutmann and Thompson 1996) stating principles that ought to govern fair procedures in making specific allocation decisions in healthcare. Before doing so, however, he ventures to rebut a part (one that I find pivotal) of the deliberative democratic architecture: Daniels claims that, when, in the book, Gutmann and Thompson outline arguments to discuss ‘deliberatively’ actual issues such as affirmative action policy or welfare reform, their somewhat vague principles can only effectively be put to work because the notions of these principles, e.g. ‘agreed on principles’, ‘basic liberty’ or ‘fair opportunity’,

⁴² This evidence is reviewed, for example, in Richard Wilkinson and Kate Pickett’s *The Spirit Level* (Wilkinson and Pickett 2009) and Michael Marmot’s review *Fair Society, Healthy Lives* (*Fair Society, Healthy Lives. The Marmot Review* 2010).

have, “for twenty-five years, largely been fleshed out and examined in debate about the adequacy of Rawls’s theory and its extensions” (Daniels 1999, 199). For Gutmann and Thompson fail to take into account more foundational issues concerning those principles—so Daniels’ argument goes—their discussion cannot stand on its feet alone. In a sense, Daniels accuses the authors of having been too shy about their own foundational assumptions, therefore having been left with little guidance in the application of those vaguely defined principles. Without a proper theory of justice, Daniels contends, “Gutmann and Thompson’s invocation of basic liberty, basic opportunity, and fair opportunity as constitutional constraints lacks adequate support and clarity” (Daniels 1999, 201). And it does not really matter, to Daniels, that Gutmann and Thompson suggest deliberating about the actual content of those principles regulating deliberation, because, after all, compared to Rawls’ theory of justice, this might be “more “spin” than real difference” (Daniels 1999, 201).

Norman Daniels’ is indeed a theory of justice applied to health. As he puts it, his research has focused on extending the application of the Rawlsian fair equality of opportunity framework to issues of distributive justice of health. He resorts to fair procedure for the only reason that finding middle level agreed upon principles to solve specific distributive ethical dilemmas seems impossible in the face of moral pluralism, and pure proceduralism, i.e. brute majoritarian democracy, is inadequate in most respects (as decades of democratic theory have extensively shown⁴³). But importantly, he also believes that Gutmann and Thompson’s reliance on fair procedures can only be justified if some kind of foundational justification for the principles it singles out is provided. This means that there is a clear metaphysical precedence of ethics over politics, in Daniels’ account, one whose importance cannot be discounted and upon whose consistency and robustness depends, in his view, anyone’s entire politico-philosophical architecture.

The legitimacy problem that arises when tackling specific distributive questions seems, according to Daniels, oddly not to apply to more general questions of the definition of justice. However, the only way in which this problem can be prevented from arising in actual political life, I believe, is by removing those latter category of questions, i.e. foundational questions, from the political arena altogether and straightforwardly assume that finding an answer to those is a job philosophers sitting in their armchairs are best suited to take up. General abstract questions concerning how a just society

⁴³ See, for instance, Joshua Cohen’s *Procedure and Substance in Deliberative Democracy* (Cohen 1996)

ought to look like are intuitively just as controversial as questions concerning the definition of criteria to set priorities for hemodialysis. At least they are so when the questions are asked *directly* to those that will have to abide by a system informed by those principles.

This is no place to delve into those very foundational questions, but I take Norman Daniels' charge that deliberative democracy fails to deliver on that kind of justification to be grounded. I will however show that there are reasons to believe that their giving up on justificatory efforts makes sense if one refuses to conceive of ethics as metaphysically antecedent to politics.

In the next paragraph I will show how less foundational and more practical attempts at developing a political theory for bioethics still can fail to play out as planned because they are not explicit enough about the absence of metaphysical foundations to their political action.

The uncontested ideal of a publicly engaged science

The relationship between science and society, or the public, has been changing constantly and significantly during the last couple of decades. One recognizable trend in this process of change, which I have tried to outline already in *Moral disagreement and the Life Sciences*, is the shift from a deficit model to a dialogue model of communication of science. Bioethical issues arising from techno-scientific progress, according to this new paradigm, would be best tackled by society at large, rather than by expert committees mandated by political representatives (or, at the very least, public input into science policy making must be sought for).

This trend uncorked a vast array of participatory initiatives, most of which tried to make use of participation arenas that would live up to ideal deliberative standards. Celia Davies, Margaret Wetherell and Elizabeth Barnett in introducing an interesting book reporting on a series of engagement initiatives in the U.K., argue that if one uses Arnstein's eight-rung ladder of citizen participation (redrawn in the figure below), ranging from non-participation to citizen control "with each rung corresponding to the extent of citizens' power in determining the end product" (Arnstein 1969, 217), "few initiatives today are to be found located on the very bottom rungs of the ladder, but equally there are few examples where responsibility is shared or where power has been handed over to service users themselves" (C. Davies, Wetherell, and Barnett 2006, 3).

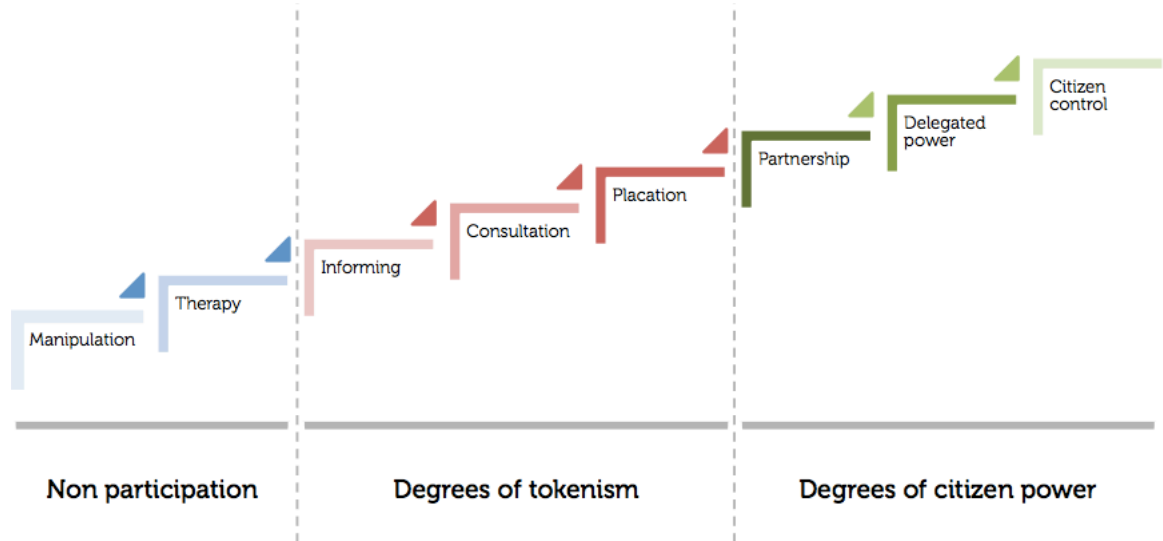


Figure 3 Arnstein's ladder of citizen participation. (Adapted from Arnstein 1969, 217).

Authors have grown increasingly interested in how nowadays uncontested goal of public engagement with science has been historically established as such. In what follows I will try and reconstruct the way some of these authors take a critical stance against these initiatives. They charge the deliberative and participatory turn with having been the result of very historically specific political needs, i.e. Tony Blair's New Labour need to restore trust in democracy thus promoting a renewed democratization of democracy, but also the party's aspiration to turn Great Britain into a knowledge intensive economy with a low degree of societal attrition to innovation. Arguments are put forward to make the point that these attempts, if seen from the suggested historical viewpoint, are not only disingenuous, but they also underlie undesirable political goals such as the further marketization of society. Though I take it to be a fact that these attempts emerged historically as a result of the theoretical developments of Demos and Giddens' influential contribution to the shaping of the New Labour rhetoric, I argue that part of the criticisms that this recognition gives rise to can be dismissed if politico-philosophical foundational questions are addressed.

Davies and colleagues are prone to recognize the flow that historically brought about the flourishing of deliberative participation initiatives in the U.K. Giddens' *Third Way* (Giddens 2013) first published in 1998, and the theoretical and practical work conducted by influential think tanks such as Demos and the Institute for Public Policy Research (IPPR) during the 1990s contributed to the establishment of a participatory agenda for the rising New Labour party (C. Davies, Wetherell, and Barnett 2006, 15–35). The authors show how the wealth of initiatives that were funded during the first two terms of Blair's

cabinet (usually with short-life funding attached) displayed some undeniable contradictions, in part, they claim, due to a failure to “distinguish clearly between the participation of people as consumers/service users and that of people as citizens” (C. Davies, Wetherell, and Barnett 2006, 32). Charles Thorpe, providing a similar historical overview, in two papers, both published at the end of 2010 (Thorpe and Gregory 2010; Thorpe 2010) went further and argued that, not only did the rhetoric of participation and innovation as leading to economic competitiveness in the global market contributed to the creation of “a congenial environment for the entry of ideas from STS into science policy under New Labour⁴⁴” (Thorpe 2010, 392), but, when practiced, it also contributed to the production of what he calls a post-Fordist public, one capable of and ready to take up the innovation that techno-scientific progress would bring about. In this sense, the endeavor of advocating for what third way thinkers termed “lean democracy” (Leadbeater and Mulgan 1994), one more readily responsive to the inputs of the population, would serve two distinct and equally problematic purposes: on the one hand it would produce technologies that better mapped or tracked citizens’ preferences, but, on the other, they would produce a public ready to consume those technologies (Thorpe and Gregory 2010, 276). Framing the issue explicitly in politico-economic terms, Thorpe and Gregory argue that participation, so construed is tantamount to a new form of exploitation. Specifically, citizens are exploited in so far as, participating, they produce immaterial labor “defined as the labor that produces the informational and cultural content of the commodity” (Lazzarato 2006, 132).

The deliberative ideal of participatory initiatives does not escape these criticisms. To the contrary, this ideal can be described as integral to the project of production of some acquiescent public, one that is only allowed to provide their input into policy making about certain issues and only resorting to a highly formal standard of dialogue. Essentially, deliberative democratic participatory initiatives, so described, are technologies of legitimation that act so as to defuse potential contestations and to prepare for the uptake of new products. “The deliberative ideal involves the disciplining of public discourse by norms of rationality, reasonableness, moderation, dispassion and hegemonic consensus” (Thorpe and Gregory 2010, 277). And in fact, criticisms were raised against the deployment of the ideal even from within the STS community that had advocated a participatory turn in science policy. Poort and colleagues highlighted the worrying tendency to foreground technical and pragmatic issues

⁴⁴ Thorpe refers here to the adjudication of the public engagement discourse coming from STS scholarship.

in deliberative participatory ethics committees, disregarding potential sources of unsolved moral disagreement (Poort, Holmberg, and Ideland 2013), Levidow submitted it that the overwhelming majority of public engagement initiatives had taken for granted the need for biotechnological progress for economic growth (which in turn had been assumed as a valuable end for science policy making) (Levidow 2008), Brian Wynne, undoubtedly one of the most vocal advocates of the shift to the dialogue paradigm, commented that engagement initiatives have systematically failed to be anything other than attempts at shoring up (damaged) trust in science and in the scientific community (Wynne 2006), Joly and Kaufman harshly criticized the initiative that led to the publication of the report on nanotechnologies heralded by public input advocates as a success story of upstream engagement (Kearnes, Macnaghten, and Wilsdon 2006), in that, as most of such kind of initiatives, it seemed subscribe to the imperative of global market competition, linking success in the global market to taking the lead in biotechnological progress.

Deliberative participation initiatives, essentially because leaning decidedly towards the side of political (democratic) practice, rather than theory, are further away from attempts, such as Daniels', at providing metaphysical foundations to the fair procedures that ought to be practiced in civic engagement when tackling bioethical issues, thus defining exactly what principles and values are to inform the process. However, these less foundational attempts are, as we have seen, clearly liable to a well-defined set of criticisms that seem to be at least related to their shyness about their own politico-philosophical foundations. In a sense, if it is theoretically unclear why we ought to pursue further engagement initiatives, it becomes easier for critiques to spot all the ways in which non-neutral values, e.g. restoring trust in science, or promoting national economic performance through biotechnological progress, seem to be pushed forward. This lack of clarity makes it possible, for critiques, to point to the dubious political opportunities that these initiatives seem to underlie. There are two main strategies to counter these arguments: first, consolidating the political theory behind the initiatives so as to clarify why and how engagement needs to be promoted, and secondly devising new initiatives that take into account the issues highlighted by critics. Pursuing the first goal is crucial to show that the problems that have been noted are contingent to the project of a more democratic bioethics, whereas furthering the second entails taking into account the contingent (and therefore correctable) ways in which past

initiatives have failed to play out as planned. To the first project I devote the next paragraphs, whereas the second issue is tackled in Part II.

The presentation of these two political theories of bioethics was meant to provide an assay of the ways in which one can be confronted with the issue of grounding the normativity of political resolution of moral disagreements. Daniels does so explicitly, mustering the well-established tradition of liberal (specifically Rawlsian) political philosophy and claiming that not doing so (Daniels argues Gutmann and Thompson fail to do so appropriately) weakens one's political theory. On the other hand, promoters of public engagement initiatives deliberately overlooking foundational issues, can be charged with criticisms concerning their dubious historical establishment. Taking these two theories as tokens of different types of foundational attempts, in what follows I define more precisely what counts as foundationalism in politics in order to propose a democratic framework, rather than any specific political theory, that develops upon a sort of middle ground between straightforward metaphysical claims à-la-Daniels and radically antifoundational claims of those Galston calls realists in political theory (Galston 2010).

Foundationalism in politics

The dilemma sketched above between normativist and antinormativist foundational attempts is reflected, though with appreciably different nuances, in the debate between foundationalist and antifoundationalist political theorists. In particular, foundationalists try and metaphysically ground political authority, whereas antifoundationalists rely on existing social practices and apparently give up on justifying some forms of authority over others.

Richard Rorty, to mention a notable example, in defining the divide between foundationalism and antifoundationalism from the latter camp, argues that foundationalists simply take idealizations of existing practices, meant to work merely as “intuition pumps”, and turn them into objects existing independently of the practices that are being idealized. Rawls and Nozick, so framed, would just be ‘pumping’ components of different existing practices: the courts of law and the marketplace to have them make the justificatory and foundational work. “As we antifoundationalists see it, the object outside the practice, the purported foundation, is always just a hypostatization of certain selected components of that practice” (Rorty 1996, 333–334), be it justice or rights. However, this stance admittedly offers very little guidance in judging the worth of specific political theories, to the point that

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Rorty says that asking the question why our societies ought to be as inclusive as possible is, “[f]rom a Darwinian point of view, [...] as pointless as asking for a reason why the primitive mammals were more worthy to survive than the giant reptiles” (Rorty 1996, 334). This is tantamount to giving up completely on solving the problem of normativity. I am instead confident that there is a viable way out of the dilemma I just sketched and I therefore present in more detail a political realist option, which seems to offer, in some instantiations, a less radical alternative to relinquishing genuinely normative efforts altogether.

Varieties of political realism

Jeremy Waldron, in his inaugural lecture for the Chichele Professorship of Social and Political Theory at the University of Oxford, subsequently published in *The Journal of Political Philosophy* with the title “*Political Political Theory*” (Waldron 2013) deliberately tried to characterize his scholarship (in a sense a scholarship he regarded as still to come) in opposition to previous, notable attempts that, however influential and eminent, had been “a little one-sided” in understanding political theory “as just applied moral philosophy” (Waldron 2013, 6).

In the essay Waldron sets out to reassess Hume’s dichotomy in political theory: a dichotomy, in its original formulation, between a focus on citizens’ virtues and a focus on political institutions. Theorists who focus on the first usually proceed from the assumption that certain institutional arrangements just cannot be made to work properly unless those who inhabit those institutions are endowed with specific virtues. Interestingly, in this first account, given some ideals we want our institutions to pursue, it is people that ought to be changed in order for those ideals to be maximally (or optimally) realized. Others, like John Rawls in *A theory of justice* (Rawls 2005), submit it that people’s ‘nature’ or basic attitude is somewhat given (it generally is some version of the self-interested *homo oeconomicus*) and political and economic institutions ought to be designed so as to have those people bring about the justest of societies⁴⁵.

Waldron however argues that this dichotomy might be unfit to describe the actual range of takes that one might have on how to design a better society and recommends replacing it with a *trichotomy* in

⁴⁵ Waldron takes doctors’ salaries as a case in point for Rawls’ attitude here (Waldron 2013, 4). Rawls argued that even very unequally high salaries for MDs are fair in that lowering those would result in further worsening of the medical service that the already worse off receive. This, however, only holds true if MDs work as merely self-interested subjects.

which the third kind of (more or less exclusive) focus is on the ends and ideals that a good society ought to promote. I share with Waldron the view that most mainstream analytic political philosophers have been focusing primarily on this third branch of the trichotomy. He cites Robert Nozick (Nozick 1999), Ronald Dworkin (Dworkin 2011), Amartya Sen (A. K. Sen 2009) and Michael Walzer (Walzer 1983) as examples of classics that have consistently taken this approach. This focus, he contends, produced a disproportionate wealth of contributions delving into societal issues through the narrow lens of justice and equality. He quotes Isaiah Berlin saying that “[t]he business of political philosophy is to examine the validity of various claims made for various social goals, and the justification of the methods of specifying and attaining these” and “no true political philosopher has omitted to do this” (Jahanbegloo 2011, 46–7), to support the view that most political philosophers have conceived of their “business” as precisely deductively applying moral philosophy. Waldron himself admits having contributed to this literature, treating justice and equality as essentially moral concepts (Waldron 2003) to be applied to the political domain. However, he claims, this almost exclusive focus on moral principles has resulted in political theory being essentially very little political. This sort of oddly non-political political theory led to very fundamental questions concerning the degree to which the principles, values and ideals that the theories postulate to be shared, objectively exist and are shared as a matter of fact. The existence of these principles, values and ideals, and the belief that these are actually shared are preconditions for these theories to have any (legitimate) bearing onto actual political life, i.e. for their claims to be effectively normative. Unfortunately, as Waldron notes, “whether these values are objective or not, we have disagreement about them; people who are thoroughly committed to their objectivity disagree about them” (Waldron 2013, 9). Rawls and Nozick having been working in the same corridor at the same academic institution for years ironically proves this point more compellingly than any empirically sophisticated claim could. These, foundational, political theories, essentially inherit the unsolved controversies of moral theory and can therefore only be appealing to an audience sharing in a specific set of moral premises. The reality of political life urges us to consider some ways to go beyond this forcibly sectarian architecture of competing political theories, which stands hardly any chance of effectively organizing social practices.

And in fact, this way of undertaking philosophical work concerning issues belonging to the third branch of the trichotomy, i.e. studying the ends and ideals the good society ought to pursue, is of

course not the only way in which one can conceivably address the problem of normativity in politics. There have been authors who tried to kindle a different, distinctively more political, tradition of political theory, one that does not simply presuppose some sort of primacy or priority of morality over politics.

William Galston provided a rich overview of the apparent “ragtag band” of theorists that tried to resist the long-standing preeminence of foundational liberalism in political theorizing (Galston 2010, 385). He did so in an attempt to show that there is some systematicity to this dissenting position, (which, following Bernard Williams’ preferred term, he called political realism) meaning that some hallmarks can be identified that distinguish the diverse range of theorists falling under the heading. The theme that, according to Galston, makes it possible to identify this group of theorists as indeed one group, is “the belief that high liberalism represents a desire to evade, displace, or escape from politics” (Galston 2010, 386). This clearly animated their desire to suggest more *political* political theories, restating the importance of politics above and beyond ethics. The hallmarks of political realism that Galston identifies are:

- A decidedly and twofold *anti-utopian stance*: political realists remind us how historically recent the apparently ultimate adjudication of democracy is. They are therefore concerned primarily with the chance that political coordination regresses to undesirable past schemes, e.g. Nazism and fascisms, Communism and more generally authoritarian regimes. Political realists are anti-utopian in a further sense, though: they do not regard the conceptualization of justice as a fruitful way to politically theorize because “many questions of justice only arise once people behave unjustly” in the words of Kwame Anthony Appiah (Nielsen 2006, 9). The creative intellectual job of imagining a just liberal state makes little sense because our imagination “is inevitably compromised in the practical process of translating the ideal into political reality for the utterly prosaic reason that political conduct is driven by motives and desires that, while they can be contained, disciplined, and to some extent laundered through political procedures and institutions and through deliberation and debate, cannot ever be wholly expunged of personal desires and ambitions” (Philp 2007, 111). This implies, for political realists, that relying on deduction from general principles to practical political solutions can and sometimes

will result in more harm than good for the very reason that it was an attempt at doing too much good.

- A belief in the *ineradicable ubiquity of conflict*: Chantal Mouffe, for instance, whose latest book is revealingly entitled *Agonistics*, takes conflict to be a defining feature of politics. She claims that “[w]hat characterizes democratic politics is the confrontation between conflicting hegemonic projects, a confrontation with no possibility of final reconciliation” (Mouffe 2013, 43). The recognition of the centrality of conflict for political theorizing has not led to its full-blown advocacy (at least not for everyone in the realist camp): Honig recognizes that the “perpetuity of conflict is not easy to celebrate” (Honig 1993, 14 cited in Galston 2010, 396) and that political realists are thus compelled to engage in the assessment of the duality between conflict and consensus, disruption and stabilization.
- A commitment to *value pluralism*: many political realists maintain reason alone can neither determine agreement concerning basic values, nor provide guidance in solving puzzles that concern balancing those values (Galston 2010). This conviction has two important implications: first, although a derogatory stance of the political power of reason alone does not have to mean that reason cannot be of *some* help in finding some forms of agreement, the essential matrix of political discourses must be that of political conflict rather than that of intellectual disagreement; second, political adversaries must not be seen as people who are wrong or mistaken, as if the only form of political contestation available was epistemic in kind, but rather as political actors belonging to some opposed faction who might win or lose.
- A need for *psychological and motivational realism*: not only does reason not constrain one’s motivations to act to the degree high liberals would like it to do, there also are passions and emotions that cannot be accounted for resorting merely to interests which are highly effective in motivating people’s behavior. These range from “anger, hatred, the urge to dominate, the desire to destroy” (Galston 2010, 398) and tackling the problem of normativity in politics without taking into consideration the existence of these motivational factors dooms one’s theory either to irrelevance or to failure.
- A firm *skepticism about deliberation*: according to Galston, most political realists reject deliberation as the most desirable way of social coordination with two main reasons. The first is that they do not share in the premise that people are all epistemic equals: there exist

inequalities in the degree to which people are capable to acquire property, but these exist alongside inequalities in cognitive capabilities. Secondly, deliberation *per se* lacks (i) decision rules for those likely occasions in which consensus is not forthcoming, and (ii) properly deliberative means to establish deliberation itself (Galston 2010, 399–400).

This multifaceted red thread notwithstanding, political realism remains a very fuzzy category comprising attitudes with varying degrees of skepticism towards the actual existence of the values that political theories postulate and advocate the maximization of. This makes the whole array of such theories fall squarely within the category of antifoundational political theories, but also qualifies some of the theories as more committedly antifoundational than others. Authors such as Rorty, as I have shown, believe the enterprise of politics ought to be a celebration of conflict, and conflict therefore ought not be overcome, in that there is no hope of finding reasons to be compelled by some solution to the problem of social coordination over some other (Rorty 1996).

One of the main defenders of this kind of radically anti-foundational or anti-deductive claims about the nature of politics is Raymond Geuss. Geuss takes the expression “real politics” (instead of political realism, used heretofore) which has a long history in political thinking and resignifies it constructing a bundle of *four interrelated theses* that provide the label with a new meaning. These theses are partially overlapping with the motives just listed, but it makes sense to take a closer look at this radically skeptical version of realism in order to be able to characterize, in opposition, a relatively moderate realism in politics. According to Geuss’ proposal, political philosophy must be realist in the sense that it ought to be concerned with “the way social, economic, political, etc. institutions actually operate in some society at some given time” (Geuss 2008, 9). Secondly, political philosophy ought to be concerned with actions and contexts of action rather than with beliefs and propositions. Thirdly, politics needs to be taken to be historically situated and fourth, politics should be regarded as some kind of technique, or craft, rather than as the application of some theory.

The prescription to desert theory altogether must be seen as a clue that a political philosophy compliant with Geuss’ standards will inevitably be very vague and its practical implications hard to grasp in detail. Within such a framework, or adhering to this kind of radical program, essentially no space for prescriptive normative theorizing is allowed and it is hard to imagine exactly how political efforts can be organized and furthered (at least if they are *extra-academic* political efforts), without

subscribing to genuinely normative and prescriptive claims. In a sense, the little guidance that this stance offers to positive political theorization seems to run counter the anti-utopian stance described above, in that it either limits political philosophy to the constrained domain of mere *ex-post* analyses, or, if we take seriously the possibility of a thoroughly a-theoretical art of politics, it turns politics into the hopeless blind efforts of groups of ‘believing craftsmen’, who promote their own political views out of non-theoretical conviction alone. As Galston notes, instead, the real challenge for political realists is to allow some space for ideal theory because “few would accept a conception of political theory that merely ratifies the status quo” (Galston 2010, 406). The right sort of ideal theory would therefore build in the theory itself assumptions and expectations that are challenging but feasible in a specific domain of application, which should comprise historical and local circumstances.

This space for ideal theory, I contend, can be found in a relatively milder way of interpreting political realists’ skepticism about genuinely political values and abstract principles, one according to which we can assume with some degree of certainty that values A and B are indeed values that ought to be sought after in designing our institutions, but whose centrality is nonetheless clearly historically contingent. In a sense, I am advocating very roughly translating the multifaceted concept of scientific realism into the domain of politics and will explain this proposal more in detail below. I maintain that Bernard Williams’ take on political realism offers a sensible starting point for the further elaboration of this claim.

In a seminal essay unfortunately only released posthumous in the collection entitled *In the Beginning Was the Deed. Realism and Moralism in Political Argument* (Williams 2005) Williams presented the difference between moralism and realism in politics with unparalleled clarity. Political moralism, according to his distinction, comprises a number of models of political theory that assume “the priority of the moral over the political” (Williams 2005, 2). Among these, Williams singles out John Rawls’ *Political Liberalism* (Rawls 1993) because Rawls, in that book, deliberately tries to conceal the hegemony of morality over politics in a way that, however Williams contends, reveals how disingenuous his attempt is:

Rawls is not merely giving an answer to the question of stability in terms of citizens’ morality; he is giving a moral answer. This comes out in his

repeated claim (for example, *PL*, 147⁴⁶) that the conditions of pluralism under which liberalism is possible do not represent “a mere *modus vivendi*.” Rather, the basis of co-existence, and the qualities elicited by these conditions, include the highest moral powers, above all a sense of fairness.

(Williams 2005, 2)

In opposing a mere *modus vivendi* (where the emphasis would be on the “mere”) to his, self-proclaimed, *political* conception of justice, Rawls fails to give up on the imperialistic attitude that his own political conception of justice exercises over other, competing, at least equally political, conceptions. To this mode of conceptualizing political theory using the terms of the theorists’ own moral vocabulary, Williams opposes a distinctively more political conception of political theory, what he calls, and we have already described as, political realism. He characterizes political realism as being concerned with a set of questions wholly different from that with which much high liberalist political philosophy has been engaging. In particular he centers his analysis on Hobbes’ ‘first’ question of politics, i.e. how to secure “order, protection, safety, trust, and the conditions of cooperation” (Williams 2005, 3). Answering this question is essential, because the answer to any further question depends on the solution to this first problem. Of course any answer can be given to the first question, without that implying anything as to the answer’s legitimacy. Solving the problem of security is, Williams claims, a necessary but not a sufficient condition of legitimacy: without a solution to the first problem, no legitimacy obtains, but having solved the problem does not warrant the solution’s legitimacy. Clearly, the definition of legitimacy, taken as probably the most foundational of concepts in political theory, plays a pivotal role in a political realist’s attitude towards the answers that have historically been given in response to the first question. And in this respect, Williams does only part of the definitional job: he sets a lower bound for the acceptability of answers to the problem, a line that divides legitimate from illegitimate answers. This line is traced using the concept of “Basic Legitimation Demand” (BLD) and arguing that this demand is not met in case a group of subjects to the state (state meant here in the broadest sense possible as any solution to the problem of security and order) is “radically disadvantaged”, meaning they are, within the state, “no better off than enemies of the state” (Williams 2005, 5), at will coerced, tortured, humiliated, killed. To the extent that within a state there is one such

⁴⁶ Williams refers here to *Political Liberalism*, (Rawls 1993, 147).

group, that state, to that group, fails to properly meet the BLD and is therefore illegitimate. It is illegitimate, moreover, because it fails to deliver a solution to the first problem that is more acceptable than the problem it was meant to remedy in the first place, i.e. the Hobbesian mythological state of nature.

The BLD, so defined, though vague, is not empty: it helps us articulate the reasons why, for instance, slaves can regard the state they live in as illegitimate and rightly rise up against it. In fact, these radically disadvantaged groups can argue that their state claims authority over them, but denies any justification for why they ought to submit to it. Also, this definition of the BLD allows for, according to Williams, an authentically non-moral foundation for the endeavor of political philosophy. The BLD might indeed be conceived of as a moral principle, but *if* it is a moral principle, then it enjoys the sort of morality that is not prior to politics, a morality that presupposes the existence of a first political question, rather than grounding one's answer to it.

However, there is a sense in which the BLD, so defined, is just too vague—to the point that it might not be useful. The BLD, as Williams construes it, has an in-built requirement for justification: the state, Williams assumes, “has to offer a justification of its power *to each subject*” (Williams 2005, 4). This assumption has the interesting implication that any state meeting the BLD satisfactorily must allow for some form of free speech, so that demands for justification are voiced in case they were to arise. Unfortunately though, excluding only justifications that merely assert the domination that is prompting the demand for a justification⁴⁷—as Williams does—, the assumption offers very little guidance in discerning what counts as an acceptable justification and what does not. To try and make his case for such a loose conception of justification more compelling, Williams resorts to the hermeneutical category of “making sense”. This category, so his argument goes, could help defining, in a historically and locally situated manner, where the line between illegitimate and legitimate authoritative orders would lie, but it would always do so with reference to somebody issuing the statement that the justification for some order of authority X “makes/does not make sense” as a legitimation (Williams 2005, 11). Regrettably, this hermeneutical approach can do little to adjudicate actual political quarrels, and the same disagreement that threatens the utility of moralistic constructions of politics, seriously challenges the utility of a political realism that can only go so far as to claim that “what we

⁴⁷ Something along the lines of ‘the state has a legitimate power over you, because the state has more power than you do’.

acknowledge as LEG, here and now, is what, here and now, MS as a legitimation of power as authority⁴⁸” (Williams 2005, 11). To make my point clearer, consider what follows: there is a whole bunch of people who would be willing to acknowledge as legitimate here and now the weirdest forms of legitimation of power. Just consider the example of ethnicity or race as a firm ground to claim legitimate authority or power over others. And the mere fact that there is someone for whom these forms make sense as legitimations of power seems too broad a criterion to work out what is a justification that makes some authoritative order legitimate. Especially in the light of the deflationary approach with which Williams defines what concepts make sense in the face of discussions about their worth: “the fact that we use these concepts is what shows us that they MS” (Williams 2005, 11).

If my interpretation of Williams’ proposal is sound, then it seems to me that the way he conceptualizes legitimacy in the space between facts and norms makes little to no reference to the actual nature of normativity, to rely mostly, if not solely, on the facticity of norms, i.e. the way in which they exist and how they perform in practice. This issue prevents Williams’ account from unfolding into a full-fledged political theory. This can however be seen, in a jargon borrowed from informatics, as a feature of his own position, rather than as a bug. After all, renouncing the normative part of political theory makes sense for a political realist committed to discarding any moral foundation of legitimacy. However not being able to establish even tentative criteria for the definition of acceptable justifications of some authoritative order might be self-defeating for authors, such as political realists are, well aware of the constant risk of regress from the actual solution to the first political question, to previous, more immediately unacceptable, solutions. In a sense, the recognition of the possibility of going back to a state that does not successfully secure the conditions of social cooperation makes a strong case for the need to shore up what here and now look like more acceptable forms of justification of authoritative orders. They might indeed turn out to be wrong in the end, but this is no reason not to use them as benchmarks for new legitimation demands, for new answers to the first question of politics.

This means that Williams’ political realism is a good starting point for the development of a *political* political theory of bioethics, but not much more than that. In order to progress further, I will suggest that there is a sense in which scientific and political realism are not only related in the realm of words,

⁴⁸ For reasons that remain obscure to me, Williams uses acronyms for a number of expressions in this essay. In this passage MS stands for “makes sense” and LEG stands for “legitimacy”.

i.e. they are accidentally referred to with same term. Quite the contrary, scientific realism can highlight relevant and interesting ways in which political realism can give rise to progressive prescriptive normative theories that make use of tentative political concepts to propose more legitimate institutional arrangements. Thus, in the remainder of this paragraph I mean to show that concepts used to justify authoritative orders here and now to provide an answer to the BLD are indeed always tentative, but this tentative nature is more similar to that of hypotheses within an hypothetico-deductive model of inquiry. The space of these hypotheses is not unconstrained, but needs to come to terms with feasibility concerns and with what might be loosely referred to as *prior political knowledge*. These constraints can be used as boundaries within which to set up societal experimental practices to seek for, in a piecemeal approach, better answers to issue-specific legitimation demands.

This proposal can also be regarded as a promising way out of the dilemmatic problem of normativity in politics in that it does not rely on axiomatic postulations to ground the legitimacy of authoritative decisions, but it does not take social or hermeneutical practices at face value either.

Fallibilism and democracy

So far we have seen that bioethics is a thoroughly political activity and that, as such, it deserves a genuinely political theory. Such a political theory, I showed, cannot be grounded in any arbitrary set of moral assumptions on what affords the normativity of norms, i.e. what makes it unacceptable that one does not comply with the norm. If this were the case, inevitably those not sharing in those premises would be allowed to defy the coordination scheme. These theories fall in a category that has been characterized as political moralism. Political realist theories are instead *political* in a stronger sense: namely they do not take morality as prior to politics and try and provide genuinely political answers to the political demand of legitimacy of collectively binding norms. We have also seen, however, that notable political realists have failed to devise successful criteria for distinguishing between acceptable and unacceptable political answers to the questioned legitimacy of norms. In a sense, then, properly political realists were proven unable to solve the problem of normativity satisfactorily. In closing the previous paragraph I hinted at a way to revise political realism so as to have it fit desirable normative and prescriptive political theorizing in a way that might also put the problem of normativity to rest once and for all. This would be pushing an analogy between political realism and scientific realism. In this paragraph I will roughly outline what scientific realism is in philosophy of science and then

highlight the interesting features that might usefully qualify political realism in a sense that makes it internally consistent. I will furthermore argue that, once we grant this analogy, there is a straightforward sense in which normative political theories and their underlying conceptions of legitimacy can be fruitfully discussed both theoretically and empirically. That is if we conceptualize those theories as hypotheses. This will help single out democracy as the framework within which to devise and test these theories.

Scientific and political realism

Richard Boyd, in a very old paper, deliberately tried to defeat moral relativism and, by the same token, to offer a compelling defense of what he called moral realism (accidentally, he defended moral realism using nonutilitarian consequentialism as a case in point). To do so, he claimed and argued it made sense to draw a closer analogy between scientific realism, a thesis he had previously defended, and morality. In particular he claimed that moral realism was untenable only under a naïve and unsophisticated reading of the term realism, which, in turn had been long qualified and précised in years of philosophy of science. I will not follow Boyd in his argument for moral realism, which I find convoluted, hard to grasp and more importantly, given what I said about grounding political theory in moral values, essentially pointless for my purposes. I will however rely on a similar strategy to construct a definition of political realism that does not give up entirely on normative theorizing.

In the opening of his essay, Boyd summarizes what scientific realism is by saying:

Scientific realism is the doctrine that scientific theories should be understood as putative descriptions of real phenomena, that ordinary scientific methods constitute a reliable procedure for obtaining and improving (approximate) knowledge of the real phenomena which scientific theories describe, and that the reality described by scientific theories is largely independent of our theorizing (Boyd 1988, 181).

There is a relatively high degree of variability in the definition of scientific realism. However, authors discussing it, in general, as Chakravartty notes, all share in one common feature of their definitions, “a commitment to the idea that our best theories have a certain epistemic status: they yield knowledge of aspects of the world, including unobservable aspects” (Chakravartty 2013, 3). Science, in this sense,

can be very abstractly characterized as the pursuit of truth via scientific theories, and scientific realism, in turn taken to entail that scientific theories are approximately true descriptions of a reality existing independently of its observers.

In a rhetorically impressive move, Boyd (along with plenty of other realist philosophers of science, e.g. Armstrong (1973), Goldman (1967) or Quine (1969)) argued that it is precisely the theory-dependence, a posteriority and contingency of scientific methodologies—traits of the methodology that anti-realists had used to defend their anti-realist claims—that commands a scientifically realist stance. The reliance on those methodologies, and their fundamental reliability, can in fact only be explained under a scientific realist conception of reality, i.e. assuming that reality is prior to thought. In particular, according to Boyd, two features of the scientific enterprise seem to point directly to this conclusion: first, the cumulative nature of scientific research, and second, the “*dialectical relationship between current theory and the methodology for its improvement*” (Boyd 1988, 190 emphasis in the original). These two contribute to outlining a picture of science as a progressive endeavor, in which the means by which we arrive at new theories depend on previous theories. The reliability of *current* scientific practices therefore remains a mystery unless we adopt “a realistic conception of scientific knowledge”. Current scientific success is, in Hilary Putnam’s words, “a miracle” (Putnam 1975, 73) under non-realist or anti-realist interpretations. In a nice chiasm, then, “if by the “objectivity” of scientific methodology we mean its capacity to lead to the discovery of *theory-independent reality*, then scientific methodology is objective precisely because it *is theory-dependent*” (Boyd 1988, 191). The theory-dependence of scientific theories thus helps us define our preference for new scientific theories, which are plausible in the light of some established set of available theories⁴⁹.

Boyd, after laying out his educated definition of scientific realism proceeds to defend the claim that moral statements and moral theories are relevantly similar to scientific statements and scientific theories. As I said, I am not interested in whether this strategy is worth pursuing, given that I take the problem of the moral foundations of political institutions to be a political problem, rather than a meta-ethical issue. I am instead interested in seeing how and whether at all, this description of scientific realism can be translated into the domain of politics. To this point I now turn.

⁴⁹ This last point is relevant to my argument to the extent that, as I said above, normative and prescriptive ideal political theories must be defined within a space of prior political knowledge whose domain is not unconstrained. More on this later.

At approximately the same level of abstraction at which science can be characterized as the pursuit of truth, politics can be characterized, as I did above, as the pursuit of legitimacy, that is, as the quest for the best solution possible to the problem of social coordination, or what Williams, following Hobbes, called the first political question. If we translate the scientific version of realism as just sketched, straight onto the domain of politics, we may construe political realism as:

The doctrine that *political theories* should be understood as putative descriptions of real *political phenomena* and that *ordinary political methods* constitute a reliable procedure for obtaining and improving (approximate) knowledge of the political phenomena which political theories describe, and that the reality described by political theories is largely independent of our theorizing.

This very rough translation clearly needs some qualifications to be made sense of and in order for it not to remain just an arbitrary juxtaposition.

- i. First, what are political theories?
- ii. Second, what are political phenomena?
- iii. Third, what constitutes an ordinary political method?
- iv. And fourth, have these actually proven reliable in obtaining and improving our knowledge of real political phenomena?

I shall now propose my answers to these four questions. These, I believe, can contribute to a definition of political realism that can function well as a framework for the development of tentative institutional prescriptions, which are tested in practice and adjudicated according to provisional criteria of legitimacy presented in detail below.

A tentative definition of political theories

Political theories, as I define them here, have a somewhat oblique relationship to scientific theories. The latter, in fact, are taken by scientific realists to describe truthfully, or approximately so, “aspects of a mind-independent world” (Chakravartty 2013, 6). Clearly, political theories are not meant to describe “the world” as such, but are rather supposed to describe *principles, values and ideals* that (putatively) make up the multi-faceted and articulated idea of legitimacy. I take this idea, i.e. the idea of legitimacy, in a

literally realist understanding, to be mind-independent. Therefore, (our best) political theories are truthful, or approximately truthful descriptions of these *principles, values and ideals*. These can of course be moral in kind, but, given that they structure political theories, they must be tested, as I will show below, against political (and not moral) standards. It is in this sense that my political realism inherits the primacy of politics over morality that political realists advocate, but also retains moral concepts as useful theoretical constructs.

As the “our best” in parenthesis above suggests, scientific realism, as a doctrine in its general outlook, does not entail realism about just any scientific theory. Instead, genuine but savvy realists are realist about some scientific theories, namely, our best scientific theories. Criteria to tell apart good and bad scientific theories are appropriate and needed also—probably more desperately so—in politics. Below, I will present two criteria that I believe can sensibly settle this issue in politics, whereas here I want to introduce a straightforward but important distinction between political theories as descriptions of principles, values and ideals that make up legitimacy and the institutional designs that these political theories prompt. Political theories that merely describe and qualify abstract principles, values and ideals are hard to adjudicate solely on their own grounds. There may be better or worse arguments in favor of one set of principles, values and ideals over some other, on purely rational grounds (their internal consistency is the easiest example that comes to mind), but rational grounds alone cannot settle actual political issues, in that in most of the cases solutions to those issues rely on internally consistent, but reasonably objectionable definitions of those principles, values and ideals and, what is most important, they generally *underdetermine* the institutional arrangements that suit those principles, i.e. more than one arrangement can be implied by the same set of principles.

These two intertwined problems make political theorization of little help, if any, in case it is conceived as a merely theoretical activity. In order to overcome this impasse, I argue that genuinely *political* political theories must comprise actionable institutional arrangements, whose essential role is that of providing ways to *mediate* test the actual extent to which the theory describes legitimacy (or better, as I will show further on, specific aspects of it). In a sense, then, the problem of the underdetermination of institutions, given some specific political theory, must be solved by proponents of the theory *as a matter of practice*. The normative work of realist political theorists, hence, is supposed to be twofold: first it has to comprise the specification of principles, values and ideals that can putatively ground a more

legitimate solution to the political problem at hand, and secondly, it must lay out the details of the institutional arrangement that should embody those principles. This second part of the theoretical work enjoys a kind of normativity relevantly similar to that scientific hypotheses have: the institutional arrangement is, in this analogy, the protocol by means of which others can test one's political theory in its original interpretation.

Political theories, as defined here, are then relatively intuitively similar to scientific theories in that they are constituted of a specification of their theoretical constructs (i.e. principles, ideals and values) that putatively describe legitimacy in a specific context (as scientific theories putatively describe specific aspects of reality) and a detailed description of the operational ways in which they are mediately detected (institutions) that feedback onto the theory and whose reliability as measuring devices depends in turn on the historical adjudication of the theory itself.

Interestingly, the analogy with science suggests a further insight: just like no one specific theory describes all aspects of a mind-independent world, it is very unlikely that one political theory will capture and encapsulate all relevant aspects of a mind-independent idea of legitimacy. More probably, instead, specific political theories will apply to specific political problems, providing some guidance as to how these might be handled legitimately. They will do so outlining the tentative features of some institution supposed to manage the problem of social coordination in some domain with a higher degree of legitimacy, hypothetically postulated according to one's preferred political theory (more on this last point below).

A tentative definition of political phenomena

I define political phenomena as all events happening within or somehow affecting the public sphere. This is indeed a very inclusive definition, extending to anything that constitutes how we live together. The reason why it is sensible to lump together any of these phenomena as relevantly political is that, as Jane Mansbridge put it, activities that range from formal talk among elected representatives down to "everyday talk in formally private spaces about things the public ought to discuss" all add up to what she called "the deliberative system" (Mansbridge 1999, 211), a system that effectively ends up informing collectively binding decisions, i.e. decisions imposed upon one another, and that ought to therefore be regarded as essentially political.

There is one problem, however, with the definition of political realism attempted above, in relation to this characterization of political phenomena. As I just said, political theories are stipulated here to describe abstract features of legitimacy, i.e. principles, values and ideals, and to, subordinately, specify viable institutional arrangements that embody those principles. Hence, a political theory is not supposed, within this framework, to describe political phenomena. Nevertheless, any of these phenomena play a legitimate role in authentically *political* political theories: their observation is informative about the tentative, but approximately true, postulations of our best theories. Observing political phenomena can of course be more or less informative about one's political theory, and although, as I will argue further below (see Evidence-Based democratic theory), it is hard to make a case for a rigid hierarchy of evidence in politics, some observations are more informative than others due to the underlying structure of the observation. The discussion of a fictional example might clarify in what sense some observations of political phenomena are more informative than others due to their underlying structure.

First, suppose some institutional arrangement 'naturally occurred'. I take the natural occurrence of the arrangement here to mean simply that the arrangement was not brought about with deliberately experimental purposes in mind, and not that it was *not* deliberately brought about. As it happens, institutional arrangements are *always* brought about by the will of some group of people, in that institutions are norms, or rules endowed with sanctionatory mechanisms that result in regularities, therefore the existence of an institution implies, by definition, someone's willingness to abide by those rules and norms. We are not concerned here, however, with the ways in which this specific institutional arrangement came into being. Let us, instead, suppose further that this naturally occurred institutional arrangement solves the first political problem relying on a tyrannical distribution of all powers, whereby one person only, the tyrant, legislates, judges and executes policies. This tyrant happens to issue rules that enhance the well being of his subjects according to some unspecified measure. Sometimes, some citizens (say a relatively small number) feel unhappy with the way power is handled, specifically with the distribution of political entitlements, regardless of the satisfactory output yielded by the political authority. The public sphere is here so constructed that these subtle forms of discontent are hardly visible by those who are not directly experiencing the discontent. These expressions of dissatisfaction and distrust in the authority are indeed still political phenomena

according to the definition I gave above. They are however very hard to be made sense of without (i) any proper benchmarking mechanism, e.g. how the arrangement has fared in different contexts; (ii) a reasonable contextual knowledge, e.g. to what extent it would really be possible to gauge discontent in this setting; and (iii) an explicit metric for descriptive legitimacy in mind, e.g. to what degree subjects perceive the arrangement and its output to be legitimate (more on the definition of descriptive legitimacy later on). The fictional scenario can still be assessed according to one's political theory, but the import of political phenomena on this assessment would be little, if any, and the core part of the judgment would instead rely on principles, values, and ideals that are already part and parcel of that political theory—which is only supposedly true—rendering the assessment just an estimate of the degree to which the institutional arrangement works according to them. As I will argue below, this is a fairly uninteresting way to go about political theorizing, and a decidedly non-empirical way as well. Essentially the way in which the institutions work as a matter of fact plays no role in what we know about the 'groundedness' of the makeup of our political theory. This is the case for two features of the example that are structural in kind: first, in the scenario described, the political system does not allow for properly experimental institutions, i.e. institutions constitutively open-ended, built so as to be reformed on the data that can be gathered by successive local implementations of their architecture, and second, feedback that might be generated is not systematically organized, by which I mean there is no corollary institution (more on these below), equally open-ended, supposed to gauge the effect the core institution has on the perceived legitimacy of its output.

In the next paragraph I will suggest that democracy seems to offer the best tools to systematically tackle these two structural issues. In particular, I will argue, democracy can be conceived as the open-ended analogous of ordinary scientific methods, in that it offers a vantage point for the assessment of institutions whose experimental implementation would depend on the putative description of principles, values and ideals that one's political theory assumes. This last part of the analogy between scientific and political realism will secure the role of democratic experimentalism as the 'scientific method of politics', thus requiring the same a-posteriori foundation that scientific methodologies entertain, one that depends on its success in adjudicating political theories that turn out to yield legitimacy.

Democracy as ordinary political methods

Most scientific realists are fallibilists (Chakravartty 2013), meaning that they submit that even our best scientific theories cannot be adjudicated once and for all. What we believe to be true today may in the future turn out to be mistaken, but this, according to scientific realists, generally does not exclude grounds for genuine realism about what we do know today. There is a sense in which this fallibilist account fits well with the scope of political realism as it is being defended here. Michael Saward, however, has in the past defended the view that fallibilism in politics favors democracy *as a political theory* (that is, his own definition of participatory democracy). In this paragraph I will explain why I believe his defense is not compelling and I will rescue the idea of applying fallibilism in politics to characterize the role of democratic machinery as that of a ‘scientific method of politics’ rather than a political theory among others.

In this fairly old essay entitled "Democratic Theory and Indices of Democratization" (published in the anthology *Defining and measuring democracy* edited by David Beetham (1994)) Saward (Saward 1994), very much in a foundationally naïf vein, grounded his definition of democracy in the idea of political equality. In order to ground political equality in turn, he provides a *fallibilist* account of politics, according to which—within politics—no one is ever “entitled to assume that our knowledge - whether moral or factual - is beyond doubt” (Saward 1994, 9). In order to defend this view he resorts to a distinction between non-contingent and contingent knowledge claims, the former being claims that are “*not* confined to any one or any sub-set of a political community's spheres of activity” ((Saward 1994, 9); spheres of activity being defined following Walzer's spheres of justice (Walzer 1983)), whereas the latter being claims obtaining in specialized, technical domains or spheres of activity. This way Saward, or at least so his argument contends, can in principle accept unequal individual standing in science while rejecting elitism in politics. His analogy, especially in the light of what I have been showing so far concerning scientific realism, seems unfortunate. In fact, in this essay, Saward fails to provide a compelling argument for the claim that politics enjoys indeed the special status he contends it entertains, thus failing to compellingly ground the idea of political equality as antecedent to (and providing a foundation for) that of democracy. His efforts in this sense were motivated, as the title of the anthology he contributed to suggests, by the need to find some agreed upon definition of democracy which would instruct sensible indices of democratization that could be used to measure the

degree of democratic legitimacy of specific polities. In order to accomplish this definitional task, Saward first discarded some strategies as simply ill posed: he stroke out the possibility of a definition via induction from some specific existing democracy, in that some political systems that are called democratic enjoy features that are inconsistent with those of other systems we call democratic as well (it is however not infrequent to find examples of this kind of definitions of democracy in the literature, see for instance Della Porta (2013)). Etymological reconstructions, Saward argues, do not take us much further either: 'rule by the people' is ambiguous in a number of ways, most relevantly, who are to count as 'the people'? Listing principles, finally, is the most commonly deployed strategy, but, according to Saward, it inevitably gives rise to very reasonable, but reasonably objectionable, definitions. Any of these seems contestable somehow. Beetham's definition, for instance, relies on the conjunction of two principles, further grounded in two distinct intuitions about human nature: the principle of popular control "is underpinned by the value that we give to people as self-determining agents", whereas the principle of political equality "is underpinned by the assumption that everyone (or at least every adult) has an equal capacity for self-determination" (Beetham 1993, 7). This is a fairly stereotypical case in which intuitive principles are isolated and subsequently grounded in further, supposedly ultimate, intuitions. As in most cases of this kind, unfortunately, both founding assumptions and the conjunction of the two principles are pretty straightforwardly objectionable. As Saward notes, first, the conjunction of the two principles does not single out democracy exclusively. Equality in politics and popular control are clearly compatible with anarchical arrangements, which are in turn inconsistent with democracy. Secondly, the assumption on which the second principle relies is patently false: not every adult has an equal capacity for self-determination. Some people lack it altogether and some others enjoy it only partially. Furthermore, the bold claim that we all give value to people as self-determining agents is not as widely shared as a more or less universal political theory would require: there is a widespread intuition that the reason why we might give value to others goes above and beyond their capacity for self-determination. And in fact some people do entertain the belief that those lacking that capacity still are to be valued (for some other reason which is not interesting to be delved into here).

To overcome these shortcomings, Saward offers what he calls fallibilism as an alternative. He defines fallibilism as the doctrine according to which no one is ever "entitled to assume that our knowledge -

whether moral or factual - is beyond doubt” (Saward 1994, 9). This, he notes, is a claim of mere epistemic impossibility, but *not* a claim of impossibility *tout court*: we cannot genuinely hold the belief that we are right about X *without any doubt*. But it can of course be the case that we are indeed right about X. Interestingly, he resorts to a definition of fallibilism which is drawn almost verbatim from renown contributions to philosophy of science: he cites Popper (Popper 1983), Lakatos (Lakatos 1980), Laudan (Laudan 1990) and, most importantly, Peirce’s definition of fallibilism about knowledge:

“fallibilism is the doctrine that our knowledge is never absolute but always swims, as it were, in a continuum of uncertainty and of indeterminacy”
(Peirce 1940, 356)

The abovementioned claim of epistemic impossibility, Saward says, grounds the impossibility of adjudicating the superiority of knowledge claims. It only does so, as anticipated above, for a subset of claims to superior knowledge though. This he calls the class of non-contingent knowledge, i.e. knowledge “*not* confined to any one or any sub-set of a political community's spheres of activity” (Saward 1994, 9). No one is entitled to claims of superior non-contingent knowledge. Fallibilism in *contingent* knowledge claims, where by such class Saward identifies any claim made within a specialized, technical domain, then does not imply the impossibility to identify superiority. Saward mentions very mundane examples, such as the mechanic knowing better than he does how to repair his car, to argue that we do accept claims of superior knowledge. But, or so his argument purports to show, we only do so (or are only compelled to do so) when the claims span within a specialized technical domain. And politics is no such domain.

In fact, provided that these two classes of knowledge claims exist and are distinguishable, Saward pushes the point that superiority claims only obtain within the category of non-contingent knowledge claims. In a sense, if his move were sound, it would define specific domains, or spheres of activity—specialized and technical—within which someone can be said to be right, and someone can be said to be wrong (thereby allowing for a certain degree of inequality in the distribution of powers within the spheres), and it would furthermore tell these domains apart from the domain of politics as a non-technical domain. Politics, as a result of this contention, would enjoy a special status: within the sphere of politics, for reasons that Saward presents and which I am going to criticize in a second, only non-contingent knowledge claims would obtain and these cannot be adjudicated as superior or inferior.

What is more, in a relatively standard anti-technocratic blow, Saward argues that no superiority claim of contingent knowledge obtaining within specialized domains can and should percolate into the domain of politics. Hence, the domain of politics does not afford any degree of inequality, thus ultimately grounding Saward's principle of political equality in a way that escapes the objection of factual inequality in the distribution of the capacity for self-determination: it might be true that some people are more capable of self-determination, but we do not know with any firm degree of certainty who knows best what to do *politically*, hence everyone is equally politically entitled.

All of this argumentative architecture depends on the tenability of the idea that politics is indeed the unique domain of non-contingent knowledge. Saward proceeds from Walzer's conviction that politics is a sphere of activity *qualitatively* different from *all* other spheres.

“[P]olitical power is a special sort of good. [...] It is like other things that men and women make, value, change and share; sometimes dominant, sometimes not; sometimes widely held, sometimes the possession of the few. [...] It is unlike *all* the other things because, however it is had and whoever has it, political power is the regulative agency for social goods generally” (Walzer 1983, 15; emphasis added).

Saward admits that Walzer's line of argument fails if taken to ground the idea that politics is special in that the domain of non-contingent knowledge. I side with Saward's recognition of the fact that, in Walzer's regulative respect, politics is relevantly similar to other spheres of activity whose distribution of resources impacts and lays constraints onto other spheres (e.g. health, education, cultural standing or financial/economic origin, all distribute resources and constraints valuable in other spheres). Essentially, then, politics cannot be told apart from other spheres of activity on the ground that it regulates other activities, unless one takes Walzer's claims as essentially normative and not descriptive, meaning interpreting his claim as saying that political power, differently from powers obtaining within other spheres, rightfully, or justly, extends beyond the sphere of politics. This would however be tantamount to assuming the conclusion of the argument for the specialty of politics.

Saward, instead, believes that qualifying politics as the domain of non-contingent knowledge (therefore excluding the possibility of superiority claims) can single its sphere out as indeed special, or unique. He

therefore offers three, partly related, arguments supporting the idea that politics is the domain of non-contingent knowledge:

- The *implication argument*

In a rather obscure passage Saward says that “insofar as the conception, creation and appropriate form of distribution of social goods is dependent upon social understandings, it is dependent upon social *interests*” (Saward 1994, 11). I will take this to mean simply that social interests change the extent to which independent spheres of activities are indeed independent and therefore any such independent sphere must depend in a relevant sense on the ways in which it is defined politically (politics being here roughly power, conflict and interests).

- The *cumulative argument*

Granting the implication argument, Saward goes on to say that the way in which politics is implied in all other spheres is not simply the sum of the role politics plays within all other spheres. The network of spheres in which politics is implied, is in fact technically complex and the role politics plays overall, at the community level, adds up to more than the sum of its roles within individual spheres. Politics, furthermore, influences not only activities within other spheres, but also the boundaries between those spheres. This complexity, according to Saward, dooms any effort at analytically reconstructing politics overall: looking at politics through a somewhat mechanistic lens would obfuscate properties of a political system that are emergent from and unaccountable given the mere parts of the mechanism.

- The *temporal argument*

The complexity just described is augmented when seen in the light of the changes that happen within and between spheres of activity over time. And these changes over time add “yet more to the complex - and qualitatively different - nature of political power” (Saward 1994, 12).

These three arguments combined, Saward believes, make a good case for the specialty of the domain of political power. This specialty would render non-contingent knowledge claims the only claims admissible, in principle, in politics. These claims, as Saward insists, are amenable to a fallibilist objection according to which no one is entitled to non-contingent superiority claims. Therefore, in

politics, we all participate with an equal standing, even though, for some unspecified reason, democratically elected representatives, while in office, are allowed to breach what he calls the quality assumption and lay “legitimate non-contingent claims to superior political knowledge” (Saward 1994, 13).

Saward then essentially goes on to say that from the equality assumption (apparently undeniable on his fallibilist epistemic impossibility assumption) descends that “there should be necessary correspondence between acts of government and the equally weighted express wishes of citizens with respect to those acts” (Saward 1994, 13). This, alongside May (1978), he dubs the responsive rule. A political arrangement, then, is democratic to the extent that it realizes such a rule and it does realize such a rule depending on the degree to which a long list of “conditions for democracy” are satisfied.

I believe these three arguments are unsound and ultimately do not prove Saward’s point. Furthermore I take Saward’s use of fallibilism as an “attractive sceptical ground upon which to build a justification for an open-ended polity” (Saward 1994, 9) to be fundamentally misposed. I will first outline the reasons why I believe his arguments are not acceptable and then I will contend that fallibilism can indeed be used as a skeptical ground, one upon which to build a justification for democratic experimentalism though, democratic experimentalism being a framework in which democratic machinery is not a political theory, but rather our standard (improvable but ultimately reliable) political methods.

First, the *implication argument* is simply a statement of the extent to which all spheres of activities are influenced by the interests (be them conflicting or not) of those who populate a given community. This, however, does not seem to imply that politics has or is to have an aegis over those spheres at all, therefore some spheres can remain independent of and unencumbered by politics. Think, for instance, of the private choice to remain a single man. This of course can be construed as an ideologically charged decision, one whose nature, as I have recalled above, is indeed political. This does not entail at any rate that politics need be implied in one such decision though. At least not in any sense other than that, as I said, this is one’s private choice, still political in kind. Nor does the *implication argument* suggest anything as to the complexity of the network of spheres over which political authority supposedly spans. Which leads to my second objection.

The alleged complexity of interactions intra- and inter-spheres (at specific time points or over time) that Saward portrays, as Saward himself alerts us to, does not say anything as to superiority claims in politics. Even granting the fact that it is ultimately impossible to know mechanistically the workings of the system, this does not mean that one cannot know better than someone else (or everyone for that matter) how the system works. Systems biology, for instance, has developed so far on the assumption that the behavior of complex systems, i.e. systems whose characteristic properties require, for their description, a high number of variables (Hayek 1994, 56–7), is unpredictable on account of its underlying mechanisms. This however, to the best of my knowledge, has never grounded the claim that all models trying to make sense of complex phenomena in systems biology are equally defensible and no one is entitled to claims of superiority.

If these two objections stand, then Saward has failed to characterize the domain of politics as “a realm in which only non-contingent claims are admissible in principle” (Saward 1994, 12). However, even assuming, for the sake of the argument, that his contentions hold, i.e. (i) political authority is implied in *all* spheres and in their definition, (ii) the network of interactions within and between spheres is *complex* and (iii) that this complexity develops unpredictably *through time*, these remarks do not qualify the sphere of politics as the domain of exclusively non-contingent knowledge claims and this is because the very definition of the non-contingency of knowledge claims makes little sense in the first place. Saward glosses over a crucial point by saying that “the strength of the fallibilist argument applies only to a limited class of claims to superior knowledge”, by which he refers to non-contingent knowledge claims, defined, as we have seen above, as claims that range over each and every sphere of activity of some specific community (Saward 1994, 9). Even neglecting the *ad hoc* nature of this definition, which, as it turns out, according to Saward oddly applies essentially only to claims made within the domain of politics, the claim that the strength of the fallibilist argument only applies to this limited class of claims of superior knowledge is false. The reason why it was interesting to remark the disciplinary ascent of Saward’s definition of fallibilism is that, strangely enough, he uses fallibilism to ground the acceptability of superiority claims in the sciences and the unacceptability of those very claims in politics. Fallibilism, however, in the original formulations Saward himself makes reference to, is supposed to apply to claims which, according to his own definition, are contingent. Fallibilism is essentially a profession of humility, which is meant to apply *especially* to scientific and technical claims. The very

point of stressing the fallible nature of those claims is that we do recognize their superiority, but still it is impossible to know whether they are ultimately true. For the reasons I gave above, this seems to be the case also for superiority claims within the domain of politics, which has been shown not to be special in any of the relevant respects. This is not to say that politics is a *techné* or to rejoin the fascination of a Platonic rule of the knowers. My point here is just that democracy, *as a political theory*, cannot be adjudicated on the grounds that the fallibilist argument applies to its domain in a way in which it does not apply to other spheres of activity of a community. The principles, values and ideals that make up the political theory of democracy (in one of its numerous instantiations) cannot be grounded once and for all, at least not resorting to this line of argument. These principles, values and ideals will perforce be only putatively true, because fallibilism indeed applies to *any* political theory—democracy as a political theory included. The democracy that Saward and other contributors to the volume were trying to define in 1994 is essentially a political theory itself, that is one among competing political theories. I contend, instead, that democracy is better conceived as an instrumental epistemic endeavor, i.e. as the class of our ordinary *political* methods, and therefore it should not be grounded in some set of principles, values and ideals, but ought rather to be conceived as inheriting its grounding from the a-posteriori success of the political theories whose legitimacy it adjudicates telling apart legitimate and illegitimate institutions. This way the relationship between democratic experimentalist machinery and political theories can mirror the “*dialectical relationship between current theory and the methodology for its improvement*” (Boyd 1988, 190) that has contributed to the success of science, which in turn has built a convincing case for a genuinely realist stance, one that does not make the success of science a miracle.

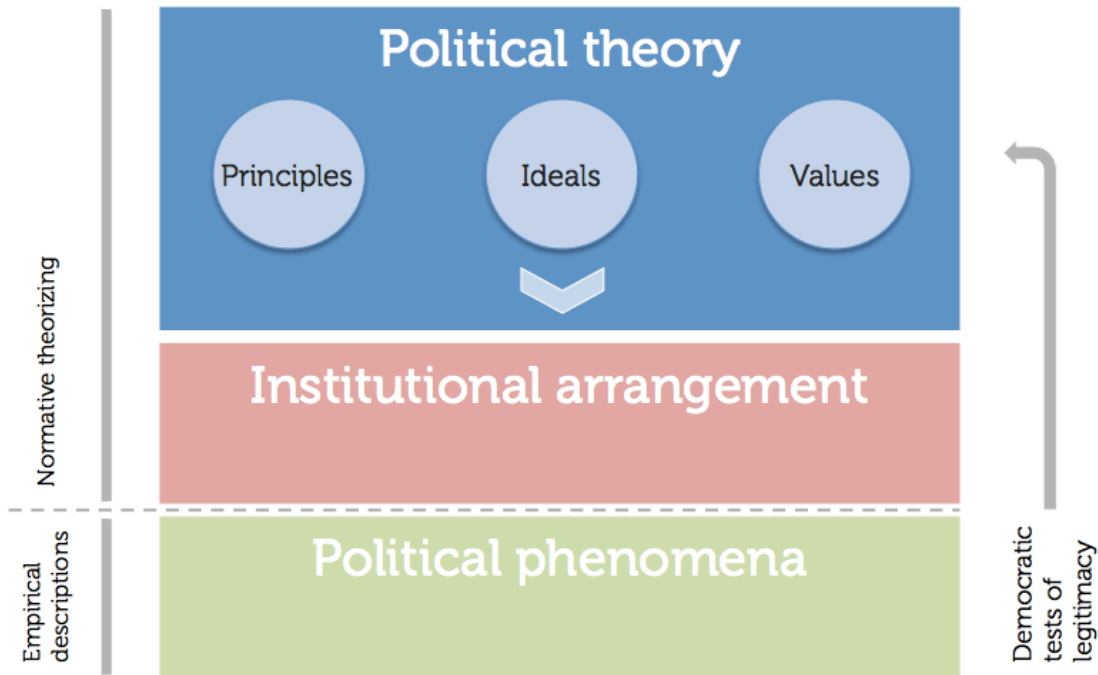


Figure 4 What a scheme for a renewed version of political realism looks like.

So far, what I have been proposing can be visually summarized as in Figure 4: political theories, in blue, specify the theoretical constructs that are hypothesized to yield legitimacy. These constructs are then used to develop institutional arrangements (in red) whose specification is required due to the underdetermination of institutions by political theories. These institutions then serve as the interface for democratic tests that are meant to survey the empirical legitimacy that they obtain. Political phenomena, properly analyzed, can provide precisely a measure of legitimacy, which is then used to feed back onto our political theory.

Summing up what we have said so far, a revised definition of political realism would therefore read something along these lines:

Political realism is the doctrine that *political theories* should be understood as putative descriptions of *principles, ideals and values* that make up legitimacy *within a specific political domain*, and that *institutional experimentation* within a *democratic framework* constitutes a reliable procedure for obtaining and improving (approximate) knowledge of the principles, ideals and values which political theories describe, and that the legitimacy described by political theories is largely independent of our theorizing.

I must stress, however, that so far I have only suggested, or at best posited, that institutional experimentation within a democratic framework ought to be the open-ended methodology for the improvement of political theories, that, in a sense, democratic experimentalism needs be the scientific methodology of politics. In the next paragraph I will try and make the case for democratic experimentalism as our ordinary political methodology, specifically trying to argue that the current intermingling of political theory and political science is the result of a historical process that progressively secured some of the principles, values and ideals that ground today's best political theories.

Deweyan democracy as ordinary political methodology

In the issue of *The Economist* published on March 1st 2014 features a long form essay about the state of democracy worldwide. Its title and subtitle are telling: "What's gone wrong with democracy. Democracy was the most successful political idea of the 20th century. Why has it run into trouble, and what can be done to revive it?"⁵⁰ The article contends that the ways in which democratic machinery has been deployed in countries that had only recently overturned autocratic regimes is fundamentally mistaken and has therefore generated a slight reversal in the long-term trend towards the end of history, i.e. the inevitable and progressive realization of the historical *telos* of the democratization of all nation states that Fukuyama had partly diagnosed and partly prophesized after the fall of the Berlin Wall (Fukuyama 1992). As the essay reports, "[b]etween 1980 and 2000 the cause of democracy experienced only a few setbacks, but since 2000 there have been many" (The Economist 2014). Among these, importantly, nascent democracies have both raised hopes and failed to live up to expectations. The most impressive case being the Egyptian specification of the so-called Arab Spring. Having overthrown the 30-year-long regime of Mubarak in 2011, Egypt held free democratic elections in June 2012. Mohamed Morsi, leading member of the Muslim Brotherhood (an explicitly Islamist transnational organization), won to become the first democratically elected president of Egypt. Once in charge, Morsi initiated a decidedly confessional shift in the government of the country, first claiming unlimited powers for himself and refusing any judicial oversight on his acts, then drafting an openly Islamist constitution. This turn to a confessional state led to a new period of violent unrest and

⁵⁰ The essay is available online at <http://www.economist.com/news/essays/21596796-democracy-was-most-successful-political-idea-20th-century-why-has-it-run-trouble-and-what-can-be-do> (last access September 3rd 2014)

uprisings⁵¹, which, in the summer of 2013, brought to the removal of Morsi at the hands of an opposition guided by general Abdel Fatah el-sisi⁵². Eventually this led to the drafting of a new constitution and to the second democratic elections of the country, in June 2014⁵³. el-sisi won the elections with almost the 97% of votes, though over a relatively small proportion of the whole population enjoying voting rights (the turnout was as low as 47%)⁵⁴. The observers of Democracy International felt compelled to state that “although Egypt’s constitution guarantees freedom of speech and association, continued suppression of political dissent and restrictions on fundamental freedoms have prevented free political participation and severely compromised the broader electoral environment” (Democracy International 2014, 1), in particular highlighting how unorthodox decisions such as the extension of the voting days (from two to three) had signaled scarce respect for agreed upon democratic procedures, which should only be changed due to extraordinary circumstances, clearly not obtaining in the two days of elections that the observers monitored.

But the hurdles of democracy are clearly not restricted to countries that only recently started to struggle for more freedom. In fact, what is most worrying to democracy enthusiasts is the state of well-established democratic nations. The influence that the inequality in the distribution of economic wealth in Western countries, and more specifically in the U.S., has on the political life of those countries has led some democratic theorists to speak of ours as a new gilded age, one in which “[r]apid economic expansion and transformation coexisted with intense partisan conflict and Political corruption” (Bartels 2008, 23). This coexistence is rendered even more dubious due to the self-reinforcing mechanism that seems to favor policies that advantage the advantaged because they have more leverage over those who govern. As Paul Krugman put it, “[f]rom tax cuts that favor the rich to bankruptcy “reform” that punishes the unlucky, almost every domestic policy [in the U.S.] seems intended to accelerate our march back to the robber baron era” (Krugman 2005, A21)⁵⁵.

⁵¹ See, for instance, <http://www.theatlantic.com/infocus/2013/07/millions-march-in-egyptian-protests/100543/> (last access September 5th, 2014).

⁵² See <http://www.theguardian.com/world/middle-east-live/2013/jul/03/egypt-countdown-army-deadline-live> (last access September 5th, 2014).

⁵³ The schedule for Egyptian elections can be found here: https://www.elections.eg/images/pdfs/2014Presidential-Election-Time-Schedule_en.pdf (last access September 5th, 2014).

⁵⁴ The data, as reported by the Guardian, can be found here: <http://www.theguardian.com/world/2014/jun/03/abdel-fatah-el-sisi-presidential-election-vote-egypt> (last access September 5th, 2014).

⁵⁵ The op-ed can be retrieved online here: <http://www.nytimes.com/2005/06/10/opinion/10krugman.html>

Disparities in income have been consistently argued to have a discernible impact on the actual degree of political equality that is only formally granted by constitutional principles. Gilens and Page, in a paper widely commented upon way ahead of publication (and currently still forthcoming in *Perspectives on Politics*⁵⁶) purportedly showed that there is very little empirical support to the thesis that the median voter or organized mass-based interest groups have had an independent impact onto policy making in the U.S. between 1981 and 2002. They also showed how economic elites’—Americans in the 90th income percentile—preferences, did instead have a recognizable impact onto policy making in a number of settings along the same span of years (Gilens and Page 2014).

And the old Europe does not convey a more comforting image of the health of the ideal of democracy (however defined) either. Key decisions in the development of the Union itself in the last years have been systematically taken technocratically. The new currency was introduced in 1999 without nation-state level referendums, and where the decision was subjected to popular veto—Denmark and Sweden—, it was rejected. The Treaty of Lisbon (European Union 2007) laying out the principles, values and institutional architecture of the Union has initially failed to garner popular approval (the only country holding a referendum for the approval of the Treaty was Ireland; this referendum failed at first⁵⁷, and the Treaty was only later approved by a second referendum that anyway delayed the ratification of the Treaty in the whole Union. Referendums ratifying it in other countries have been left unattempted ever since. Most recently, democracies as firm as Great Britain and France have witnessed the rise of far-right political parties, heralding strong nationalist, sometimes xenophobic, anti-immigration stances. This rise is well represented by the outcome of the last EU elections: in the U.K. the United Kingdom Independence Party mustered more than the 26% of votes and was the most voted party; in France, Marine Le Pen’s Front National was voted by almost the 25% of people and again was the most voted party at these elections⁵⁸. The elections overall had the lowest voters turnout

⁵⁶ A draft of the paper was made available by the authors here: <http://www.polisci.northwestern.edu/people/documents/TestingTheoriesOfAmericanPoliticsFINALforProduction6March2014.pdf> (last access September 5th 2014).

⁵⁷ The news as reported by the Guardian. <http://www.theguardian.com/world/2008/jun/13/ireland> (last access September 5th 2014).

⁵⁸ Both of these figures come from the EU elections official website. <http://www.results-elections2014.eu/en/country-results-el-2014.html> (last access September 5th 2014).

in the history of the EU (42.54%), which is clearly suggestive of a scarce popularity that the project of the Union enjoys, but also consistent with nation state level trends⁵⁹.

The authors of the abovementioned editorial in *the Economist* identified three clusters of threats to nowadays-established democracies (The Economist 2014). The first, are menaces coming from above, so to say: global trends that led nation state democracies to give up ever more powers to the forces of the market and to the supranational bodies overseeing trade and financial flows. The second group of threats lumps together changes that come from below democratic systems, such as the growing influence of lobbies and NGOs onto policy making, or the disruptive import of the Internet on the organization of dissent and on political activities more generally. The remaining threats come from within those mature democracies themselves: a widespread disillusionment in democratic institutions, a consistently declining party membership, which has now reached a historical low (see, for instance Van Biezen, Mair, and Poguntke 2012), suggesting an overall higher degree of individualism, and unfortunate economic policies systematically run on a deficit in the attempt to capture voters' favor in the short term without much of a concern for their long-term effects.

The combination of these trends seems to point to a radical and structural crisis of the ideal of democracy and, at least *prima facie*, seriously questions the very contention of this dissertation: that bioethics, as a political endeavor, ought to be democratized (the meaning of democratization in this specific context being explored in detail in Part II). However, these, or similar trends, are not new to the history of democracy. In fact, democracy in the U.S. had been facing a similar set of challenges in the early 20th century. A similar kind of skepticism in the possibilities that democracy afforded back then pervaded the work of Walter Lippmann (Lippmann 2011), for instance. Dewey, who followed suit Lippmann's sociological analysis, would summarize, in 1927, what he called "the eclipse of the public" as follows:

"The number of voters who take advantage of their majestic right is steadily decreasing[...]. Skepticism regarding the efficacy of voting is openly expressed, not only in the theories of intellectuals, but in the words

⁵⁹ A historical overview of voters turnout at EU elections is available here: [http://www.europarl.europa.eu/aboutparliament/en/000cdcd9d4/Turnout-\(1979-2009\).html](http://www.europarl.europa.eu/aboutparliament/en/000cdcd9d4/Turnout-(1979-2009).html) (last access September 5th 2014) and data for the 2014 elections are available here: <http://www.results-elections2014.eu/en/election-results-2014.html> (last access September 5th 2014).

of lowbrow masses[...]. Those still more inclined to generalization assert that the whole apparatus of political activities is a kind of protective coloration to conceal the fact that big business rules the governmental roost in any case. [...P]arties yield in piecemeal accommodation to social currents, irrespective of professed principles. [...] Even in times of political excitement, artificially accelerated, [the electorate's] opinions are moved by the current of the group rather than by independent personal judgment.” (Dewey 1954, 117–126)

When confronted with these issues, Dewey asked himself how the institutional machinery that was in place at the time, could cope successfully with the disruptive forces of what he called the Great Society, brought about⁶⁰ by technological progress and by the increasing complexity of most of the problems which any government was asked to regulate (it is interesting to note, in passing, that he made explicit reference to “matters like sanitation, public health”—among others—as prototypically “technical matters” that posed a serious threat to the head counting solution democracies seemed to propose (Dewey 1954, 124–5)). The traditional institutional machinery, to Dewey, was unsurprisingly inadequate to tackle the new issues arising in a society that shared little with the ones in which the machinery was first developed. He therefore proposed to turn to more radical, and radically new, forms of democracy: forms that did not take established principles, values and ideals at face value, but rather as devices which served pragmatic purposes that had changed as a result of history and that instead were still living “to cumber the political ground, obstructing progress, all the more so because they were uttered and held not as hypotheses with which to direct social experimentation, but as final truths, dogmas” (Dewey 1954, 146). Dewey’s new machinery was meant to produce a Great Community (as opposed to the scattered Great Society) through democracy meant “not [as] an alternative to other principles of associated life” but rather as “the idea of community life itself” (Dewey 1954, 148). This is to say that democracy can effectively be conceived as something different from a political theory among competing political theory (defined above as tentative, but—in case they are our best political theories—approximately true, specifications of principles, ideals and values that

⁶⁰ He did not make any technologically deterministic argument, but he clearly believed technological progress had had a discernible disruptive impact onto the institutional machinery of his times.

ground the legitimacy of norms). Democracy can be conceived as a political methodology—what the scientific methodology is to science.

Dewey himself made this passage fairly explicitly, and given the definition of political realism I have been outlining so far, it is not farfetched to present John Dewey as a political realist at heart, though definitely *ante litteram*. In fact, his broad conception of what counts as politics intertwines both theory and practice in a way that, though at times imprecise, seems to mirror closely the relationship between normative prescriptive theorizing and empirical tests of legitimacy that has been constructed above as a more fruitful reading of political realism. In 1927 Dewey was upfront in refusing to conceive of political philosophy as a merely theoretical or empirically analytical task and builds normative theorizing and institutional hypotheses in the definition of the discipline itself.

“[T]he problem of discovering the state is not a problem for theoretical inquirers engaged solely in surveying institutions which already exist. It is a practical problem of human beings living in association with one another, of mankind generically.” (Dewey 1954, 32)

Furthermore he advocated vocally for a translation of the experimental method into the domain of politics. He would write that:

“The formation of states must be an experimental process. The trial process may go on with diverse degrees of blindness and accident, and at the cost of unregulated procedures of cut and try, of fumbling and groping, without insight into what men are after or clear knowledge of a good state even when it is achieved. Or it may proceed more intelligently, because guided by knowledge of the conditions which must be fulfilled. But it is still experimental. And since conditions of action and of inquiry and knowledge are always changing, the experiment must always be retried; the State must always be rediscovered” (Dewey 1954, 33–4)

Unfortunately, Dewey offered little guidance as to the actual meaning that his proposal might have had. Charles Sabel says that “when it came to questions of institutional design—of specifying how various domains of activity might be organized to advance joint problem solving and individual

development—Dewey had [...] next to nothing to say” (Sabel 2012, 35). In the next paragraph I review the work of authors such as Cohen, Sabel, and Zeitlin in defining democratic experimentalism and what a democratic experimentalist framework might look like. Then I proceed to highlight some of the limitations of their relatively limited focus to one pragmatic institutional arrangement and propose my own definition of democratic experimentalism.

Democratic experimentalism

In his 2012 essay, Charles Sabel (Sabel 2012) highlighted two renowned contributions of Dewey’s political philosophy to contemporary democratic theory: first, Dewey made clear and stressed to a very large extent—as the passage quoted above convincingly shows—how institutional habits can be left to drift into unquestioned routines that hide assumptions progressively removed from individuals’ scrutiny. He remarked how this process of entrenchment of assumptions into institutions might hamper the development of individuals, which, according to Dewey, is necessarily linked to the change and development of institutions themselves. Secondly, Sabel underscored Dewey’s insistence on the continuous need for the mutually linked rethinking of the means and ends of democracy. This entailed a progressive redefinition of first democratic principles every time they were to be applied in practice. These two sharp theoretical stances notwithstanding, Dewey remained surprisingly silent both as to the design of actual “institutions that reduce the chance of organizational habits congealing into limiting routines” and concerning “the mechanisms for avoiding and correcting error in the institutions of democracy” (Sabel 2012, 36). The project of democratic experimentalism set out to remedy to these apparent lacks.

It did so proposing a clear institutional arrangement, meant to combine “the advantages of local learning and self-government with the advantages (and discipline) of wider social learning and heightened political accountability that result when the outcomes of many concurrent experiments are pooled to permit public scrutiny of the effectiveness of strategies and leaders” (Cohen and Sabel 1997, 314). This arrangement expects *highest-level jurisdictions* to provide agreed-upon broad framework goals and *lower level actors*, endowed with sufficient discretionary powers, to implement those goals as they wish, provided that they rely on explicit interpretations of the goals and metrics for their measurement.

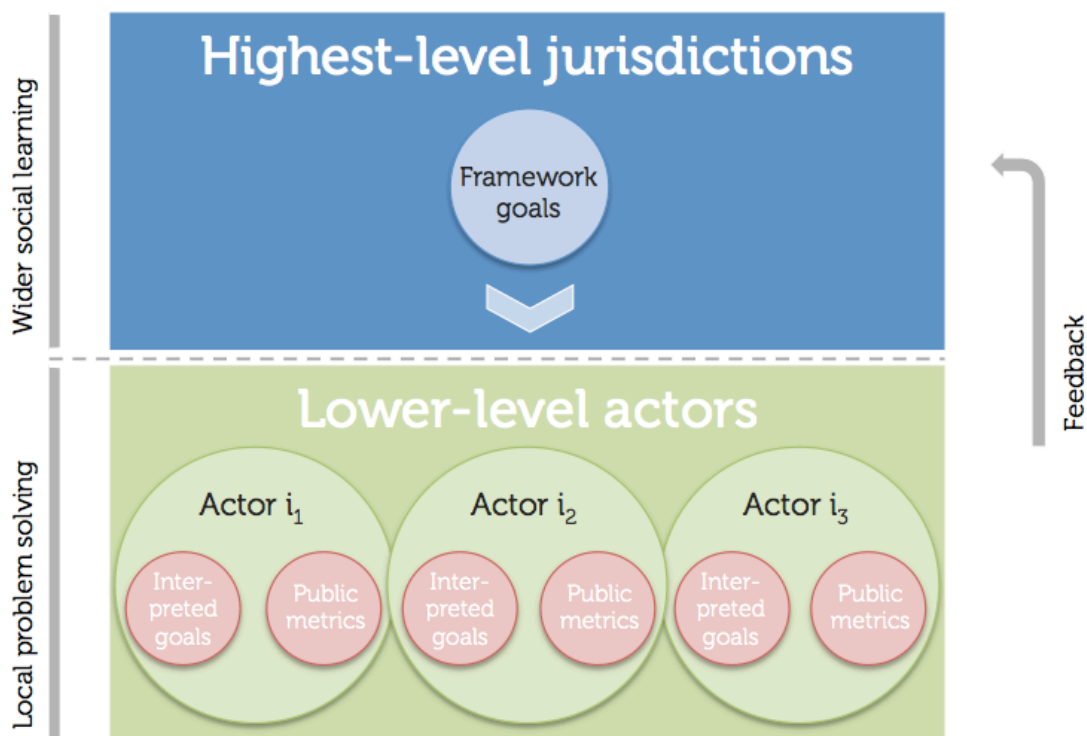


Figure 5 Democratic experimentalist arrangement: highest level jurisdictions setting broad framework goals, lower level actors implementing those goals with some degree of discretion and public metrics. Actors at this second level mutually benchmark their work and offer feedback onto the more general framework.

As **Figure 5** shows, a number of local actors implement framework goals whose vagueness is somewhat instrumental to the exercise of the local knowledge unavailable to higher-level, central actors. Local implementations, to the extent that they explicitly provide an interpretation of the goals and a metric to gauge the success of the experiment, can both provide a benchmark for other local actors and feedback onto the broader framework, enabling wider social learning.

“The shift towards experimentalist lawmaking requires complementary changes in the way laws are constructed and the way they are administered or applied to various contexts: the law has to encourage adaption and revision when applied in context; the contextual adaption has to make possible the detection of local error, permit learning across contexts, and prompt reconsideration of the original legislation when, on reflection, necessary.” (Sabel 2012, 46)

The suggestion that this political arrangement might work better than traditional solutions to problems of social organization comes from the recognition that any attempt at operating old political categories such as the market, the state, the civil society and the like (thus suggesting using more—or less—of one or the other) is doomed to fail because those very categories have been disrupted by recent

developments in society. Cohen and Sabel, in their seminal essay (1997) presented examples of such critical developments, like school decentralization programs which encouraged the replacement of central bureaucratic control with mechanisms of governance that leverage directly on the free choice of parents, and their participation alongside teachers (Cohen and Sabel 1997, 315). Their examples show clearly how the supposed trichotomy between straightforward market regulation, central state control and planning, and civil society or grassroots organization simply cannot stand the test of facts: these three categories blend into one another as a matter of fact creating governance arrangements for which those categories are analytically pointless and pragmatically sterile.

“The arrangements are not conventionally public because, in solving problems, they operate autonomously from the dictates of legislatures or public agencies; they are not conventionally private in that they do exercise problem-solving powers and their governance works through discussion among citizens rather than the assignment of ownership rights. At the same time, they do not presuppose a successful, densely organised, trust-inspiring network of associations. Indeed, they often emerge precisely against a background of associative distress” (Cohen and Sabel 1997, 316).

Against this backdrop, Cohen and Sabel proposed⁶¹ a democratic scheme that would leverage on these novel arrangements, therefore both yielding desirable problem-solving advantages and allowing for deliberative direct participation. They called it *directly-deliberative polyarchy*, as distinct from Dahl’s polyarchy—“a political order distinguished at the most general level by two broad characteristics: Citizenship is extended to a relatively high proportion of adults, and the rights of citizenship include the opportunity to oppose and vote out the highest officials in government” (Dahl 1989, 220)—for the “substantial degree of directly-deliberative problem solving” (Cohen and Sabel 1997, 318) that it demands.

The way this project has been unfolded by its most prominent theorists, however, really ends up losing part of the appeal Dewey’s democracy seemed to have, i.e. its openness to experimentation both *within*

⁶¹ The proposal, published on the *European Law Journal*, was mostly targeting confederation of states, more specifically, the EU, suggesting an institutional architecture that might have allowed for nation state level interpretation of framework programs, enabling directly-deliberative participation at all levels. This, to some extent has been the blueprint for some EU institutions. See, for instance, <http://europa.eu/sinapse/> (last access September 10th 2014). See also Sabel and Zeitlin (2008) in which the issue of democratic experimentalist governance in the EU is tackled head on.

and with institutions. Sabel, Cohen and Zeitlin’s work all point to one specific institutional arrangement and suggest how this might be put to work so as to have it both enhancing legitimacy via participation and augmenting the problem-solving capacity of central bodies. But the architecture itself is not open to revision in any genuine experimental sense. In a relevant sense, it is not experimented with. Once interacting local actors have collected measurable and comparable results, these feed back onto the framework goals, but they do so seemingly not affecting the way in which new goals will be put to test by local actors at the next round of experimentation. This led Cohen and Sabel, for instance, to be very (and partly naively so) upfront about the foundations of their polyarchy, postulating reasons why this architecture would be preferable to others. They singled out “three virtues” (Cohen and Sabel 1997, 318–20) of democracy as a system for collective decision-making. These fall into commonly understood categories of reasons to value democracy—or other political theories, for that matter: consequential, and non-consequential reasons⁶². Among the latter, Cohen and Sabel suggest that “democratic arrangements have the intrinsic value of treating those who are subject to binding collective decisions with respect, as free and equal” (Cohen and Sabel 1997, 319). Among the former, democracy is alleged (i) to be instrumental to the protection of “basic rights of citizens” and to the advancement of “their interests, as defined by the ends and projects with which they identify”, and (ii) to have an educative import, both pooling dispersed information and making it available. There are reasons to doubt that this very brief foundational attempt suffices to granting priority to democracy and, more specifically, to the directly-deliberative democracy the authors subscribe to. Most of these reasons were explored above and are shared by any foundational attempt at grounding democracy, thus I will not rehearse the argument here. I want, instead, to point out that, though reasonable and to a large extent shareable, these three values are posited in a way that seems inconsistent with the openness to revision that Dewey preached as central to democratic systems that work within changing societies relying on changing sets of values.

From this standpoint, two considerations apparently obtain that make democratic experimentalism, at least in this form, perfectible.

First, the foundational attempt just summarized entails the radical discounting of the value there is in experimenting with institutions themselves and the political theories they purport to embed. It is

⁶² See, for instance Waldron (2013), Smith (2009), or Ottonelli (2012).

conceivable that Cohen and Sabel's radical form of democracy is unfit to handle some specific political problem, for reasons that are *not* independent of their democratic theory and which cannot be dismissed simply by saying that more participation of a more direct sort is an intuitively appealing ideal for collective decision-making (as they do on page 314). As I argued above, foundational attempts fail to address the normativity problem in a way that is genuinely *political*, and are thus likely to give rise to illegitimacy claims. In this particular case, listing the three virtues of democracy simply cannot suffice to engender the normative import needed of laws, even when administered experimentally. The first virtue, i.e. democracy treats free and equals with respect, is only a virtue for those who regard others as equals (which in politics, as we saw above, is not always the case); the second virtue, i.e. democracy furthers effectively the interests of all citizens, is dependent on empirical evidence, which seems lacking, as of today, as the introductory paragraph above shows (see Deweyan democracy as ordinary political methodology); the third virtue, i.e. democracy educates citizens, is (i) dubious on empirical grounds (again compare the claim with what we have seen above about the state of the EU democratic nations) and (ii) only a virtue on the assumption that we value more education above, say, more wealth.

Political realism, as I defined it here, offers a solution to this kind of shortcoming, in that, as a polity, we need only share in the premise that *any* specific institutional arrangement and the values that it embodies can only be approximately true and therefore new institutional arrangements ought to constantly be experimented with. The way in which we experiment with institutions, trying to gather information about our political theories, allows for the dialectical development of democratic experimental arrangements and political theories whose scientific counterparts have historically adjudicated realism in science.

Second, and relatedly, the authors who developed democratic experimentalist governance, have unduly assumed that there is *one* democratic model, superior to all others that ought to be consistently applied irrespective of the political problem at hand. This second objection has been articulated in more detail by Mark Warren and in the next paragraph I report on his argument essentially summarizing and commenting upon it. In doing so, I recapitulate my own stance on democratic experimentalism to specify the role that democratic experimentalist governance, as defended by Sabel, Cohen and Zeitlin, might play within it.

Against democratic models

Directly-deliberative polyarchy underlies the suggestion that the kind of radical democracy advocated by its proponents has some sort of primacy over competing encompassing definitions of democracy. This looks very much like an example of what Mark Warren has argued to be the “less productive” of two ways to debate in political (and more specifically democratic) theory (Warren 2012, 1). Warren identified two alternative ways to think of political theory: one proceeds in terms of models of democracy (but the scope of the argument, I believe, can and should be expanded to models of politics), which center on the defense of one single political feature pivotal to the model, e.g. voting for electoral democracy, deliberation for deliberative democracy, non-domination for republican democracy, and so forth, and extends the defense of that feature to an entire political system. This happened most visibly, Warren contends, in the debate about deliberative democracy, which came to be characterized by its focus on deliberation as some sort of all-purpose democratic device. Although, according to Warren deliberation is a wonderful theoretical and practical tool for addressing the problem of collective will formation, it is, for instance of hardly any use as a democratic means for collective decision-making. Both proponents and critics of deliberative democracy have contributed to the framing of this issue as a frontal opposition between so-called aggregative and so-called deliberative models of democracy. Irrespective of historical responsibilities, this, which Warren characterizes as models thinking in political theory, led the entire debate to a stalemate.

On the other hand, Warren suggests, we might be focusing instead on how each of the features that purport to characterize allegedly mutually exclusive democratic models, might suit the solution of specific political problems. Warren argues that this second theoretical standpoint is more productive for two main reasons: first, the intuitive consideration that its alternative, i.e. models thinking, as I have summarized, leads to theoretical dead-ends; secondly, the remark that political systems raise different functional demands concerning different problems. These demands, arising from some spaces within political systems, can be met with specific means without the need to mobilize full-fledged political models.

Warren’s overall concern in the contribution I have hereby been reviewing is mostly with (i) a definition of democracy that comprises three main functions (empowered inclusion, communication and collective will-formation, and collective decision-making) and (ii) with how an open list of political

mechanisms (for the purposes of the paper Warren lists five: deliberation, voting, association, consensus, and market-like competition) can deploy those functions in solving specific democratic problems. I am not so much concerned here with whether those three features are necessary (or sufficient) for the definition of democracy⁶³, nor with how those mechanisms can effectively deploy those functions. Warren's argument is however relevant to the development of my own definition of political realism to the extent that it encourages the confinement of political theories, as defined above, to the solution of specific political problems. A solution that is experimental in kind, and whose experimental prescriptions are defined in the form of an institutional arrangement supposed to realize the values, ideals and principles specified by the political theory we are being realist about in some specific context. In this picture, a functioning political system will essentially be a patchwork of all the tentative institutions (each of which resorts to specific political mechanisms such as the five Warren listed) that seemingly function together to serve the specific purposes of some political theory applied to a specific set of political problems.

In this sense, it is otiose to think of one political theory, in order to then derive what that implies for moral disagreement in bioethics. In Part II I will therefore proceed in a somewhat opposite direction: from the recognition of the political problems related to bioethics highlighted in the introduction of the thesis (see *Moral disagreement and the Life Sciences*) I will construct a political theory from which to derive the mix of mechanisms to be institutionally and experimentally implemented.

Democratic experimentalism redefined according to Warren's problem-based approach is, contrary to Sabel, Cohen and Zeitlin's experimentalist governance, a method for the adjudication of political theories as opposed to a political theory for the solution of all political problems. This makes it a sensible candidate for the role of experimental method of politics that Dewey seemed to be envisaging.

So far, however, one central theoretical question has been left unanswered: how do we choose what political theory to start from and develop further to tackle specific political problems? This question can be rephrased in our political realist jargon as: what theory should we be realist about in some given context, relative to some given set of political problems? In the next paragraph I outline a set of criteria to be used in the process of singling out the political theory we are suggesting ought to be

⁶³ I extensively explained why I believe there is no need for such a definition other than for prescriptive experimental purposes within a political realist framework.

tested. Then, in closing, I provide some reasons why argumentation, i.e. the application of practical reason, rather than other means of adjudication, makes sense in picking and defending the normative theory one is willing to deploy experimentally.

What political theories should we be realist about then?

The method of democratic experimentalism, as it has been characterized so far, offers fairly limited guidance in the decision of which political theory—and with what institutional interfaces—one should pick in order to tackle a specific class of political problems. This implies that, if one wants to take seriously the prospect of actually democratically experimenting, she needs to constrain the space of political hypotheses using some additional set of criteria. The addition of these criteria is however not problematic to the extent that science already does rely on criteria that serve an analogous purpose when deciding what theories to put to test. Essentially, the decision presupposes some answer to the question: what political theories are we actually realist about? From these, one will proceed to draw new hypotheses, supposedly feeding back onto the theory itself.

I will contend here that there are at least three necessary criteria to identify political theories we can be reasonably realist about. As it will be apparent in a while, there is some degree of vagueness to the definition of each of the criteria. The simultaneous satisfaction of these criteria, then, though necessary, might turn out not to be sufficient in completely informing one's decision, i.e. in singling out one theory only. This will thus require some effort, on the part of the proponent of the experimental implementation to argue for one specific arrangement, from among the array of those consistent with the criteria. The demand for an argumentative justification of the experimental test, accidentally rescues the role of practical reason, as I will show below, as a heuristic tool, rather than as a justificatory standard of political legitimacy, i.e. a solution to the normativity problem.

The first two criteria to tell apart theories we can genuinely be realist about from theories we should not are *sufficient maturity* and *non-adhocness*. These are both criteria commonly seen as functioning in fetching the same distinction in science and I will try and suggest that they make pretty much the same sense in the context of political theory. *Sufficient maturity* in science “may be thought of in terms of the well established nature of the field in which a theory is developed, or the duration of time a theory has survived, or its survival in the face of significant testing,” whereas *non-adhocness* “is intended to guard against theories that are “cooked up” (that is, posited merely) in order to account for some known

observations in the absence of rigorous testing” (Chakravartty 2013, 7). In this sense, political theories that purport to be tested experimentally ought (i) to be developed as branches of older theories that have lasted long and survived significant challenges (where the age of the theoretical ascent and the significance of the challenges are, as I said, susceptible to interpretation and to be specified, so to say, in context) and (ii) though specific to some set of political problems, the tentative theories ought not to rely on wild speculations that would account for observational anomalies only within the specific context at hand. These general (and to some appreciable extent generic) features of theories can be more fruitfully conceptualized as concerning not so much the theories in and of themselves, but rather their constituent parts. More specifically, what is relevant to making a compelling case for a theory to be one we can genuinely be realist about (therefore drawing institutional hypotheses from) are “the theoretical constituents of past genuine successful theories that made essential contributions to their successes” (Psillos 1999, 105). Identifying these theoretical bits within a theory makes it possible to sensibly regard it as *sufficiently mature* and relevantly *non-adhoc*.

Scientific realists, furthermore, generally complement these two criteria with a third criterion: the ability of a theory to make predictions that turn out to be true (Chakravartty 2013, 8). Truth is not what politics is concerned with, though. Hence, as previously done for the general outlook of a ‘reloaded’ political realism, I propose a political translation of the predictive success of political theories along with a summary of the political translation of the first two criteria just provided.

In my proposed political translation, this last criterion essentially commands that political theorists, when proposing a normative theory from which to derive a specific institutional arrangement make explicit reference to principles, ideals and values (which are the constituent parts of political theories) belonging to theories that have been successful in adjudicating legitimacy claims in the past—where the legitimacy bestowed upon political decisions by these theories in the past is the analogous of the truth of the predictions drawn from a scientific theory—and that can be assumed to have contributed to those successes in relevant contexts. This means that scholarly efforts at fitting in a debate that is academically relevant and relevantly contemporary are not an issue of professional self-indulgence. Quite the opposite, the debate in mainstream political philosophy today offers an essential point of reference for the development of theories that work on the back of past successes in grounding legitimacy. As recalled above, Norman Daniels claimed that actual discussions developed by Gutmann

and Thompson concerning issues such as affirmative action in *Democracy and disagreement* only made sense within their deliberative democratic non-constitutional framework because political philosophers had been trafficking in the concepts they were using for more than twenty years. This, I believe, makes only partial sense in that the concepts, i.e. principles, values and ideals referred to by Gutmann and Thompson, had and still have to date currency in political philosophy for the very reason that they have been distilled from and inform (in the guise of ideal theories) the ways in which we live together, the ways in which we have successfully solved the first political questions.

The reasons why these three criteria make sense in science are pretty much the same that make a case for using them in politics. New hypothesized political theories will have to be guided by the tenets of old theories in order to avoid sacrificing the relevant knowledge that has been acquired in centuries of successful social coordination. If we take politics as a way to explore the means to achieve higher political legitimacy, ignoring what has managed to purport that legitimacy in the past would be either self-defeating or, in case of ad-hoc theories, disingenuous.

In Part II I will provide a background justification for the development of the specific normative political theory that I advance for bioethics and set out to preliminarily test empirically in the thesis. The way in which the theory is presented as sufficiently mature, non-adhoc and successful in predicting legitimacy is essentially argumentative. Therefore there is a sense in which practical reason, even though it ultimately fails to ground the normativity of norms that regulate a community, still can be used to ground a different sort of normativity, i.e. the normativity of experimental prescriptions. In the next paragraph I briefly explore this last point to then introduce the pressing task of defining legitimacy from a political realist point of view and the relatedly pressing question whether the legitimacy that political theories purportedly describe can be measured and how.

The heuristic role of practical reason and the normativity of institutional design prescriptions

In *Between Facts and Norms* Habermas famously proposed to reconstruct normativity as emerging from the tension between facticity and validity, a tension inherent in any communicative illocutionary exchange, i.e. an exchange pertaining to the aims of the speakers in making their linguistic utterances. Proceeding from the recognition that practical reason—i.e. “the general human capacity for resolving, through reflection, the question of what one is to do” (Wallace 2014, 1)—had been disenchanting, and that its centrality could not be rebuilt on the grounds of historical adjudication, in that “neither in the

teleology of history nor in the constitution of the human species can we find the content of practical reason, once its philosophical foundation in the knowing subject has been shattered, nor can we justify such content simply on the basis of the fortuitous resources of successful histories and traditions” (Habermas 1996, 3), he suggested giving up entirely on the concept itself and develop the idea of communicative reason instead. This, according to Habermas would allow to go beyond the dichotomy between both approaches to politics that, following Geuss (Geuss 2008), have been characterized as “ethics-first” and radically anti-essentialist approaches that fall under the heading of political realism (Galston 2010).

Arguments against straightforward foundationalism of this kind have been presented previously and I believe these arguments can be said to stand also against this reloaded version of the public justification principle. Kevin Vallier and Fred D’Agostino, in the Stanford Encyclopedia of Philosophy entry they coauthored, raise against foundational attempts that rely on the idea of public reason what they call the *self-refutation objection*. The objection, in sketch form, can be summarized as follows. The public justification principle (PJP) “holds that all coercive actions or laws must be justified to each member of the public” (Vallier and D’Agostino 2013, 37). Then disagreement about the PJP defeats the legitimacy of the PJP itself. On the other hand, *if* the PJP needn’t be justified then, privileging this or that PJP means arbitrarily picking one over some other. Without indulging into further details this objection can intuitively apply to the foundation that Habermas lays for a legitimacy that rests in between facts and norms. However, as I said in the previous paragraph, even a non-foundational theory such as the political realism that I have been designing so far, can rely on genuine forms of normative prescription without any need to ground those ‘once and for all’, so to say. In the construction of these prescriptions, I suggested it makes sense to rely on the application of three main criteria for the argumentative defense of one’s normative theory as a theory we can be genuinely realist about (though, of course, the epistemic impossibility of knowing whether the theory *really* describes actual feature of the make-up of legitimacy remains out of reach).

If practical reason has been given up as a means to back up the normativity of politically authoritative norms, then one might reasonably ask why we should deploy rational standards to adjudicate—so to say ‘on paper’—the viability (i.e. whether or not it deserves our realist commitment and therefore being empirically tested) of a tentative political theory in the first place? The answer I provide to this

question, in a nutshell, is that one ought to abide by rational standards in the construction of theories that supposedly satisfy the criteria of sufficient maturity, non-adhocness and predictive import, merely *on pragmatical grounds*. There are two main pragmatical reasons why we ought to deploy the standards of practical reason.

First, practical reason, as defined above, and even in the face of its historical failure in adjudicating a political theory over *all* others, seems the candidate best suited to the task of prescribing “what one is to do” in order to test empirically an institutional hypotheses meant to tackle a specific political problem or set of problems. This is so because practical reason allows for the fruitful analysis of the discussion over the theoretical tenability of a theory (tenability which, of course does not imply in any way that the theory is the only one that should inform the laws that govern our society). The back and forth of arguments aiming at testing the rational consistency of a tentative political theory could not be supported in any way other than with a discussion that relies on rational standards. Seen from this perspective, then, as Habermas reminded us to, “the received concept of practical reason also acquires a different, more or less heuristic status. It no longer provides a direct blueprint for a normative theory of law and morality. Rather, it offers a guide for reconstructing the network of discourses that, aimed at forming opinions and preparing decisions, provides the matrix from which democratic authority emerges” (Habermas 1996, 5).

Second, in addition to working as a standard that regulates theoretical debates about competing normative political theories, practical reason does retain a form of normativity for political theories. One that is however unrelated to the legitimacy of the political theory itself: this is the normativity of hypotheses whose empirical test requires the intelligibility of its internally consistent precepts. Political theories, as they stand, have little to no use if they do not enjoy this kind of normativity. These theories, as I said previously, need then to be articulated so as to have specific inbuilt deployment mechanisms, which only can allow for an actual *political* test of legitimacy. These are the institutional arrangements, which can be regarded as the interface between theory and practice in politics.

Hence, pragmatically, it is necessary to rely on some way to make one’s preferred institutional arrangement, and its underlying political theory, publicly available, i.e. intelligible. Generally speaking, this public standard is what makes the replication of experimental results possible and, more importantly, meaningful. What it amounts to, specifically, is a list of prescriptions that instructs any

experimenter on how to perform the experiment in a way that produced the results in the first place. This is, I believe, a genuine form of normativity, in that it prescribes standards of compliance that define what counts as a legitimate experiment of some given political theory.

If what I have said so far holds, then normative, prescriptive political theories, contrary to what seems to be the contention of most political realists, do indeed have citizenship in debates about how to organize society. And practical reason provides the most intuitive standard to regulate these debates also playing a fundamental heuristic role in informing the experimental test of institutions. This means there is no need to retain any definition of public reason as the ultimate foundation of the normativity of norms, which we have seen is liable to compelling objections.

From what we have seen so far, it is apparent that one's political theory for bioethics (but I assume this to be true of any other political problem) must be proposed as a set of consistent principles, ideals and values alongside some institutional prescriptions consistent with those principles, ideals and values. If this is to be recognized as possibly the best political theory for bioethics, an open-ended democratic framework for institutional experimentation must be in place. One in which there clearly is some space for normative prescriptive theorization and superiority claims of some *political* political theory over others, with respect to one political problem or a set of political problems.

Summing up very roughly the arguments presented above, political theories within a political realist framework of the kind I have developed here are constructed and defended via practical reason, and tested experimentally via institutional devices. However, this framework cannot be worked out without a sensible definition of what counts as a measuring device of the institutions' legitimacy. In fact, all institutional devices making use of the political mechanisms or features that a theorist endows them with, are both supposed to solve political problems *and* to contribute to an overall political system which is a better answer to the *first* political problem, that is to say they must contribute to an overall *more legitimate* political arrangement. In order to know whether one system, as it stands, is indeed more or less legitimate than previous lump sets of institutional devices, it makes sense to have a refined definition of legitimacy itself and one that is furthermore operational enough to be able to gauge, in a relevant sense, the extent to which the concept of legitimacy is realized politically by those devices. Only such a definition can allow for the abovementioned superiority claims

It is essential, then, to specify the mechanism for the adjudication of those claims, i.e. how we mean to measure the legitimacy that competing institutions drawn from competing political theories yield. To the measurement of legitimacy I devote the next and last chapter of this first part.

The multi-faceted concept of political legitimacy

Political legitimacy has been dubbed “the core of political organization” (Alagappa 1995a, 3), a concept “central to virtually all of political science” (Gilley 2006, 499), “the central issue in social and political theory” (Beetham 1991, 41) or “the master question of politics” (Crick 1992, 150). For the use of legitimacy as opposed to more straightforwardly moral foundations for political authority—such as, for instance, justice—distinguishes realist approaches from political moralism broadly understood, it is arguably of pivotal importance to define compellingly legitimacy for any attempt at developing what we called *political* political theories.

The apparent centrality of legitimacy in political theory and political science notwithstanding, a shared definition of the concept is crucially lacking (Gilley 2006). This lack evidently hampers the possibility of measuring legitimacy. Measuring legitimacy is in turn an essential stage in the process of progressive adjustment of political theories we are realist about via democratic experimentation (within the framework I have been describing and advocating in this part of the work). Hence, it is possibly even more important to the project of this thesis, than it is for other political theories in general, to establish some grounds for an effective and reliable measure of the legitimacy of institutions and of their outputs. In what follows I will therefore define legitimacy rehearsing the conceptual distinction underlying its hybrid, both normative and descriptive nature. Then I will refer to a further distinction that is needed to operate the concept of legitimacy properly: that between input (or procedural) and output legitimacy. These remarks will allow me to chart accurately the relevant aspects of legitimacy and to establish which of these, and to what extent, are empirically measurable and which are not. In Part II I then also argue that deliberative democratic theorists have failed to provide a measure of legitimacy that is indeed as political as it should.

Relatively intuitively, I will however not propose any *general* measure of legitimacy of political systems, but I will rather suggest that attempts at measuring legitimacy empirically ought to be pursued with the same kind of problem-based, piecemeal approach that was argued for in the previous chapter. With a substantial distinction, though: a relevant level of investigation for the measure of legitimacy, contrary to what seems to be the case for investigations in political theory, can be the all-encompassing unit of the State, whose legitimacy can be fruitfully measured alongside that of specific institutional interfaces. I only point to this last issue, without delving into it in much detail.

Normative and descriptive legitimacy

Max Weber's definition of political legitimacy offers a nice starting point for the exploration of the concept for both historical and analytical reasons. Historically, the Weberian account of political legitimacy has informed much of the debate ever since the delivery of his lecture *Politics as a Vocation* in 1919⁶⁴ (Weber 2004). But his account of legitimacy also offers a perfect analytical platform in that the definition Weber offers manages to cast light on two essential features of the concept itself: first its relation to the *monopoly of physical violence* within some boundaries and secondly its dependence upon individual beliefs, i.e. its ultimate *psychological nature*.

In the abovementioned lecture Weber insists that:

“[T]he state is the form of human community that (successfully) lays claim to the *monopoly of legitimate physical violence* within a particular territory—and this idea of “territory” is an essential defining feature. [...A]ll other organizations or individuals can assert the right to use physical violence only insofar as the *state* permits them to do so. The state is regarded as the sole source of the “right” to use violence.” (Weber 2004, 33)

Legitimacy belonging within set contingent boundaries, both historical and geographical, is a trait of the definition that has been retained in most contemporary accounts of the concept. Alagappa, for instance, stresses how political legitimacy must be regarded as a multifaceted social practice that changes over time, and whose dependence upon societal and historical contingencies ought not to be underplayed. Any sensible analysis of the concept of political legitimacy, Alagappa contends, must therefore be contextualized to “a specific society at a specified time” (Alagappa 1995b, 11). This intuitive remark does not allow for straightforward relativism as to the nature of legitimacy. It rather commands the inclusion of the actual circumstances in which legitimacy is being analyzed, which is consistent with the overall attitude of political realism to see political philosophy as essentially concerned with “the way social, economic, political, etc. institutions actually operate in some society at some given time” (Geuss 2008, 9).

⁶⁴The cited edition of the Vocation Lectures, curated and introduced by David Owen and Tracy B. Strong, offers a nice reconstruction of the reluctance with which Weber approached his second lecture, the one on politics, during a period of harsh social and political unrest in Germany. See Weber 2004, xxxiv–lxii.

Relatively uncontroversially, the use of physical violence alone does not characterize politically legitimate authorities. Weber resorts then to the idea of an exclusive “right” to use violence, the state (standing here for *the* politically legitimate authority) being “regarded as the sole source” of this right. Herein lies an ambiguity that recapitulates the two-fold nature of the concept of legitimacy with which this paragraph is concerned. On the one hand, the state, however defined, is the sole source of legitimacy, political authority, so to say, ensues from the state. Weber, in the lecture, goes on at some length specifying what has historically played the justificatory role for the legitimacy of states⁶⁵, thus attempting to lay out a description of historically validated definitions of the state. These definitions, above and beyond Weber’s reconstruction, generally assume the form of attempts at spelling out and justifying “principles that determine what it is for political authority to *be* legitimate (*de jure*)” (Fossen 2013, 427). A task traditionally attributed to the normative political philosopher/theorist and, as we have previously seen, one carried out mostly from a peculiarly moral (or, following Bernard Williams, politically moralist) point of view.

On the other hand, however, in Weber’s definition, the state is simply *regarded* as being such a source. This second facet of the ambiguity points to the descriptive nature of the concept of legitimacy, highlighting “the conditions under which authority is *taken to be* legitimate by subjects (*de facto*)” (Fossen 2013, 427). In a later contribution, expanding on this second part of the notion, Weber claimed that “the basis of every system of authority, and correspondingly of every kind of willingness to obey, is a belief, a belief by virtue of which persons exercising authority are lent prestige” (Weber 1964, 382). The analysis of this second aspect of legitimacy has been traditionally regarded as the domain of descriptivist social and political scientists. A task fulfilled from a supposedly value-neutral point of view. Although the sociological analysis of descriptive legitimacy can be framed as unconcerned with normative issues, its subject matter, the concept of legitimacy, still remains a moral and normative concept to some extent, even in its psychological manifestations. As Gilley puts it, “[l]egitimacy is an endorsement of the state by citizens *at a moral or normative level*” (Gilley 2006, 502. Emphasis added). The stance that subjects take on the legitimacy of commands issued by some authority is moral, at least to the extent that it underlies the claim that one ought to obey those commands and he/she can be *rightfully* punished for defying to comply with those commands.

⁶⁵ This is the famous passage in which Max Weber identifies three internal grounds for legitimacy: custom or tradition, charisma and the belief in the rule of law (Weber 2004, 34)

This last remark notwithstanding, normative and descriptive accounts of legitimacy, as just presented, offer two distinctive points of view on the intellectual labor that pertains to politics: normative theorists take care of the definition of the ‘ought’ of legitimacy, i.e. what would theoretically make decisions politically more legitimate, thus specifying principles, ideals and values that should be embodied in procedures and outcomes of a legitimate authority. Descriptive efforts are instead meant to investigate how outcomes and procedures play out in practice, to what extent they are regarded as realizing political legitimacy, whatever the definition people entertain.

The analytical divide between normative and descriptive accounts of legitimacy does not imply that the two activities just described need to be pursued by intellectual communities that work apart from one another. I have actually been arguing, and the present dissertation is testimony to this argument, that the two activities ought to be conducted within a thoroughly interdisciplinary domain. The two accounts are not only *not* mutually exclusive, but studying legitimacy ‘in context’ seems to require some understanding of a community’s normative definition of political legitimacy. In order for a descriptive analysis to be compelling, some account of what is regarded as legitimate is needed.

It is important at this point to clarify that legitimacy always refers to some object upon which one is casting a judgment: a state can be legitimate, a specific institution might or might not be legitimate, some decision taken by some institution might or might not be legitimate. Crucially, without a proper identification of what the object of analysis is, judgments of legitimacy, both at the normative and at the descriptive level, make little sense. Roughly speaking, the objects of legitimacy analysis, be it normative or descriptive, can be grouped under two headings: input and output. Input lumps together procedures one can subject to legitimacy analysis, e.g. an institution, a mechanism, a regime and so forth. Output legitimacy is instead concerned with the results of any of those procedures. Both input and output legitimacy can be analyzed from a normative and a descriptive standpoint. A matrix accounting for these two conceptual distinctions would look like that represented in the table below.

	Normative	Descriptive
Input	Does the procedure embody and/or realize the values we hold dear?	Is the procedure regarded as casting legitimacy upon the outcome?
Output	Does the decision embody the values we hold dear?	Is the outcome of the procedure regarded as legitimate?

Table 1 A matrix describing normative and descriptive legitimacy in their input and output specifications.

A normative account meant to guide political practice and to inform the measurement of the legitimacy that the practice yields, fits well within the picture of political realism I have developed so far. Within this framework, any normative account of legitimacy is perforce dependent on one’s hypothetical political theory concerning a problem and it must offer a tentative operational definition of the principles, ideals and values it leverages so as to have their realization subsequently measured empirically. Further on I delve into the case of the deliberative democratic definition of legitimacy and argue that a compelling metric for it requires both the pre-existence of the definition and its openness to revision on account of empirical findings. The interplay between these two sides of political legitimacy can be illustrated, as in **Figure 6**, by what Weatherford characterized as the difference between a macro and micro perspective on political legitimacy, the former “emphasizing formal system properties”, the latter “emphasizing citizens’ attitudes and actions” (Weatherford 1992, 149). This distinction maps precisely onto the distinction between normative and descriptive accounts of legitimacy, and if we set aside the terminological differences, Weatherford’s suggestion is that of complementing the “View from Above” and its empirical analysis of systemic properties, with the “View from the Grass Roots”, leveraging on the large dataset concerning individual-level attitudes and orientations towards political regimes that started accumulating with the development of survey research methodology after World War II.

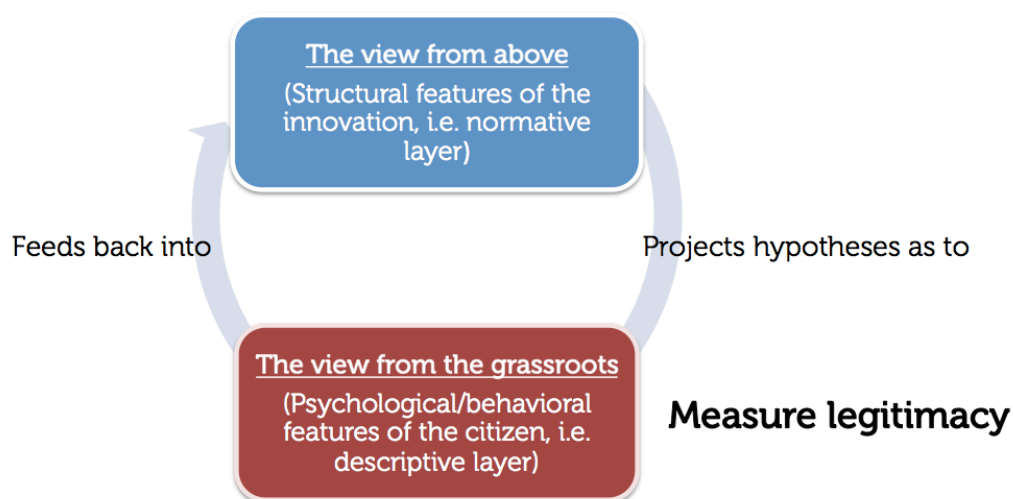


Figure 6 A visual representation of the interplay between normative and descriptive legitimacy

Again, if we move these remarks into the framework for political realist democratic experimentation described above, political theories can be seen as tentative normative definitions of legitimacy—i.e. the principles, ideals and values that make up legitimacy—explicitly argued to apply to some specific

political problem or set of political problems. This normative account of legitimacy serves as a precursor to the empirical measurement of the extent to which institutions hypothesized to solve that political problem give rise to more legitimacy in practice. Measuring empirically the legitimacy to which institutions give rise, in this sense, is a two-fold task: on the one hand it requires a normative definition of legitimacy upon which to rely when measuring the degree to which our experimental institution complied with that definition. In this first respect, according to Waldron (2013), there are two ways to evaluate some object of legitimacy: its consequential and its intrinsic value (more on this below). On the other hand, it requires some broader conception of descriptive legitimacy that effectively takes into account the “View from the Grass Roots” regardless of the normative definition of legitimacy that is supposed to apply.

In the next paragraph I specify the definition of consequential and intrinsic value of specific objects of legitimacy, arguing that any assessment of normative legitimacy (both input and output) other than empirical and consequential makes very little sense. Then I go on to argue that descriptive input and output legitimacy intermingle empirically to a degree that seems to call for both ‘pragmatic’ and survey measures of each respectively.

Consequential and non-consequential assessment of input and output normative legitimacy

In the essay on *political* political theories we already analyzed extensively, Waldron fetches a very interesting, though at a deeper inspection shaky, distinction between consequential and non-consequential reasons to value institutions. Consequential evaluation can be performed in either of two ways:

“On the one hand, there is our assessment of the output of a given institution (compared to the different output that a different institution or a different system of institutions might have yielded). Assessing this means mapping values like justice, equality, liberty, utility, and aggregate prosperity onto the social results of implementing our policies. [...] On the other hand, there are side-effects of the operation of our institutions on people—often good side-effects, like the educational impact that John Stuart Mill or, in twentieth century political theory, Carole Pateman expected from participatory democracy” (Waldron 2013, 11).

Developing this scheme, Waldron proposes to have institutions evaluated consequentially along three axes: the realization of values inherent in their outputs, the so-called spillover effects (or realization of procedurally-produced values) and the costs of operating the institutions. The first two axes account for the empirical input and output normative legitimacy of the institutions, while the last one simply embodies a concern for efficiency.

The non-consequential assessment of institutions as presented by Waldron has instead to do with values intrinsically entrenched in the institutions, which are not and ought not to be valued instrumentally. The time spent in the courtroom to allow for a fair trial to any suspect is, as far as Waldron is concerned, a “tribute [...] to the dignity of the person on trial” (Waldron 2013, 12), for instance. A tribute we ought to pay to their dignity *regardless* of whether this is a cost-effective way of increasing the likelihood of correct verdicts, but also, oddly enough, regardless of whether spending this time actually turns out to be the tribute to the dignity of the person on trial we wanted it to be in the first place.

Whereas the consequential assessment of institutions fits nicely within the framework I have developed and I believe there is no need to specify further how, in general, consequential assessments of institutional performance can and should feed back onto one’s hypothetical political theory, the non-consequential assessment of institutions as described by Waldron looks like a peculiarly unhelpful way to define, or conceptualize, normative legitimacy. One can in fact reasonably interpret the non-consequential assessment of institutions as either being an attempt at developing a political theory and its related institutional arrangement completely unencumbered by facts, or as some twisted sort of empirical judgment. On the former interpretation the proposed political theory clearly escapes the domain of politics and is therefore liable to the objections I already moved to political moralism. On the latter interpretation, essentially what we would do is postulate some definition of human dignity (or equally non-consequential values) and devise institutional mechanisms that supposedly respect that value for its own sake. The claim that institutions relying on such and such mechanisms foster (or secure) human dignity, however, can turn out to be wrong *as a matter of fact*. Take, for instance, democratic institutions that grant formal equality, which can be said to embody a concern for equal respect, in turn grounded in personal dignity. This claim does not hold *irrespective* of the fact that the institutions end up promoting equal respect and personal dignity. If institutions designed so as to

embed a concern for human dignity do not deliver precisely on human dignity, then it seems to me there are good reasons to revise the institution, granted that we do value human dignity.

One relatively simple and concrete example to underscore this point could be “one man, one vote” delegation mechanisms in representative democracies allegedly grounded in the value of equal respect for everyone’s dignity. These mechanisms have been proven to lend themselves rather easily to forms of so-called oligarchic capture, by means of which formal equality is turned on its head and functions as a mechanism to preserve forms of *de facto* domination exercised onto the majority of the population⁶⁶. Precisely because these institutional devices have failed to respect equality and hence human dignity, we ought to devise new ones, whose architecture might not directly grant formal equality. Revising the institutions as suggested in the example would be indulging in a consequential consideration of its value, therefore making non-consequential assessment simply an empty category. Non-consequential assessment then, if what I just said holds, is either objectionable on firm theoretical grounds, or must simply be reduced to consequential assessment.

Consequential measures of the value of institutions, i.e. measures of input and output normative legitimacy, are however still insufficient to gauge legitimacy and to inform new institutional hypotheses. This is because measures of input and output normative legitimacy merely describe institutional performance according to parameters that have been *theoretically hypothesized* (as there is no chance of adjudicating a conception of normative legitimacy once and for all on purely rational standards). Some insight into whether or not this normative definition of legitimacy indeed applies to the political problem at hand, that is whether it enhances the legitimacy of the institution and of its output, can only be found in a proper analysis of the descriptive legitimacy that the institution yields, both as to its output and as to its input. In the next paragraph I will show that empirical (psychological) evidence suggests the deployment of a hybrid measure of input and output descriptive legitimacy.

⁶⁶ I do not have space to go more into the details of this argument here and it is not essential, for the sake of my argument, that what I sketch in this passage is true. However, a series of papers both in English and Italian have been coauthored by Matteo Mameli and Lorenzo Del Savio pushing (compellingly, I believe) this and related points. See, for instance “Anti-Politics and the 1%” published on truth-out.org (<http://www.truth-out.org/opinion/item/25260-anti-politics-and-the-1> last access 22nd September 2014), “Anti-representative democracy and oligarchic capture” published on opendemocracy.net (<https://www.opendemocracy.net/lorenzo-del-savio-matteo-mameli/antirepresentative-democracy-and-oligarchic-capture> last access 22nd September 2014).

Input and output descriptive legitimacy

In general, input and output descriptive legitimacy intuitively intermingle, at least to some extent. Whether a decision is perceived as legitimate depends on whether one perceives the procedure that brings it about to be legitimate, and if the decisions of some institution are regarded as legitimate that must have some impact onto the belief in the legitimacy of the institution that issued them. Irrespective of the ways in which this happens in general, it is relevant, to the purposes of this specific thesis—which is grappling with the political nature of bioethics—to have an accurate account of how they do intermingle when it comes to moral issues, dealt with politically. Luckily, quite some substantial scholarly effort has been put already in analyzing (i) how individuals perceive the justice of decisions vis-à-vis the perceived procedural fairness of the institutions issuing the decisions and (ii) how the legitimacy of institutions interacts with decisions concerning morally controversial issues such as laws regulating bioethical issues.

Robust psychological research has shown that when people strongly hold moral beliefs (technically, when they are subject to *moral mandates*) that inform their preference for one out of a class of outcomes some institution is out to decide about, their judgment as to the institution's procedural fairness plays little to no role in the degree to which people see the actual outcome as just or unjust (Mullen and Skitka 2006; Skitka and Houston 2001). When “people perceive outcomes to be relevant to their moral beliefs, they base their fairness judgments on whether outcomes are consistent or inconsistent with their outcome preferences and consider procedural information to a much lesser degree, if at all” (Bauman and Skitka 2009, 42). This seems to hold true as well when people are involved in institutional procedures that directly prompt their voices on some morally charged issue, to the point that the benefits of fair procedures essentially vanish when the decision taken is inconsistent with one's moral preferences (Bauman and Skitka 2009).

More to the point of legitimacy, in 2009, Skitka, Bauman and Lyle published a study (Skitka, Bauman, and Lytle 2009) set up explicitly to tackle empirically the relation that there exists between the legitimacy of institutional authorities and the legitimacy of their decisions. In particular, the authors wanted to “test whether legitimacy protects authorities from backlash when they make not only a disliked decision but also one that perceivers believe is morally or religiously wrong” (Skitka, Bauman, and Lytle 2009, 567). In both cases legitimacy here was meant to refer to the descriptive part of the

concept, i.e. the legitimacy as perceived and reported by subjects to the decisions of the institutional authorities. The goal of the study was to cast light on what happens when the descriptive legitimacy of institutions (input descriptive legitimacy) and the descriptive legitimacy of their outputs misalign, that is when an institution perceived to be procedurally legitimate issues a decision that the perceiver regards as illegitimate on some (strongly-held) moral grounds. The study concluded that, in the case of the U.S. Supreme Court ruling on physician-assisted suicide (PAS), “[p]re-ruling perceptions of the Supreme Court’s legitimacy had no significant effect on post-ruling judgments of outcome fairness and decision acceptance,” whereas “support/opposition to PAS only had an effect on post-ruling perceptions of the Supreme Court’s legitimacy when people’s position reflected strong, [...] rather than weak moral convictions” (Skitka, Bauman, and Lytle 2009, 573–74).

These findings seem to suggest, on the one hand, that output perceived legitimacy is linked to people’s strongly-held moral beliefs, but essentially independent of the perceived legitimacy of the input, i.e. input legitimacy fails to percolate to output legitimacy when moral mandates are at stake. On the other hand, they point to the impact that outputs perceived as inconsistent with one’s moral beliefs can have on the descriptive legitimacy of the institution that issues the output, i.e. its input descriptive legitimacy. This makes it hard to disentangle the input and output merits of subjects’ judgments on procedures and decisions, which, in turn, seriously threatens the feasibility of a sensible description of the legitimacy that some institutions and their decisions are able to produce. At least this is the case if we merely ask subjects to political authority, more or less directly⁶⁷, how legitimate they perceive an institution and its decisions to be.

Against this problematic backdrop, it seems to make sense, at least it does in the specific case of bioethical issues (issues that touch upon moral convictions by definition), to try and measure only the descriptive legitimacy of the decisions that are institutionally taken. I suggest here, however, that there is a more intuitive and fruitful way, as compared to standard surveying methods, to measure output descriptive legitimacy. This is leveraging specific loci in the public sphere explicitly allowing for forms of engagement with legitimacy claims that concern *solely* decisional outcomes. Psychological measures

⁶⁷ Scales to measure the descriptive legitimacy of some institutions generally are multiple-item questionnaires that ask people’s level of agreement with statements concerning the institution and its dispensability. For instance, Caldeira and Gibson’s five item measure of perceived legitimacy of the Supreme Court asks subjects to what extent they agree to statements such as “It would not make much difference to me if the U.S. Constitution were rewritten so as to reduce the powers of the Supreme Court” (Caldeira and Gibson 1992).

to screen for the perceived legitimacy of institutions will in this sense only be used as a second best tool, one that is unlikely to offer properly conclusive, and therefore properly action-guiding, information.

This solution has two main advantages over the mere reliance on survey metrics for both input and output legitimacy. The practical engagement with legitimacy-claims and deliberate stance-taking (either acquiescing to or contesting the decision of a specific institution) yields two crucial results vis-à-vis the use of verbal reports concerning output descriptive legitimacy:

- i. If politics is the “*stance-taking between subjects and authorities*” (Fossen 2013, 435), then focusing on the subjects’ practical engagement with legitimacy-claims makes it possible to gauge descriptive political legitimacy *where politics happens* and social practices actually unfold, i.e. in the public sphere as opposed to sheets of paper or survey webpages. I will call the loci hosting the expression of dissent towards specific decision *corollary institutions* (corollary with respect to the ones that are being directly deployed as means to tentatively solve the political problem at hand), which keep institutional experiments in check and lower the odds that they produce illegitimate decisions;
- ii. Given that, in a nutshell, output impacts input, but not vice versa, when there are high moral stakes, we can take the influence that the descriptive legitimacy of the output can have on the descriptive legitimacy of the input, interpreting the legitimacy-claims issued by concerned subjects about specific decisions as, cumulatively, hinting at the perfectibility of the procedure that the institutions deploys. The systematic failure in identifying outcomes that turn out to be legitimate can in this respect be taken to make a case against the further experimentation of that institutional arrangement. But the feedback on specific decisions will also be pointing immediately to some problematic core in the substantive values that the decisions taken via that institution embody.

Second, given the influence that output legitimacy has on the perceived legitimacy of institutions, any ‘behavioral’ metric of input legitimacy would be unsatisfactory, i.e. it would be hard to infer to the illegitimacy of the institutional arrangement from public claims of illegitimacy of the institutional arrangement because they might be caused by the contingency of the output. Survey metrics, then, can be systematically, i.e. periodically, used to test for the legitimacy of all institutions in an attempt at

monitoring the perception of those as verbally reported, i.e. in a relatively non-political context. These attempts could be conducted without drawing any link to the decisions that those institutions have taken and stressing instead the description of the procedures that the institution deploys. This simple cover-up strategy is very unlikely to cancel out the effect of the decisions that have anyhow be taken, but the systematicity of the historical records of output (gauged ‘behaviorally’) and input (monitored via surveys) descriptive legitimacy that will be progressively built could be cross-checked for a more balanced assessment of the two distinct components. No control scenario will ever be available for different institutions, within the same geographical unit, issuing identical rulings⁶⁸, but one could still look at both how the procedures embedded in the institutions have, in the long run, prevented outcries and contestations, and which institutional arrangements have been more consistently perceived as legitimate through the various decisions.

In Part II, in which I develop a tentative political theory of bioethics, I will be therefore proposing a corollary institution that deliberately prompts the enactment of legitimacy claims as to decisions taken via what we might call the *main* institution. I will roughly outline a mechanism for vetoing decisions participatorily and epistocratically taken. However, the nature of corollary institutions in general, once again, will depend crucially on the specificities of the political problem.

The part of the dissertation that follows focuses on the actual details of the political theory meant to address experimentally the issues of bioethics in Italy. As I repeatedly anticipated, this theory will be complemented by a description of the institutional arrangement that the theory itself can reasonably be taken to support. The tenability of the theory is then preliminarily explored empirically in Part III.

⁶⁸ This could allow for a firmer inference to the legitimacy of institutions, regardless of the decisions they issue.

Part II

What political theory for bioethics

Introduction

The political problems of bioethics (a reminder)

In Part I, starting from a reconstruction of the so-called Stamina case, I singled out and delved into three distinctive and interrelated political problems that affect public bioethics in Italy. First, institutional actors have consistently shown a tendency to rhetorically frame their legislative efforts as ‘governance’ while failing to effectively harness the entire array of traits that are characteristics of the human technology of governance. Quite the contrary, law and policy-making, even when presented as ‘governance’ have almost systematically relied on technocratic schemes, by means of which power has been removed from both delegates and citizens and lent to boards of appointed experts. The technocratic removal of decisions from the hands of those subsequently bound by them has led in more than one case to public and vocal outcries. These (and this is the second problematic issue) have highlighted the worrying lack, in the Italian public sphere, of loci explicitly dedicated to the exercise of communicative rationality. This lack is rendered even more alarming by the inherent insufficiency of the loci themselves, were they to exist, in the absence of proper translating agencies that allow for claims to be formulated in ways that can genuinely be understandable both at the macro discursive level (unbound discourses in the public sphere) and at the micro discursive level (highly constrained public debates that immediately influence decision-making). These translating agencies, called, following Hendriks (2006), mixed discursive spheres are absent in Italy (although a viable candidate to the position exists and has historically failed to deliver on this translating function, as I show below) and this seems to have prevented a fruitful bioethical debate from unfolding. Given that no genuine confrontation could take place due to the two-fold lack just recalled, the debate on the Stamina method has drifted towards a progressive proceduralization trying to adjudicate the competing, and allegedly non-value-laden bio-objectifications of the method itself (either as a transplant or an advanced therapy medicinal product).

These three problems are tackled here tentatively with a political theory, partly anticipated above, which uses deliberative democracy and republicanism as two plausible theoretical points of reference. Defending deliberative democracy and republicanism as political theories exceeds the task of this dissertation. For theoretical reasons made clear in Part II it makes sense, instead, to specify the principles, values and ideals that my normative proposal inherits from deliberative democracy and

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republican political theory and to argue why these are defensible and how they are consistent with the institutional arrangement that is prescribed.

The Italian specificity: the National Committee for Bioethics

As I just hinted at, a viable candidate for the development of mixed discursive spheres that would carry out a genuinely translating role in bioethical issues exists in Italy. And it has existed since March 28th, 1990. It is the National Committee for Bioethics (NCB), established by the Presidency of the Council of Ministers with four main purposes: (i) summarizing the state-of-the-art of biomedical research, (ii) formulating perspectives and advice for problems ethical and juridical in kind arising from biotechnological and biomedical progress, (iii) elaborating safeguards for patients subjected to gene therapy⁶⁹ and (iv) drafting professional codes of conduct for practitioners of the field and promoting “a correct information of the public opinion”⁷⁰. These tasks contribute to qualifying the NCB as a technocratic locus of management of morally and legally thorny problems that pop up as a result of biomedical progress. In particular the fourth axis along which the work of the NCB is supposed to develop suggests that the committee ought to educate the public about, rather than directly engage it with, those issues. However, the technocratic status of the NCB has not remained unquestioned throughout the last decades. In fact there have been pressures, from within and without the committee, to embrace the deliberative turn and make the NCB into a device meant to kindle public engagement with bioethics (Incorvati 2007). Unfortunately, these pressures have been resisted so far and the work of the committee has been substantially limited to that of gathering politically appointed alleged experts in the domains that make up the interdisciplinary thrust of bioethics and have them express their opinions concerning problems that the government asks to be elucidated. These opinions have had and still enjoy an unclear status in that they are never directly enforced, nor translated into laws and policies.

Furthermore, in all instances of harsh societal division, the committee has proved incapable of producing documents that would authentically mirror some sort of consensus, presenting instead the legislator with contrasting and irreconcilable positions. NCB’s opinion about assisted reproduction (Comitato Nazionale per la Bioetica 1995), for instance, featured a clearly confessional (catholic)

⁶⁹ This part of article 1 was clearly contingent upon the cutting edge of biomedical research in the early 1990s.

⁷⁰ The decree is available here: http://www.governo.it/bioetica/normativa/decreto_istitutivo.pdf (last access September 17th 2014). The quote is from article 1 and it is my translation.

solution to the problem, alongside a lay set of recommendations. The two did not overlap to any (theoretical nor practical) degree. The Parliament subsequently issued law 40/2004, which would roughly embody (though it is hard to say to what extent the NCB's opinion actually informed the minutes of the law) the concerns of the catholic stance on the issue. The Italian Constitutional Court has recently repealed the law, after a decade of legal quarrels.

These two remarks, highlighting the failed attempts of both technocratic and democratic representative institutions at regulating issues that raise moral disagreement could have prompted a reform of the role of the NCB, which was at times asked for, but however never taken up (see, for instance (Neri 2003)). The committee is nevertheless almost ideally situated to operate as a mixed discursive sphere and as a translational device allowing for the expression of genuine communicative rationality in that it is almost equally distant from both the parliament and organized interest groups and activists (thus making it neither a micro, nor a macro discursive sphere properly speaking). Crucially though, it lacks the essential participatory and deliberative nature that is proper of mixed spheres.

To some extent, then, my institutional proposal in this part of the dissertation can be read as an attempt at reforming the role and status of the NCB so as to turn it into a mixed discursive sphere proper. This tentative reform purports to make the committee more participatory (though epistocratically so), reliant on ICTs and part of a larger set of political mechanisms that are presented as corollary, but that indeed play a pivotal role for the institutional arrangement.

In what follows I defend each of these features in turn.

Moderate Epistocracy for Deliberative Bioethics

In this paragraph I explore the normative political theory that I purport to apply to bioethics. This is a version of epistocracy, as recently presented by Jason Brennan (J. Brennan 2011), but in a relevant sense it also is more than that: I present and argue for different mechanisms applying to different stages in the law- and policy-making process for bioethics. All of these mechanisms contribute to characterizing the overall institutional arrangement that I defend and suggest should be experimented with.

I shall start from a reconstruction of Graham Smith's framework for democratic innovation and essentially rely on a subset of his democratic values that it seems we should focus on in order to

effectively tackle the political problems summarized above. The reliance on these principles must be seen, however, as non-foundational and essentially hypothetical, therefore revisable in the light of actual institutional experimentation.

Smith's framework for democratic innovations

Graham Smith's *Democratic Innovations* has contributed in numerous ways to the development of a more compelling case for a democratic theory that genuinely engages with empirical facts. In doing so, Smith also developed a full-fledged analytical framework for the assessment of what he calls democratic innovations, i.e. "new ways of engaging citizens in the political decision-making process" (Smith 2009, 1). Given a recognizably empirical focus, his analytical framework centers on institutions rather than on theoretical democratic models and in introducing the framework Smith remarks the reasons why no democratic model is explicitly subscribed to in his book. One of these reasons is that institutional analysis is not supposed to adjudicate between competing definitions of democracy and of the principles that are taken to make up those democratic theory. Being "situated within debates between competing democratic theories" (Smith 2009, 9) committing to one model would unfairly skew the assessment of institutions inspired by different sets of democratic principles. However in order for his institutional assessment to make any sense Smith is compelled to commit to a given set of what he calls "democratic goods". These are inclusiveness, popular control, considered judgment and transparency. Inclusiveness is the quality of institutions that is supposed to ameliorate the persistent problem of uneven participation. When assessing the inclusiveness that institutions realize one should be relying on data about the demographics of the participating population. Popular control is the value that underscores concerns for "the equal right to take part in collective decisions" (Smith 2009, 22) and its consideration in assessing institutional arrangements is meant to do justice to the idea that people who do participate in fact exert some kind of influence on actual political outcomes. Considered judgment is instead the good that most versions of deliberative democratic models revolve around: people ought to evenly participate to effectual decisions about which they express informed preferences, as opposed to raw, untutored, interested preferences. Finally, transparency presupposes the "ability of citizens to scrutinise the activities of institutions" (Smith 2009, 24) and its importance is linked to the nourishment of a sense of trust in the authority. These four democratic goods are then, according to Smith, complemented by two additional goods that are, as it were, not democratic in kind:

these are efficiency and transferability. The first is a straightforward economic concern that speaks to the feasibility of a democratic innovation while the second is an epistemic concern, i.e. an attempt at making sure that the knowledge acquired via the resort to the innovation is robust enough as to be transferred to relevantly similar contexts.

Smith ventures to claim that the “four [democratic] goods are particularly apposite for evaluating the democratic qualities of innovations because, arguably, they are fundamental to *any* theoretical account of the democratic legitimacy of institutions” (Smith 2009, 12). The author refers here to the normative definition of legitimacy that democratic theorists argue for or simply postulate. Though it is true that intuitively these qualities would feature as central to most democratic theories, equally intuitively, assessing institutions along these four axes *before* having weighed them according to one’s preferred democratic (or more generally political) theory would do little to adjudicate empirically the normative legitimacy of the institutions. Roughly said, even though we know that one design fares better as to the considered judgment that it promotes, still we have no reason to value that design over some other because we have no idea of the role that considered judgment plays as a principle in our normative definition of legitimacy. Therefore, however helpful as a framework for comparative qualitative analysis of institutional designs, it must ultimately fail without some other means for the adjudication of those very designs according to some normative definition of legitimacy.

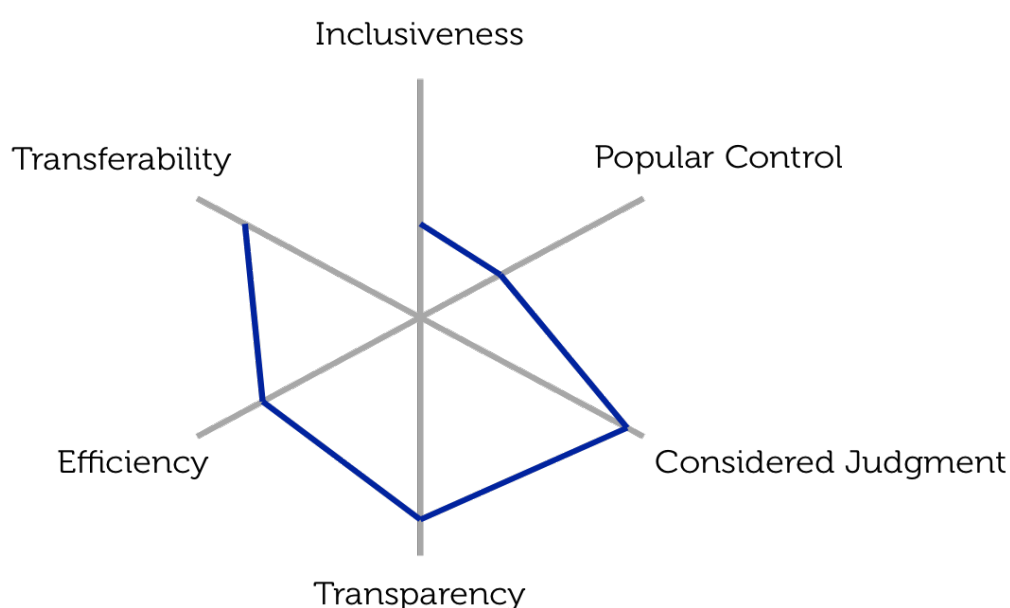


Figure 7 A matrix combining the assessment of some fictional institution along the six dimensions Graham Smith articulates.

It is indeed crucial to be able to say whether or not a given institutional design delivers on precisely the values that a political theory supposes to be enhancive of normative legitimacy. After all, an institutional arrangement that does not yield the goods that we want it to, is simply not the right institution for the political theory from whose standpoint it was developed. And in order to be able to do so, one needs to articulate his/her own political theory first.

However, such an approach—i.e. laying out the specifics of one's political theory and measuring the extent to which its purported goods are realized in practice—still fails for a second reason. The approach does not take into account any concern for the relation that there exists between normative and descriptive legitimacy as construed above. In fact, if we suppose the institutional design to deliver on the promises of its political theory, we still have no guarantee that the outcome of that institution and the institution itself will be perceived as legitimate. Failing to recognize the centrality of descriptive legitimacy in this context entails forgoing completely the possibility of having innovative experimental institutions feed back onto our tentative, i.e. hypothetical, political theory and the principles, ideals and values that we endow it with.

For these reasons I will first articulate the central contentions of my own hypothetical political theory, specifying what goods it is supposed to deliver. In doing so, I shall indulge in the arguments that I believe make a compelling case, on paper, for this specific political theory, trying to make clear how it fits within a sufficiently mature domain, how it is relevantly non ad-hoc and suggesting why we might predict it to have a legitimacy-enhancing import. Then I will present a corollary institution meant to assess the descriptive legitimacy that the core institutional arrangement is hypothesized to yield.

Moderate epistocracy for deliberative bioethics

I proceed here from the reconstruction of a recent and relevant development in political philosophy that revived the debate between epistocrats, i.e. those advocating forms of government that give more power to those who know more (though, as will be apparent in a while, this very definition does not fit well Brennan's contentions) and democratic anti-elitists. The academic pedigree of the arguments rehearsed here should suffice as a justification for the *non-ad hocness* of this political theory and for the sufficient maturity of the debate from which the hypothetical speculation concerning the theory enhancing legitimacy in bioethics moves. The arguments presented are then all ways of pointing to the reasons why this theory can be held to predict a higher legitimacy.

'Epistocratic' institutional bodies are widely resorted to in contemporary advanced democracies to attend to issues that seem to require some acquaintance with technical knowledge about scientifically complex topics such as, for instance, air pollution, public health, or biomedical research. The degree to which the use of these bodies has become entrenched in democratic systems has led influential commentators to speak of a fifth branch of government dealing explicitly with science policy-making (Jasanoff 1990) and partly escaping democratic scrutiny, acting on the grounds of a ultimately technocratic form of authority. In this context, public bioethics bodies have increasingly been resorted to as controversial scientific claims in policy-making progressively became characterized in moral rather than merely technical terms (Nelkin 1994). However, whereas science advisory boards have historically had a recognizable impact onto actual policy-making—and at times they did so with apparent perceived legitimacy—bioethics advisory boards' opinions "have had limited direct impact in defining science policy and have not succeeded in producing societal consensus on controversial issues" (Kelly 2003, 340). Therefore, as we saw in Part I, unless public bioethics bodies are conceived as agencies mandated by the scientific community and set up to deliberately try and shore up trust in science and research, it looks surprising that a participatory and deliberative turn was so enthusiastically embraced in public bioethics as well as in science policy-making. Public bioethics bodies were apparently lacking legitimacy, before the participatory turn, in a very abstract sense, that is they were lacking legitimacy in normative politico-philosophical terms. And in fact, how could it possibly be that institutions that are not charged with issuing decisions and whose advisory impact has consistently been feeble—to say the least—are perceived as illegitimate? Illegitimacy claims, more or less visible in public outcries such as the one described in introduction, seem to point more to the institutions that took the decisions, explicitly turning science advisers into policy-makers. These remarks notwithstanding, public bioethics bodies have been increasingly foregrounded in the debate concerning the right way to politically manage moral disagreement in the life sciences. Which suggests that there is some real merit in the claims, summarized above, that the participatory and deliberative turn was leveraged mostly for opportunistic reasons and as indeed a tool restore the lost legitimacy of the scientific community. In the light of this perplexing evolution of the standing and role that public bioethics bodies play in contemporary societies, it makes sense to reappraise more fundamental arguments as to the tenability of genuinely epistocratic forms of authority in bioethics and suggest that, at this relatively high level of abstraction, the political theory that might suit bioethics is one that

combines *both* epistocracy and participation. This will lead me to reconsider then the objections raised against past participatory forms of governance to argue in what ways the institutional mix between epistocracy and democratic participation described addresses those objections.

This relatively high theoretical work is not meant to underplay the role that legitimacy plays in the framework outlined so far. Quite the contrary, in order for legitimacy claims to work as tests that provide feedback as to our principles, values and ideals, the articulation of this core part of the political theory hypothetically applying to bioethics is subsequently complemented by corollary institutions meant to gauge the extent to which outcomes of the institutional arrangement overall will be perceived as descriptively legitimate.

Jason Brennan's alleged moderate epistocracy

Jason Brennan has recently argued that a form of mild or moderate epistocracy is morally preferable to unrestricted universal suffrage. In his paper, Brennan defends his view against classical anti-elitist arguments and proposes that members of the electorate be subject to *una tantum* voters' exams that test for basic institutional knowledge and politico-economic expertise. He admits, however, that his proposal has two major weaknesses:

- i. It violates what Estlund calls the *qualified acceptability requirement*. According to this principle, legitimacy requires that the exercise of political powers "be justifiable in terms acceptable to all qualified points of view (where "qualified" will be filled in by "reasonable" or some such thing)" (Estlund 2009, 41).
- ii. Given that epistocracy is unjust in this respect (even though still preferable to unrestricted universal suffrage) its degree of moral acceptability varies according to the acceptability of voters' exams. "The better we can show that the exam tracks the real difference between competence and incompetence, the less objectionable the exam is" (Brennan 2011, 718).

In this section I argue that, were it true that epistocracy violates the qualified acceptability requirement that would be less of a problem if conceived within a republican framework. Such a framework entails a conception of liberty as non-domination, rather than as non-interference.

Secondly, I argue that Brennan's voters' exams—on which the very acceptability of his proposal depends—can be criticized in a number of respects and hence significantly improved upon.

Finally, I sketch the outline of a participatory process that relies on issue-specific tests and provide a practical implementational example. I argue that such tests would better serve the purpose of limiting access to bioethics advisory boards to those who know *enough*.

In *Polluting the Polls: When Citizens Should Not Vote* (2009) Jason Brennan argued that citizens have a moral obligation not to vote badly⁷¹. In this paper he explicitly excluded that an argument from harm could ground the claim that one ought not to vote badly. The expected disutility of a single bad vote cast in standard presidential U.S. elections—calculated according to the formula for the expected utility of votes by G. Brennan and Lomasky (1993 56-7, 119)—is approximately thousands of orders of magnitude below a penny. “Bad voting is collectively, not individually, harmful” (J. Brennan 2009, 539). This makes the claim that bad voting should be avoided in that it imposes harm at least farfetched⁷².

Unsurprisingly, then, when he argues, in his later work (J. Brennan 2011), that citizens should be prevented from voting if they do not live up to moral and epistemic standards, he does not do so on harm grounds. Individual votes are very unlikely to be decisive in large-scale societies. This holds true both for democracy with unrestricted suffrage and for epistocracy. In fact one cannot exclude that some political arrangement will yield collectively good policies in the face of bad individual choices but this—so Brennan claims—is no ground to justify those arrangements. They will still lack legitimacy. A standard analogy supports this claim. Juries do not “have authority or legitimacy only when they make *correct* decisions” (J. Brennan 2011, 705). Rather, they lack authority and legitimacy whenever they decide incompetently or on the basis of morally unreasonable claims. Likewise, distributions of political power that fail to satisfy some set of epistocratic criteria (unrestricted suffrage being the most prominent example) are unjust in that citizens have a basic right not to be deprived “of life, liberty or property”, or to have “their life prospects [altered] significantly, by force and threats of force as a result of decisions made by an incompetent or morally unreasonable deliberative body, or as a result of

⁷¹ What “voting badly” amounts to is controversial. We will not analyse this controversy in detail. Brennan's own definition should suffice. According to Brennan “bad voting occurs when a citizen votes *without sufficient reason* for harmful or unjust policies or for candidates that are likely to enact harmful or unjust policies” (Brennan 2009, 537)

⁷² Thus, Brennan structures his argument as follows: (P1) One ought not to do X, when (a) collectively doing X might result in harm to others and (b) refraining from doing X has individually negligible costs. (P2) Collectively voting badly might result in harm to others. (P3) Not voting badly while retaining a right to do so has negligible costs. (C) One ought not to vote badly.

decisions made in an incompetent or morally unreasonable way”⁷³ (J. Brennan 2011, 704). Brennan therefore suggests screening out individual incompetent voters using written voter exams.

In order to probe his claims, Brennan goes through two main objections to epistocracy put forth by Estlund (2009). He shows that the first objection does not apply to his form of epistocracy, whereas the second one is not decisive.

The first kind of objection can be raised against defenses of epistocracy that rely on three main tenets: (i) the *truth tenet*, according to which there are right answers to political questions; (ii) the *knowledge tenet*, according to which some people know more of these truths; (iii) the *authority tenet*, which justifies giving more power over others to those who know more. The authority tenet should be rejected—so the objection goes—in that it commits the so-called expert/boss fallacy, which amounts to unduly assuming that being an expert is sufficient grounds for a citizen to hold power over others. However, Brennan’s case for epistocracy does not rely on the authority tenet, but rather on a negative version of it, which Brennan dubs the *anti-authority tenet*. The *anti-authority tenet* asserts that moral unreasonability and ignorance are sufficient reasons to justify *not granting* someone political authority over others. Hence epistocracy, so justified, does not commit the expert/boss fallacy.

Yet, Brennan admits, his argument is vulnerable to a second kind of objection. In fact, epistocratically restricted suffrage can be said to violate what Estlund calls the *qualified acceptability requirement*. Widely shared in liberal political philosophy, the principle states that “[n]o one has authority or legitimate coercive power over another without a justification that could be accepted by all qualified points of view” (Estlund 2009, 33). The procedure that embodies the debatable justification for distributing political power is, in Brennan’s case, the written test that he suggests ought to be used in order to prevent morally unreasonable and ignorant people from participating. We, as a polity, could agree that there is a difference between competent and incompetent people (this is a commonsensical and widespread intuition), nonetheless we might not be able to find an agreement among reasonable people as to the proper means to track the distinction between competence and incompetence. Hence, Brennan concludes, epistocracy is unjust in this respect. More specifically, it is unjust insofar as the test that allegedly tracks the distinction between competence and incompetence is qualifiedly objectionable.

⁷³ This he calls the *competence principle*.

Brennan's justification of epistocracy

It is hard to figure how one could consistently justify preventing a subset of the populace from exercising their basic right to political participation on the basis of epistocratic criteria within a high liberal political framework à la Rawls. As we said previously, within such a framework, the legitimacy of the institution of epistocracy depends on it being acceptable by any qualified, i.e. reasonable, point of view. The exam meant to tell apart competent and incompetent voters is likely to be a locus of reasonable but strenuous (and possibly endless) disagreement, which might in turn take the political system to an impasse. However, as Brennan points out, given that a choice must be made, one cannot but opt for the lesser injustice between the enforcement of policies picked by an incompetent deliberative body (entailed by unrestricted suffrage) and the discontent of someone with the test that licenses voters. His preference for the latter option is upheld by two considerations that I find objectionable.

- i. The violation of the *competence principle* implied by democracy with unrestricted suffrage is inherently worse than the violation of the *qualified acceptability requirement* entailed by mild forms of epistocracy. On the one hand, voting age laws, he claims, are a form of mild epistocracy that enforce the competence principle notwithstanding the qualified acceptability requirement. On the other, we ought not to accept that incompetent people have a say on citizens' lives, liberty and property for the same reasons that we do not accept decisions taken by juries made up of unreasonable and incompetent people.
- ii. Epistocratically produced policies are likely to be better, whereby better Brennan means more just and "better able to achieve prosperity and various humanitarian goals" (J. Brennan 2011, 717).

At first blush (i) seems fallacious. The fact that we already accept forms of mild epistocracy cannot possibly entail that we ought to do so. This would amount to committing the is-ought fallacy famously described by David Hume in his *Treatise* (Hume 2007, 3.1.1.27)⁷⁴. However, a more charitable interpretation of the argument would render the claim sounder. We accept voting-age laws for reasons that are, according to Brennan, essentially epistocratic. Infants are generally considered not competent

⁷⁴ Numbers in parentheses indicate Book, Part, Section and paragraph respectively.

enough to express sensible voting preferences. Why shouldn't we, then, accept forms of epistocracy other than voting-age laws? Specifically more just forms of epistocracy? The argument goes hence from normative assumptions—i.e. we already share moral reasons to support some form of epistocracy—no one is likely to deny, to normative conclusions. Even construed as a non-fallacious argument, however, the fact that we accept voting age laws for reasons that are ultimately epistocratic is not uncontroversial. Voting age laws can in fact be said *not* to depend in any relevant sense on the competence of older minors. The age threshold has been historically linked to traits that have fairly little to do with competence and way more to do with one's ability to cooperate or productively contribute to society, such as the economic independence of teenagers (being subject to taxation entitles you, therefore until you are actually taxed you do not get to vote), or their being subject to conscription.

Even granting, for the sake of the argument, that we do subscribe to voting age thresholds for epistocratic reasons, Brennan's point fails to effectively support the claim that *his* epistocratic proposal is morally preferable to democracy with voting-age laws. This latter mildly epistocratic institution is in fact better able to satisfy the *qualified acceptability requirement* and is thus less morally troublesome than Brennan's epistocracy. There are two main reasons why this is the case:

- (a) Every present voter, at some point in his or her life, has been underage, thereby making this threshold for political participation more likely to be acceptable to every qualified point of view. Relying on the distinction fetched by Normal Daniels, "[a]ge groups do not age, but birth cohorts do" (Daniels 2008, 169). Recognizing a threshold that makes reference to age groups—as voting age laws do—is thus a measure that does not favor any distinct group of people⁷⁵ and should therefore be seen as *prima facie* acceptable.

One cannot exclude that the interests of those who are minors today will anyway go underrepresented as long as they remain minors, but the fact that at each election 'former minors' will have a say looks like the right kind of incentive to take their interests into fair consideration hence fostering a form of what might be called *diachronic inclusion*.

⁷⁵ This is true unless the threshold is conceived so as to dynamically track and advantage (or disadvantage) one specific birth cohort, e.g. once the 1995 cohort grows older, the threshold for participation is shifted progressively upwards so that they never really get to participate.

This is not the case for epistocratic thresholds: it might happen that one is never able, for whatever reason, to pass voters exams.

- (b) The adjudication of one's age is way less controversial than citizens' politico-economic competence. Whether one is 18 or older is easily verifiable. This does not mean that the adjudication of one's competence via the proxy of age is uncontroversial. It is sensible to claim that some fixed threshold, e.g. 18 years of age, will not map accurately onto citizens' competence. There will clearly be both false negatives, i.e. people underage competent enough, and false positives, i.e. people older than 18 not competent enough. However, the controversy concerning the accuracy of the test affects both tests for politico-economic competence and moral reasonableness, and voting age laws. The relevant difference here is that the very means to adjudicate one's competence is not subject to interpretation in the former case, whereas it is in the latter, hence making age thresholds preferable in practice to competence tests.

Argument (ii), instead, is weak. Its truth is dependent on empirical evidence and currently no evidence supports the claim that epistocratic institutions produce better policies. Quite the contrary, a rich literature is developing, concerning the output that more inclusive institutions tend to have on the governance of local and regional administrations⁷⁶. Although the evidence is not conclusive, it seems to suggest that there is something to more participatory institutions that makes them worthwhile. I am also not aware of even small-scale experiments that try and build a case for epistocratic institutions, though the experiment presented in this dissertation partly goes in this direction.

Brennan's argument also seems theoretically shaky: Grounding the assessment of epistocracy (as compared to democracy with unrestricted suffrage) on the goodness of the policies it will yield seems to deliberately overlook the distinction between the instrumental and the value of political institutions (Ottonelli 2012). Such a distinction is crucial for Brennan's argument concerning the uncoupling of decisions' legitimacy and correctness. In fact, following his argument, epistocracy might still lack authority or legitimacy even in the face of the goodness of the policies it gives rise to, for the very same reason that grants the claim that juries do not "have authority or legitimacy only when they make

⁷⁶ See, for instance (Smith 2009; Wampler 2007).

correct decisions” (J. Brennan 2011, 705). In this sense, the likelihood with which epistocracy yields correct decisions only makes it instrumentally worthy, while still illegitimate or lacking authority.

Taking stock of the considerations just made, intuitively there are ways other than those Brennan deploys to contend that epistocracy entails a lesser injustice if compared to democracy with unrestricted suffrage and democracy with voting-age laws if applied, so to say, ‘in context’. I will first attempt at providing different tentative grounds for the conclusion that some epistocratic constraints might make sense under a different democratic theoretical framework. I will then try and outline a different kind of test for competence that would better serve the purpose of epistocracy in bioethics.

Epistocracy and Republicanism

In the following paragraph I want to tentatively support Brennan’s conclusion, arguing that, from a republican perspective, the enforcement of policies chosen by an incompetent deliberative body are a genuine form of domination that hence calls for constitutional provisions meant to impede such arbitrary interference. This makes epistocracy, upon deeper inspection, less morally problematic (and more morally desirable) than democracy with unrestricted suffrage.

Republicanism is a well-established politico-philosophical tradition, therefore I will not present it in any detail. My main contention here is that the idea of *liberty as non-domination* can be nicely coupled with the *anti-authority tenet* as defined above. Pettit roughly defines non-domination as the absence of actual and potential arbitrary interference. He subscribes to a conception of liberty that is both negative and positive. More specifically:

This conception is negative to the extent that it requires the absence of domination by others, not necessarily the presence of self-mastery, whatever that is thought to involve. The conception is positive to the extent that, at least in one respect, it needs something more than the absence of interference; it requires security against interference, in particular against interference on an arbitrary basis (Pettit 1997, 51).

Within such a republican account of liberty (Pettit 1997), choice alone—the choice to participate being the case at stake here—does not have any intrinsic value. A republican is in fact likely to look “fondly on state interference, provided that such interference can be bound by constraints that make it non-arbitrary” (Pettit 1997, 78). State interference reducing the range of choices available to individual

citizens seems less problematic given that the reasons grounding such sort of interference are non-arbitrary, i.e. legitimate.

The kind of interference with citizens' liberties that Brennan's epistocracy entails is the prototype of Pettit's legitimate interference that aims at enlarging the scope of non-domination, eventually constructing, or better securing citizens' fundamental liberty. As a result, the threat to individuals' basic liberties posed by irresponsible, meaning deliberately ignorant, or morally unreasonable voting citizens, makes it unnecessary to deal with the trade off between respect for the competence principle and respect for the qualified acceptability requirement. Ignorant and morally unreasonable citizens could abstain from voting badly, but this would be an arbitrary act of mercy on their part, which makes the rest of the electorate *de facto* dominated. Thus, not allowing for the constitutional provision of a sensible legal threshold for participation—that is to say refusing to override the *qualified acceptability requirement* when the *competence principle* is violated—would be tantamount to depriving people of their basic right to have their liberty secured from arbitrary interference.

This consideration heavily bears on the moral and political desirability of epistocracy as opposed to democratic means of governance in all those cases in which direct participation is a relevant difference-maker. Political participation, at all levels, can be presented as lying along a continuum that goes from non-binding outputs, to universally binding outputs. Member of parliaments act in the proximities of the former end of the spectrum, while mundane daily political conversations, though exerting *some kind* of power over others, lie very close to the latter. To some extent paradoxically, casting a vote in secret ballots is a relatively mild exercise of power over others: the link between one's preferred political platform and actual policy-making is feeble and mediated at the very least, and, as recalled above, even granting the link, the odds that one's vote (expressed without any attempt at convincing others publicly) swings the result of elections are negligible. Therefore we may regard epistocratic constraints as increasingly relevant as the *direct* bindingness of the output of some deliberative bodies, i.e. some institution, increases, where the directness of the bindingness of the output depends on known institutional features.

Exactly what test is deployed to screen out 'bad' voters or deliberators would then still be crucial within a republican framework, to qualify participation to institutions that bind others directly. The fact that a legal threshold of competence is morally in order, in fact, does not imply that just *any*

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threshold would do. Whether a test for competence would qualify as more or less just is to be decided according to its accuracy. The better the test will be able to screen out individual incompetent and morally unreasonable voters without excluding competent and reasonable people (i.e. the least false positives and false negatives the test will return), the more legitimate (i.e. acceptable to qualified points of view) it will be. In the upcoming section I argue that the kind of tests envisaged by Brennan can and should be improved upon for theoretically and practically sound reasons.

The shortcomings of voters' exams

Despite the pivotal role that the voter test seemingly plays in the justification of Brennan's proposal, the outline of such test is only roughly sketched and substantially underdeveloped by the author. He only ventures to claim that:

A written voter exam is not the only way to attempt to enforce the competence principle. I can think of other ways, but most of them are either prohibitively costly or unrealistic (J. Brennan 2011, 714).

In the remainder of this section I suggest that Brennan's tests are likely to be an improvable way to enforce the competence principle. I further present a different—and hopefully better—way of addressing the same problem.

Brennan proposes written exams supposed to test for politico-economic knowledge and moral reasonableness. These would be tests that citizens need to pass only once, in order to be granted a sort of lifelong voting license. Despite this idea's immediate appeal, there is a sense in which the tests' scope is both too broad and too narrow. It is too narrow in that it is controversial whether only political economy would be an essential part of a responsible citizen's knowledge. It is unclear, for instance, why some basic understanding of molecular biology or sociology or engineering (just to mention a few disciplines that look in some intuitive sense relevant to policy-making and to the welfare of a nation) ought not to be a condition for the responsible exercise of political rights. Conversely, the condition that people be morally reasonable looks too broad to be even sensibly tested for. The answer to the question whether one is morally reasonable seems to rely on the underlying assumption that we have a definite and shared answer to a different, but still very broad question, namely "what makes a

good citizen (or better, a good enough citizen)⁷⁷ This question, moreover, has been and still is central to a plurality of reasonable but incompatible conceptions of the political life.

There is a further issue, which is instead due to the lifelong nature of the licenses granted according to Brennan's tests. Both political economy and morality are progressive endeavors frequently undergoing changes within the span of individuals' lifetime. The belief that racial segregation is legitimate would probably not feature as a trait associated with moral unreasonableness in the 1920s in the Southern states of the U.S. whereas it clearly would now⁷⁷. Beliefs about how to best account for externalities in public policy have changed after Coase's theories had become established. Some citizens then are inevitably given lifelong licenses that will, at some point in the future, be significantly outdated. This does not entail *per se* that people who have outdated licenses would be unjustly retaining their political powers in the face of their factually wrong and morally unacceptable beliefs. At least no more than outdated driving licenses entail that one is no more capable of driving safely. However it might happen that this is the case. The only way to remedy such problematic issue is to envisage periodic written voters' exams. This seems way more costly and organizationally cumbersome than Brennan had initially figured, and hence undesirable.

In order to redress and overcome these theoretical and practical shortcomings (again central to the very legitimacy of epistocracy), I propose that tests be devised so as to be specific to deliberative issues rather than generally relative to political representation.

Online epistocratic participation for deliberative bioethics

I have argued that epistocratic constraints to 'directly deliberative' political participation are morally desirable. It is unclear, though, exactly which constraints would be appropriate. I suggested that this is the case also because such constraints have been thought of as applying to political participation generally understood rather than to specific moments of political participation. In this last section I argue that not only these constraints should apply to directly deliberative participation, but also issue-specific restrictions to participation in online deliberative *fora* for bioethics are a good example of how epistocracy can be fruitfully specified. First I briefly introduce the idea of deliberation, secondly I show

⁷⁷ For a nice overview of cases exemplifying the historical situatedness of repugnance and moral acceptability see (Roth 2007).

that bioethics is a proper locus for deliberative political control and finally I describe the main features of the online epistocratic participatory institution that I envisage.

A number of contemporary political philosophers have articulated a whole array of deliberative approaches to democracy (Boniolo 2012; Elster 1998; Bohman 1996; Gutmann and Thompson 2004; Dryzek 2000). Despite there being more or less significant differences between such approaches, all of the authors share a broad definition of deliberative democracy which relies on two main kernels: (i) the *democratic kernel*: decisions affecting people's lives ought to be taken by those people themselves and (ii) the *deliberative kernel*: collective decision-making ought to be the result of argument and the use of public reason by free and equal citizens (Elster 1998, 8). This general account has been extensively discussed and reformed through the years. I maintain, and I have extensively explored this claim in the thesis, that accepting deliberative democracy as the sole political theory according to which institutions ought to be designed would be unwise. Some political arrangements are really about interest group bargaining and there seem to be nothing wrong about that. Here I will argue that some form of deliberation is appropriate to the solution of bioethical issues. In this respect, moreover, I mean to fully endorse the *deliberative kernel* while relaxing the *democratic kernel* making it compliant to the *competence principle*. In the terms of Smith's goods of democracy outlined above, my main concern here is with considered judgment and its compatibility with inclusiveness. All other goods do not seem to be in tension in this participatory epistocratic scheme: as will be pointed out, concerns for cost-effectiveness partly ground the online nature of this arrangement; transparency and popular control are, by definition, as compared to the transparency and popular control afforded by closed-doors experts meetings advising about regulations in bioethics, visibly enhanced, no matter the extent to which the institution will realize those values in practice; finally, the transferability of the democratic innovation described here could only be explored with reference to a set of experimental implementations which is not available as of today.

Bioethics essentially concerns the pursuit of collectively binding decisions that would be legitimate in the face of harsh moral disagreement. Thus, if politics is the means by which people's views inform their own government, then bioethics is a political endeavor throughout⁷⁸. Institutions meant to deal

⁷⁸ I explored the political nature of bioethics in depth in Part I.

with bioethics can therefore be designed according to different political theories. Already in 1997, Gutmann and Thompson had suggested that the political theory that would best suit bioethical debates is one that asks “citizens and officials to justify any demands for collective action by giving reasons that can be accepted by those who are bound by the action” (Gutmann and Thompson 1997, 38). Such is a deliberative theory of bioethics. This approach to bioethics has four main purposes: (i) to promote the legitimacy of collective decisions, (ii) to encourage public-spiritedness in public decision-making, (iii) to foster an economy of moral disagreement⁷⁹ and (iv) to help correcting mistakes due to partial understanding (Gutmann and Thompson 1997). They all contribute to making deliberative democracy promising in terms of problem-solving and legitimacy-enhancing potential.

A number of attempts at deliberative bioethics prompted by such theoretical considerations have been made so far, the ones by the U.K. *Human Fertilisation and Embryology Authority* (HFEA)⁸⁰ being some of the most influential examples. Essentially, bioethical *fora* can go from bluntly technocratic (or allegedly so), to genuinely participatory. In the former case, power is granted directly to experts (picked through more or less public and more or less reasonable procedures). In the latter, institutions are meant to be as inclusive and as open as possible. Deliberative efforts as the initiatives promoted by the HFEA, mean to be as inclusive as possible without sacrificing the considered argumentative nature proper of deliberation. In order to strike this balance, the HFEA usually organizes articulate public consultations that resort to methods ranging from standard opinion polls, to public conferences, to deliberative workshops (e.g. see HFEA 2007). This kind of workshops usually host no more than 100 people and go on over a long period of time, hence demanding a series of encounters meant to lay out the facts, outline the arguments and openly discuss them. Considered judgment requires indeed time and a definite effort of moderation and encouragement on the part of the hosting institution. If scaled up to the entire population, face-to-face deliberative workshops are hence, as Brennan seemed to suggest, very unlikely to be a cost-effective solution. Online deliberative alternatives, in this sense, look like a solution worth exploring. Hosting the deliberation online might allow for a number of advantages, e.g. cost-containment, longer availability of the forum, ubiquitous accessibility. Indeed, part of the

⁷⁹ Urging the use of moral rationales for collectively binding decisions that would minimize the rejection of opposing positions.

⁸⁰ The public consultations carried out by the HFEA can be found here <http://www.hfea.gov.uk/122.html> (last accessed: March 17th, 2013).

consultations led by the HFEA was hosted online. This solution was however implemented without any mechanism confirming that participants had actually gone through the information material (or in case they did not, that they were familiar with it). Moreover, the online participatory process did not allow for the reason giving and taking that is crucial to the deliberative kernel. The HFEA's public consultations have not been an isolated effort. As we already saw, it was part of an overall 'deliberative turn' in bioethics. This turn has very recently been characterized as lacking in method specificity (Abelson et al. 2013, 4). Therefore, it is essential, in presenting the institutional design that fits the normative considerations laid out so far, to be as precise as possible as to the methodological details of its implementation. In what follows, the design is relatively abstractly presented, whereas in Part III I go through the details of the actual characterization of the preliminary implementation of the participatory process.

The participatory process consists of three subsequent phases, each conditional to the previous one. Prior to the set up of the entire process described below, citizens will be asked to pick issues that they feel require public deliberation. This public agenda setting process will follow a stage-wise structure in turn: anyone can pick any relevantly bioethical issue they feel like deserves consideration and political engagement. The issue must be described in its problematic features. Other citizens will subsequently get to vote for any of the proposed issues. This vote expresses the interest other citizens have in seeing the issue discussed and opened up for actual policy- and law-making. All of the issues that garner support above a set threshold (proportional to the number of the actual voting population in the country⁸¹) within a given span of time, are formally taken into consideration. These selected issues are then translated into specific Yes/No questions, whose formulation is to be tested for impartiality and perspicuity by participants in a given span of time prior to the deliberation. The first two phases of the participatory process itself are meant to embed, within the technological support, the *competence principle*, thus screening out incompetent and unreasonable participants. The last phase allows for open argumentative discussion, hence making the forum genuinely deliberative. At the beginning of the deliberative process, participants will be asked to provide their intuitive and unreasoned answer to the

⁸¹ This means that given a set proportion, say the 0.1%, as the threshold for the issue to be considered, the percentage applies to the part of the population that turned out during the latest political elections, e.g. for Italy, the 75%, totaling more than 35 million people, of the population who showed up at the polls in 2013 (data from: <http://elezionistorico.interno.it/> last access October 2nd 2014). This means that each issue, to be taken into consideration, would need 35'000 subscribers. Each of the numbers is here only tentative and needs to be tuned to the actual participation and changed through time according to what has historically been the case.

deliberative question. This will allow for a sleek tracking of changes in preferences, which allows for the tracking of a component of normative legitimacy according to the current formulation within a deliberative democratic framework. Asking for pre-deliberation preferences also serves the purpose of sensibly asking participants to counterargue their own pre-deliberation preference. The phases that characterize the process are described as follows:

- i. Scientific competence: in this phase participants are individually exposed to the relevant scientific information. Information is provided via a two-way instrument, which allows for the contestation and reformulation of specific passages (in a fashion similar to that of Wikipedia entries). Participants are tested for the knowledge of basic (theoretically uncontroversial) facts contained in the information materials.
- ii. Moral competence: in this phase participants are individually exposed to the known repertoire of relevant moral arguments concerning the deliberative issue. They will then be required to object to a selection of arguments supporting their intuitive answer to the deliberative questions. This is supposed to foster the understanding of people with different perspectives, hence ameliorating the ideological opposition that sometimes characterizes this kind of confrontations.
- iii. Discussion: once both tests are passed, participants will be given access to an open forum, in which they will discuss their respective positions with each other. The process of discussion will result in the draft of a deliberative document akin to the ones that bioethical committees typically produce.

This process has a series of advantages both over Brennan's tests and over face-to-face deliberative workshops. As compared to Brennan's exams: (a) it provides properly motivated citizens with the actual chance to be competent and reasonable enough to participate, giving them the means for a non-dominated and non-dominating choice; (b) being issue-specific, shared criteria for competence are more likely to be found and agreed upon; (c) not granting lifetime licenses it is more likely to screen out people lacking knowledge relevant to specific issues and it cannot possibly incur the risk of having people with outdated licenses. As compared to face-to-face deliberative workshops: (a) it significantly

lowers costs and barriers for large-scale participation; (b) it allows for longer spans of time being allocated to constructing one's informed participation.

However epistocratic, then, it must be stressed that this institutional arrangement is meant to harness the potential for bottom-up crowdsourcing (Howe 2009) of legislation. Crowdsourcing is defined here rather narrowly as “an online, distributed, problem-solving and production model that leverages the collective intelligence of online communities to serve specific organizational goals” (Brabham 2013, xix). In the last few years, the technical possibility of online participation has made the prospect of having people actually contributing to the policy- and law-making process not only intuitively possible, but also desirable for democracies struggling to restore trust in their representative institutions. Direct engagement of the population into this kind of processes once reserved to representatives and bureaucratic elites has been on the rise, with a number of nation states in the E.U. and the E.U. itself have been introducing crowdsourcing mechanisms to allow for this type of engagement (Setala and Schiller 2012). These initiatives have been proposed with mostly two goals, one epistemic and one political, in mind: the mobilization and leveraging of dispersed knowledge and the strengthening of output legitimacy. To date, however, it is unclear whether resorting to the crowdsourcing of legislation has had the impact it was expected of it in both respects. This has been the case also in that very few of the initiatives set up turned into actual decisions, hence leaving the verdict as to the promises concerning their use still open. Carrying on experimenting with this form of democratic innovations is therefore of pivotal importance. It is even more important that this kind of experiments is given serious consideration on the part of the authorities that set them up in order for them not to result in impoverished trust in those authorities. Ricardo Blaug has described this undesirable sort of numbing effect that might obtain in case citizens consistently perceive democratic innovation as instances of mere ‘window dressing’ (Blaug 2002).

The legitimacy that the proposed innovation might yield, as was made clear in Part I, can be measured along two main axes: normative and descriptive. I will mention the tool that will be used to measure the normative component of legitimacy and argue that resorting to it is not enough for a thorough measurement of the extent to which the institutions and the political theory that informs them are capable of resulting in more legitimate decisions. Then, I will introduce the concept of corollary institutions meant to gauge the descriptive part of legitimacy.

Deliberative democracy and its notion of legitimacy

The epistocratic and participatory institution presented above is essentially a particular instantiation of the deliberative democratic ideal. Claims such as “[d]eliberative democratic theory centers on the notion that for some issues, at certain times, a simple vote for a political representative is insufficient to provide for meaningful democratic decision making” (O’Doherty et al. 2013, 3) or “[t]here is a widespread belief among many policy makers and reformers that providing opportunities for citizens to deliberate about matters of public concern is an effective response to high levels of disillusionment and disenchantment with the political process” (Smith, John, and Sturgis 2013, 709) are almost ubiquitous in the literature concerning the democratization of policy-making in the Western world. However, authors subscribing to such sort of claims fail to recognize, or simply overlook the problematic core that lies behind them. Namely that it is unclear exactly whether and how public engagement (orderly deliberative or of other kinds) is supposed to ameliorate the democratic deficit and enhance complex policy-making decisions’ legitimacy.

Participation can effectively be argued to have a number of advantages over straightforward top-down government. In developing their Better Life Index⁸², the OECD includes a dimension of civic engagement in the comparative measurement of wellbeing across countries. Once more, this is for both intrinsic and instrumental reasons. “Political voice is one of the basic freedoms and rights that are worthwhile to all humans and that people have reason to value” says their *How’s Life* report (OECD 2011, 187) referencing Amartya Sen’s *Development as Freedom* (1999) and it is therefore intrinsically better to have more occasions for the individual expression of political voice. Participation, however, also enhances wellbeing both based on the outcomes that it promotes, such as welfare rights, but also as a result of the mere existence of the participatory procedure. Stutzer and Frey managed to gauge the independent effect of what they call procedural utility, looking at the increased reported wellbeing of residents in Swiss jurisdictions with more chances for political participation, and more importantly, looking at the difference in reported wellbeing in those jurisdictions between those who enjoyed actual rights to participation and those who did not: “reported satisfaction with life is [...] smaller for foreigners, reflecting their exclusion from procedural utility” (Stutzer and Frey 2006, 412). Still, even granting that more participation is consequentially valuable in that it enhances individual wellbeing,

⁸² See <http://www.oecdbetterlifeindex.org/topics/civic-engagement/> (last access September 17th 2014).

one can say little as to the import participation has on the political legitimacy that participatory institutions can cast on their outputs.

Recent and sophisticated attempts at measuring whether participation and deliberation tap legitimacy have gone beyond the consideration of values that participation seems to realize instrumentally, e.g. wellbeing, and focused on the ways in which values inherent in the deliberative democratic ideal, values that make up the idea of political legitimacy according to deliberative democrats (i.e. that people ought to have a deliberative say as to laws that bind them) are realized empirically in deliberative democratic institutions. Even this turn however fails in addressing the issue of political legitimacy from a descriptive perspective. In a recent paper in which he grapples with the relationship between political theory and empirical work in political science, Dennis Thompson says that “[s]ome of the claims of deliberative theory are not empirical. One of the most important benefits that theorists ascribe to deliberative democracy is that the decisions it produces are more legitimate because they respect the moral agency of the participants” (Thompson 2008, 498). I have shown that legitimacy cannot and actually is not taken by most theorists as a purely normative concept and it seems intuitive to derive from this assertion the contention that one cannot take deliberation to be legitimacy-enhancing *irrespective* of its actual capacity to produce legitimacy. However, in this passage one of the most influential deliberative theorists is pushing precisely the opposite point: that deliberation yields the benefit of a more legitimate decision in virtue of its procedure alone. This claim is supported by the argument that—roughly—the moral agency of other citizens requires that they be given reasons for decisions that bind them. Encapsulating this part of the normative theory of deliberative democracy from empirical feedback looks surprisingly dubious, especially in consideration of the fact that from deliberative democracy’s capacity to produce more legitimate outcomes depends the very viability of the theory.

To be fair, further on in the essay, a distinction between normative and empirical (which is different from descriptive) legitimacy is drawn. However this is only done in order to cast light on the empirical way to properly measure the extent to which the concept of normative legitimacy is realized in practice. As I showed above, (i) attempts at assessing institutions’ normative legitimacy non-consequentially (as this seems to be the case) are somewhat disingenuous and (ii) the mere recognition of input and output normative legitimacy is insufficient to properly assess the legitimacy that the institution yields.

Therefore, even when interpreted charitably, these attempts neglect the descriptive component of legitimacy.

Deliberation is in fact only one aspect of a proper democratic theory and this needs inform a consideration of the degree to which measuring deliberation says something about the measurement of political legitimacy. My contention is that, given one measure (whichever one picks: the speech act analysis developed by Holzinger (Holzinger 2001; cited in Bächtiger, Shikano, et al. 2010), the Discourse Quality Index presented below (Steenbergen et al. 2003) or Stromer-Galley's (2007) coding scheme for deliberation's content) of deliberation, even if that is properly theoretically grounded, it will not be able to tell anything about the legitimacy of the procedure or of the output that is not already assumed by the theory that grounds the measurement. In a nutshell, it will only allow for the consequential empirical assessment of input and output normative legitimacy. This speaks forcefully to the construction of a form of measurement for political theories that takes into account indexes that are not already assumed as fundamental kernels of the theory, i.e. genuinely non-normative aspects of legitimacy.

It is interesting, in this respect, to reconstruct the history of one of the major and most widely recognized index for the quality of deliberation (an index I employ below to gauge the empirical realization of the deliberative component of normative legitimacy in our preliminary experiment). Proposed in 2003 by Steenbergen and others (Steenbergen et al. 2003), the Discourse Quality Index (henceforth DQI) managed to muster quite some recognition with notable figures in the deliberative democracy camp such as Habermas (Habermas 2005) and Thompson (Thompson 2008) mentioning it as one of the most promising attempts at bridging the gap between (deliberative democratic) political theory and empirical political science. According to some of its proponents by 2010 DQI had become established as “the most encompassing and most widely used measure of deliberation” (Bächtiger, Shikano, et al. 2010, 2). Interestingly for the purpose of my argument, proposing a revised (a 2.0) version of the DQI, these authors claimed that conceptual developments in deliberative democratic theory that followed the creation of the DQI—in particular the transition from what Bächtiger and others (Bächtiger, Niemeyer, et al. 2010) called type I deliberation, focusing exclusively on the original concept of communicative action elaborated by Habermas, towards type II deliberation, one in which forms of communication that are not properly rational are not only allowed but encouraged—needed

to be reflected in the empirical measurement of deliberation. This demand imposed by theory on empirical instruments sounds suspicious and, in a relevant sense, seems to defuse the very meaning of an empirical measurement of deliberation, one capable of feeding back into the political theory that had informed the empirical effort to be measured in the first place. In fact, the failure of DQI 1.0 to capture properly the new kind of deliberation does not seem to be linked to any of the information produced via the DQI as to deliberation. Rather, it looks like theorists' abstract elaboration of new and more sophisticated versions of deliberation generated the demand of a reform in the instrument supposed to measure how deliberative some institution (in the loose sense outlined in the introduction) is. This is like demanding that one includes a new dimension, say temperature of the city, in the construction of an index of comfort for the *sole* reason that a new theory of comfort postulates temperature as a relevant feature of comfort. Of course there can be sensible reasons to include temperature as a relevant dimension of comfort measures: however it is unclear exactly why we should plainly accept that this is a new definition of comfort that we need to measure using new instruments, namely a thermometer. How can one constrain this theoretical expansion and claim that, in our fictional case, other features are not relevant and ought therefore not to be measured? How does one go about picking one hypothesis over an infinite class of others? And what is it exactly that the measure is supposed to tell us? Does the DQI tell us straightforwardly how deliberative a procedure is? And why do we care about that information?

Measures such as the DQI are useful and can be fruitfully deployed (which, as I said, I will do in Part III) to measure specific dimensions of the performance of political institutions. However the most worrying shortcoming of such a measure is that it is structurally blind to the most important feedback that the world has to give as to the desirability of the institution and of its output: the extent to which people *perceive* these to be legitimate. A high DQI score in fact cannot possibly tell anything about how the decision will be received or the institution perceived. It will tell us whether it realized the values that our political theory postulates as central to political legitimacy and it is therefore a necessary step in the assessment of the institution. But it is nonetheless insufficient to make a contribution to the further development of political theory towards more legitimate arrangements.

Corollary institutions

Essentially, this far, I have proposed to deploy two different mechanisms to address two different problems: first I suggested making the agenda of public bioethics directly responsive to the concerns of a relatively important share of the population; second, I construed the epistocratic crowdsourcing of policy- and law-making concerning the issues selected as a viable mechanism to tentatively enhance the legitimacy of political decisions taken vis-à-vis moral disagreement. I have shown how the normative component of legitimacy will be measured and argued that measuring only this component will simply not suffice to ground the claim that more legitimacy obtains. It is essential then that the projection that more descriptive legitimacy will arise from the deployment of this institutional arrangement be put to test empirically. Whereas the normative legitimacy of the outputs of the institution can only be measured with reference to the substantive values that are at stake in specific cases and cannot thus be discussed at this level of abstraction, and the normative legitimacy of the procedure (i.e. input normative legitimacy) can and has been measured empirically in a number of ways that I summarized above, the descriptive legitimacy of the outputs⁸³ can be tracked via corollary institutions that host the potential expression of veto power that will be framed, in the following paragraph, as an institutionalized form of counterdemocratic power. These institutions complement the core institutions and provide insightful information concerning the actual enhancement of legitimacy that the democratic experiment yields.

Moderate epistocracy and counter-democratic vetos

In summarizing Rosanvallon's work, Donatella della Porta claims that "democracy needs not only legal legitimation, but also what he calls 'counter-democracy', that is a 'specific, political modality of action, a particular form of political intervention, different from decision making but still a fundamental aspect of the democratic process'" (Della Porta 2013, Ch.1, Conceptions and practices of democracy: an introduction). This implies that any sensible operational definition of democracy must account for circuits of surveillance outside institutions alongside processes of electoral accountability. To put it briefly, "democracy develops with the permanent contestation of power" (Della Porta 2013, Ch.1, Conceptions and practices of democracy: an introduction). According to Rosanvallon's reconstruction itself, in fact three metaphorical figures have progressively come to substitute the fiction (or the myth)

⁸³ Input descriptive legitimacy is not measured for reasons outlined in the end of Part I.

of the citizen as passive voter: “[t]he people as watchdogs, the people as veto-wielders, and the people as judges” (Rosanvallon 2008, Introduction). I am particularly interested here in the second metaphorical figure that ideally would help make sense of the growing role that “veto powers exercised in one form or another by social, political, and economic actors have come to play” (Rosanvallon 2008, Ch.7, Prevention and veto). This form of expression of negative power (neither authorizing authority, nor contributing to it) is still a proactive form of engagement that has little to share with the received view of anti-political populisms, which according to influential commentators such as Nadia Urbinati (2014) have a distinctively passive nature.

The reason why, in the age of the dawn of party politics and of a significant dearth of civic engagement, negative politics emerged as a recognizable trend is that coalescing, in the face of heterogeneity, against some given attempt at exercising authority is way easier than it is to organize positive action. Rosanvallon says it is easier for two main reasons: the first is that one ‘enemy’ overrides differences in membership of the coalesced and the motivations that make differently affiliated ‘rejectors’ can be disregarded for the time being, i.e. until we have this one ‘enemy’ to fight against; the second is that negative politics is very likely to achieve its results not only because negative causes more easily muster consensus, but also because their ultimate goal is undisputable and its accomplishment easily adjudicated (Rosanvallon 2008, Ch.7), at least more easily adjudicated than the attainment of vague long-term political and economic goals.

All of these remarks contribute to qualifying veto power as an essential contemporary source of legitimation for the exercise of authority. It is sensible then, to try and institutionalize dissent, so to say, in a way that renders it useful for our progressive theoretical purposes. My corollary institutions for bioethics will then be proper institutional loci for the exercise of the “democracy of rejection” (Rosanvallon 2008, Introduction) that try and provide a confined space for the expression of dissent with specific decisions in a way that also tracks more precisely the legitimacy-enhancing import of the core institutions.

In my hypothetical institutional arrangement, epistocratically crowdsourced legislation has direct and immediate efficacy, meaning that the only role that is envisaged for elected representatives is that of translating the policy into norms that are legally enforceable and harmonized with existing legal codes. The corollary institution meant to track the descriptive legitimacy of the output is then supposed to

work as a sort of second (or third, in the case of Italy) ‘popular’ chamber of the parliament that can essentially either reject the output or simply remain silent. Given what just said about the ease with which negative coalitions can effectively reach their aims, it is reasonable to set a threshold for vetoing some specific decision as a relatively high proportion of the voting share of the population. Hypothesizing, as I did, a *quorum* for the minimum amount of people that needs to subscribe to some issue so that this gets discussed at the 0.1% of the voting population, a meaningful threshold for the exercise of an effective veto would be set at the 1% of the voting population. A percentage to be reached within a limited lease of time after the legislation has been approved⁸⁴. All of these parameters are only tentative approximations that must be updated to reflect the actual levels of participation and be tweaked to reflect new insights arising from the experimentation itself. Even though tentative and arbitrary, the proportion between these two thresholds reflects the existing proportion (ten to one), in Italy, between the number of signatories required to uphold an abrogative referendum and the number of signatories needed in case the referendum is meant to present a so-called “legge di iniziativa popolare”⁸⁵.

Now that the institutional arrangement has been laid out in quite some detail, I rehearse some objections presented in Part I against participatory initiatives in science policy-making and clarify how these are countered, at least theoretically, by the institution as it is hypothesized.

Some objections and how the theory counters them

In The uncontested ideal of a publicly engaged science I highlighted common threads in the critiques moved to the ideal of a publicly engaged science and the related prescription of more participatory science policy-making. In what follows I specify how my normative proposal here sets out to counter these objections.

Open agenda setting

One of the easiest targets for critics of participatory initiatives has been the top-down and to a large extent arbitrary choice of the topic around which the initiatives revolve. These decisions have been critically framed as serving purposes other than the popular control of the scientific endeavor.

⁸⁴ In Italy this would mean asking for at least 350'000 veto wielders to express their outright rejection of the policy in its form, in, say, a month.

⁸⁵ Article 71 of our constitution requires 50'000 people to subscribe to a ‘legge di iniziativa popolare’ whilst article 75 demands that at least 500'000 people subscribe to formal requests for abrogative referendums.

Whatever these alternative—and however dubious—purposes might be, the process of selection of issues as presented above seems to sidestep this kind of objection. All issues are isolated via a process of open petitioning that responds only to the number of people that gather around them.

It is possible that, even when opened up for bottom-up participation, the reasons why people set the agenda for the discussion of controversial bioethical issues as they do are affected by and tend to reflect in suspicious ways interests that dominate the public sphere. In fact, the ways in which a country's societal agenda is construed within the public sphere might be objectionable in its own right. Economic and financial interests tend to percolate into the framing of issues as urgent as a result of the deliberate efforts that groups bearing those interests are able to put into making the issues perceived as urgent. However this seems more an objection to the way in which the public sphere performs (in this scenario, by Habermasian standards, quite poorly), rather than an objection to the indubitable improvement that letting people set the agenda for themselves would introduce.

The threat that the process of selection of issues is derailed for the reasons just hinted at is nevertheless worth of consideration. And it is therefore important to tackle this class of concerns suggesting that lobbying efforts be constrained in general so that they do not exert undue pressures on the agenda setting process. Concerns of this sort are already central to most prescriptions for a more tightly regulated self-regulating media system (see for instance Habermas 2006) and I simply follow in these footsteps in suggesting that they remain central.

Domination and information materials

I highlighted the republican nature of the core of the institutional arrangement and stressed the fact that epistocratic constraints may prevent undue forms of domination on the part of the incompetent. There is however a relatively subtler risk of domination that pertains to the institution as it has been presented, a risk that has been consistently underscored by critics of participatory initiatives: informational materials that are drafted by an organizing committee frame people's participation. The goal that these materials are supposed to fulfill is to brief participants concerning the issue that is being discussed. Supposedly, materials should offer an impartial point of view. However, this can hardly be the case when it comes to scientifically complex and morally controversial topics. The risk, then, is that the way in which materials present (whether deliberately or accidentally) the issue, already nudges participants towards one end of the spectrum of attitudes towards its regulation.

In our scientific competence stage, though, materials are presented in the form of Wiki-like documents that any participant can edit and contribute to. This has two important advantages that make for a successful reply to the objection: the first is that the objection according to which people are ‘primed’ into changing their mind in a specific direction can only stand for the very first participants that join in; the second is that it allows for the development of peer-to-peer conversations about the issue and about the ways statements are phrased, thus, in a sense, enacting the controversy that might lie behind apparently uncontroversial scientific judgments of fact.

In our moral competence stage, instead, participants are simply presented with a repertoire of arguments articulating any stance concerning the issue. Moreover, this repertoire is open to contributions by users who might find that some specific argument is missing. This is supposed to be only rough material that participants can use as references to make up their own mind and all arguments are therefore presented without any assessment, but only in their original form. It might happen that as a matter of fact, concerning some issues, publicly presented arguments that lean towards either the outright acceptance or the rejection of some practice are prevalent. Since these arguments are only meant to work as primers to the actual deliberative session, it does not seem to make sense to require that the repertoire of moral arguments be presented as ‘artificially’ balanced. Participants will discuss the issue for themselves and will be able to gather whether the skewed representation of arguments was due to a flaw in the presentation itself or was rather an honest rendering of the state-of-the-art of the debate.

The assumed societal goal of economic competition in the global market

A compelling argument that some STS critics of participatory science governance put forth submits it that the framing of issues in economic terms, specifically in terms of international market competition, has consistently hampered the openness of the discussion of these very aims as relevant aims that a polity ought to pursue. It is crucial, then, to highlight two features of our core institutional arrangement that have a bearing on this objection: (i) the foregrounding of the moral, as opposed to economic, issues that arise in connection with the problematic development being discussed and (ii), once again, the collaborative nature of the materials that inform the discussion.

As to (i), the explicit goal of the institutional arrangement is to discuss the moral boundaries that ought to apply to biomedical research and progress more generally, therefore it is sensible to assume that

economic reasons will play a secondary, if any, role in the arguments presented. This is not to say that arguments that leverage economic reasons to support a specific conclusion will be disregarded, but rather that participation encourages a moral perspective from which to appreciate and articulate arguments that might have some economic import.

As to (ii), the fact that materials informing the discussion are meant to be updated with user-generated content again makes a good case for any skewedness in the ways issues are framed, presented and discussed to be due to the participants' desires and mindsets. In a sense this works as an alibi in that the committee charged with setting up the consultation may always claim that any influence that their stance on the issue might have played could have been countered by the contributions of participants. However, it might be the case that someone's contribution is discouraged due to the initial framing of the issue (which might be suggestive, for some reason, of a specific stance on the problem). Say one perceives the issue to be framed in liberal terms and decides not to participate to the discussion given his own conservative background; this could possibly result in an imbalance in the part of the public that contributes to the deliberation. The undesired silencing of dissenting positions could reduce the groups' heterogeneity and favor polarization (Sunstein 2009). This fact points to the inescapable need for both a particular attention to the ways in which the issue itself is presented and for recruitment strategies that preemptively try and ameliorate the potential for wildly unrepresentative participants. This last point is tackled in Part III when I describe the recruitment strategy that we decided to resort to for our exploratory experiment.

Now that the political theory and its institutional implications have been laid out in quite some detail, we can turn to the last part of this work, which addresses head on the experimental challenges that we were confronted with, in an attempt at testing at least part of the hypothetical institutional arrangement just described.

Part III

A preliminary empirical test

Introduction

Moral disagreement in the Life Sciences has been presented as raising serious challenges as to its political management: on the one hand, technocratic solutions have been shown to lack the proper kind of democratic authority, on the other, some version of the so-called competence principle has been said to apply to this specific democratic quandary, therefore demanding that participation in science policy-making be *competently inclusive*, so to say. How to strike a balance in practice between competence and inclusiveness—keeping in mind the rest of the set of democratic values that we willingly subscribe to (amongst which, the efficient use of resources stands out clearly when devising participatory innovations)—remains a tough empirical question. I therefore laid out a tentative set of normative hypotheses as to how we could increase the legitimacy of political decisions adjudicating bioethical claims. The part of the thesis that follows presents the empirical work done in order to test at least part of the hypotheses laid out in the previous chapters. In Part II of this work I translated the normative hypotheses into a class of actual features of a specific institutional arrangement that might suit the democratic management of moral disagreement in the Life Sciences. Whether some of these features would work as (theoretically) advertised could unfortunately not be tested in practice. Therefore, the empirical results that I am presenting are only a starting point for further empirical work. This clear limitation is due to two main classes of reasons.

The first depends on the specificity of our project and is essentially economic in nature. Scant resources were allowed for the experimental part of the project, which meant hampering the recruitment of a properly representative sample of the population for the experiment. This is however, only partly a limitation to the study. Leaving economic issues aside, in fact, recruiting an incentivized and properly representative sample of the population would have meant losing part of the information that was instead gathered: specifically, we would not have had access to any knowledge about the kind of population that ventures to participate in this kind of initiatives, unincentivized and, in a sense, in ‘real life’ conditions. Essentially the experiment would have told us something more perspicuous about the mechanisms underlying participation and its effects in a toy model of the population, but it would have also told us very little concerning the actual population that engages in participatory initiatives.

Economic reasons resulted in at least one more serious limitation to the study, though: we had to forgo the possibility to test whether people who did *not* take part in the process that would grant

anyone willing to join, a chance to be heard, regarded our instrument as intuitively legitimacy-enhancing (at least concerning the issue at stake) and its output as legitimate. The chance to test one of the core features of the normative theory herein developed, i.e. the centrality of descriptive legitimacy to the project of progressive democratization of bioethics, as a result, was hindered⁸⁶. We could not and did not have access to any ‘experimental subject’ who did not spontaneously join in our experiment. This worrying deficiency is tackled head on further below.

The second class of reasons why we could not test a part of the hypotheses is particularly relevant if seen from the viewpoint of the political philosophy that this work is meant to adopt and foster: the sort of systemic and realist political approach to democratic theory that I have been articulating in the first two parts of this work requires that local hypotheses, i.e. tentative institutional architectures only locally implemented, be tested relying on a number of given conditions that render the institution under test reasonably comparable to its ‘competition’. Among these conditions, arguably the most important, is the proper bindingness of the output of the institution (i.e. the bindingness that the normative theory postulates for its output). I suggested that the output of the sort of open forums that we developed and tested had to be a set of guidelines that a representative Parliament ought to either implement or send back presenting detailed reasons why the guidelines in their original form could not be harmonized with the existing legislation. Also, I argued for the availability of what I previously called, following Rosanvallon (2008), corollary counter-democratic institutions, i.e. institutions for the expression of veto power by a reasonably sized subset of the population. In our case, unfortunately, the political impact of the initiative, if any, was feeble: no institutional representative took it up. Also, even though, as will be shown, participants apparently perceived the purpose of the experiment to be clear, the report that was meant to be produced via the tool, did not have any functioning in-built mechanism for post-test usage. In addition to the output not being binding in any relevant sense, and as a reasonable consequence of the decision not being binding, we could not put in place the institution that would host the expression of counter-democratic vetoes described above. We therefore did not test the institution as it would have worked in ‘real life’ in *this* empirical sense. However, the

⁸⁶ In case there was the chance to make use of an amount of resources compatible with the scope of this task, we envisage the submission of a survey to a representative sample of the population meant to gauge the degree of perceived legitimacy of a decision that would embody the recommendations drafted by participants in the deliberative institution. This could clearly be made into a more specific and telling sort of feedback in case the decision was actually implemented and the kind of tools for counter-democracy presented and discussed in Part II were in place.

lack of institutional support and uptake of the initiative allowed for a more measured assessment of the preliminary results that concern specific features of the project.

The experiment that I am going to describe must be conceived of as a field experiment, preliminary to the actual implementation of the institutional devices, meant to provide informative data about a number of relevant features of the normative theory that range from its factual appeal for the Italian population, to its more minute workings, e.g. whether and how the institution might change people's minds. Thus, standing by the theoretical framework for democratic innovations that I constructed in Part I, the results of the experiment will be taken as *prima facie* informative of the viability and tenability of some bits of the normative theory that I developed and will therefore result in a revised version of the theory itself. This revised normative theory will hopefully serve as a blueprint for the actual test in real life, i.e. a field study proper, of a new institution that is supposed to integrate the partial information that we managed to gather concerning the institutional innovation. Taking all that I said into account, the legitimacy of the institution was only preliminarily explored and no encompassing conclusion about it can be drawn at this stage.

Some of the data presented are indeed telling about what people expect and how they turn out to interact with the environment and with each other. Further tests are however needed and a more comprehensive scheme for local implementation of the revised cluster of hypotheses is in turn.

John Dryzek says that “[m]ost PhD dissertations typically conclude with a plea for further research” (Dryzek 2007, 250). Mine does not escape this commonplace. Still, I maintain I made clear why, in this specific case, this dissertation could not have ended on any bold definitive note even if I had managed to collect all the data that would have been relevant to the theory that I have developed: any democratic theory of the kind I advocate for here, is an attempt at perfecting some previously existing normative theories meant to work as hypotheses concerning specific democratic problems. The new theory is in turn the starting point for further efforts at making it even better and more informed to information about the legitimacy of experiment-like democratic practices.

Cautionary premise

In introducing this last part of the thesis I believe it makes sense to stress once more the role that democratic experiments play in the framework that I have been constructing so far and in empirically

oriented democratic theory more generally. In order to do so, I roughly introduce the discipline of experimental political science. In doing so, I show that some enthusiasts of the experimental turn in political science take a stance on the ranking of evidence which looks peculiarly similar to the hierarchical evidential standards of Evidence-Based Medicine (EBM) in its received view. This similarity, however, is limited in that there is no straightforward political translation of some of the features of EBM preferred experimental designs. I therefore follow McDermott (2002) and Druckman et al. (2011a) and build a case for a slightly less hierarchically ordered taxonomy of experimental designs and a less ‘algorithmic’ use of evidence in democratic theory. Secondly, I specify the ‘hybrid’ type of experiment that this part of the thesis reports on, one that has an RCT-like structure, with a self-selected sample. Anticipating the details of the experimental pipeline articulated further below, I then remark its most intuitively worrying weakness, i.e. that it lacks any implementation of counterdemocratic mechanisms to measure a substantial part of the empirical legitimacy of the institutional innovation put at test. Because descriptive legitimacy, as I previously defined it, is pivotal to the normative architecture that I have built, I could not underplay the absence of devices to track the part of legitimacy, i.e. descriptive legitimacy, that is, as I presented it, genuinely novel to my account. I will try and explain this absence making reference to what I call the ‘paradox of institutional commitment’ within a democratic experimentalist framework.

Evidence-Based democratic theory

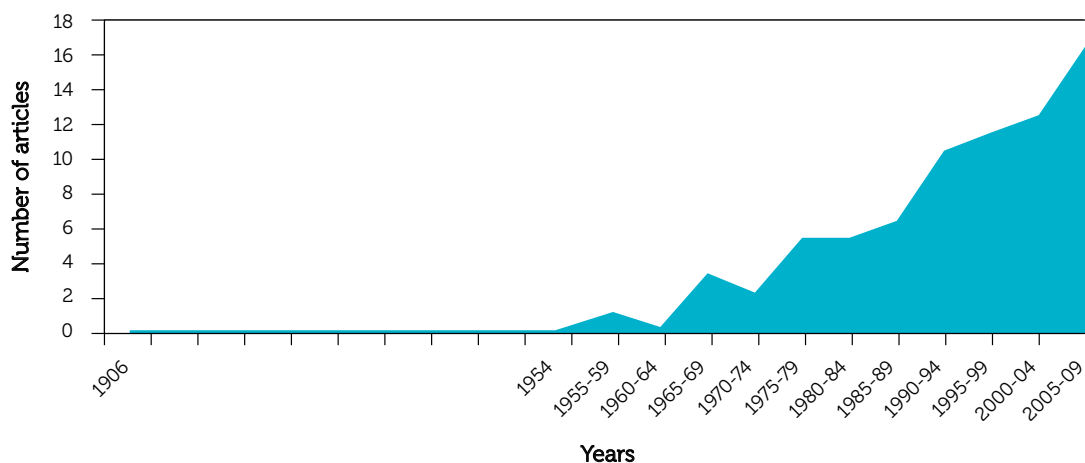


Figure 8 Experimental articles that were published in the American Political Science Review since its foundation. Adapted from: (Druckman et al. 2011b, 5)

Druckman et al. use the graph above to convincingly shows the extent to which political science has shifted towards a full-fledged experimental approach since the early 1990s. The number of

experimental papers published in the *American Political Science Review*, which is taken here to approximate trends in the whole field of political science, started to skyrocket in 1990 and grew steadily ever since. As a result of this disciplinary branching, political science seems to have, at least partly, inherited the evidential standards of Evidence-Based Medicine (EBM), which—as a self-proclaimed new paradigm in the history of medicine—emerged approximately during the same span of years (Howick 2011)⁸⁷. EBM, at least in its canonical representation, provides essentially rules of thumbs to stratify—or ‘rate’—sources of evidence according to the degree of confidence that they allow concerning the conclusion that they yield, i.e. it ranks evidence according to the degree of likelihood with which some study, or publication, reportedly supports the conclusion that a treatment has some recognizable, i.e. statistically significant, effect. Systematic reviews of published Randomized Controlled Trials (RCTs) sit on top of this hierarchy, followed by single RCTs, which in turn are more reliable than observational studies (which are considered reliable insofar as they show dramatic effects) and non-randomized studies, whose reliability still is higher than that granted by mechanistic reasoning⁸⁸. EBM evidential standards, as I said already, historically proved quite plastic: this plasticity led to their extension without the boundaries of medical research (Nardini, Annoni, and Schiavone 2012, 1001). However plastic though, such standards cannot be mapped precisely across disciplinary boundaries. In particular, experimenting with institutional design and policy-making has revealed trickier than straightforwardly randomizing a given sample to treatment and control groups⁸⁹. Despite the difficulties that are apparent in applying a similar ranking of evidence to medicine and experimental political science alike, there have been authors arguing that it makes sense to regard properly conducted experiments in political science as essentially superior sources of evidence. The Campbell Collaboration, for instance, asks authors who submit systematic reviews of intervention effect studies, to rank the quality of evidence they summarize, resorting to the so-called GRADE⁹⁰ (an acronym standing for Grading of Recommendations Assessment, Development and Evaluation) approach. This assessment is deemed optional in the guidelines, but it is interesting that the association makes explicit reference to GRADE as the method of choice to assess the quality of evidence. However interesting, it

⁸⁷ One notable example of the direction of the heritage can be found in the Campbell Collaboration whose scope and aims closely mirror those of the Cochrane Collaboration. See <http://www.campbellcollaboration.org/> (last access June 11th 2014).

⁸⁸ Roughly, these are the levels of evidence that the latest version of the Oxford Centre for Evidence Based Medicine’s “The Oxford Levels of Evidence 2” report. <http://www.cebm.net/index.aspx?o=5653> (last access July 11th 2014).

⁸⁹ Although, to be fair, even the standard depiction of EBM’s hierarchy of evidence has evolved and become more articulated over time.

⁹⁰ http://www.campbellcollaboration.org/artman2/uploads/1/About_MEC2IR_1.docx (last access July 11th 2014).

is unsurprising in that the guidelines have been drafted as an adaptation of the Cochrane Intervention Reviews. The GRADE approach clearly sees RCTs as studies of a higher quality than observational studies, and although the quality of the study can subsequently be lowered if risks of bias are identified in the study, it is noteworthy that the relationship between the two is clear-cut. Such a neat ranking is outspoken in the Campbell Collaboration Policies and Guidelines Document⁹¹. A key passage on page 9 reads:

“With rare exceptions, the best evidence [...] is provided by randomized controlled trials (RCTs). When RCTs are available for the relevant intervention, outcomes, and populations, they must be included in Campbell reviews.”

There at the very least two intermingled concerns that make this alleged ranking far from straightforward and which (combined with the reasons listed in the previous paragraph) informed our choice of conducting a hybrid experiment. The first has to do with what counts as external validity in democratic institutional experimentation, while the second accounts for one irredeemable shortcoming of experimentation in democratic practice: the lack of a properly defined control group.

External validity in democratic experiments

External validity is generally presented as referring to “the generalizability of findings from a study, or the extent to which conclusions can be applied across different populations or situations” (McDermott 2011, 34). Experiments that try and make effects visible and relevant, generally try to do so minimizing the potential disturbances to the measurement of the effect itself due to situational factors such as time, location, language, identity of the experimenters and so forth. This of course goes to the detriment of the generalizability of conclusions to populations other than those in exactly the kind of situation in which experimental subjects were. However, when it comes to experimental psychology, for instance, concerns for external validity can be somewhat restrained: some individual traits, the ones being investigated, can be assumed to be universal to the relevant part of mankind. A sort of ‘standard psychological experimental subject’ can be abstracted to some degree for experimental purposes; hence participants need only display some set of cognitive functions. When, instead, we want to single out the effects some institutional arrangements might have on some given population, it is difficult to

⁹¹ http://www.campbellcollaboration.org/lib/download/3308/C2_Policies_Guidelines_Version_1_0.pdf (last access July 11th 2014).

sidestep the issue of what counts as a sample that is representative of the actual population in a politically relevant context. An RCT in which the sample recruited for participation in an incentivized participatory initiative, representative of the population along standard demographic dimensions, is still completely uninformative of the actual people that will proactively reach out to participate to a non-experimental implementation of the same initiative. Such an experiment could be effective in making explicit effects that might never come about in normal circumstances for the simple reason that the experiment did not take place in those normal circumstances. The clearest example in this regard is the difficulty with which experimenters can endow institutions with the degree of bindingness they postulate or hypothesize for their output. The usual lab situation in which desired situational features are ‘reproduced’ and adjusted does not translate simply to the political domain: how could we feign the bindingness of decisions that our democratic innovations will yield? After all, paradoxical as it may sound, there are some features of democratic experiments that cannot be made to depend on experimental choices. I will explore more in detail this apparent paradox below and show that it is, in a sense, inescapable. As far as this paragraph is concerned, suffice it to say that the hardships of obtaining results that are properly generalizable calls for a more ecumenical methodological stance. In particular, as it has been argued (McDermott 2011), it makes a good case for systematic replication of experimental implementation, rather than abstraction, as a way to improve our knowledge about the functioning of democratic institutions. This can be achieved primarily via the kind of dialectic between local initiatives and societal master plans that is original to some democratic experimentalists (Cohen and Sabel 1997; Sabel and Zeitlin 2008; Sabel 2012) (and which I presented and elaborated on in Part I).

Control groups in democratic experiments

Given that this is the backdrop against which to construe a proper experimental setting for democratic innovations, it is hard to conceive of a sensible definition for control groups, i.e. groups of people who do not undergo ‘treatment’. The only way to experiment ‘in real life’ with control groups is to have a population randomized to two competing institutional arrangements, one of which is presented as ‘standard’. But how could we randomize a population, within the same area, to two different groups and ask that each of those be subjected to decisions taken via democratic machinery either

experimental or standard? What political geography would this solution give rise to? More importantly, could we compel people to stick to one group in case they were not willing to do so?

If, as I maintain, there is no sharp and ethically acceptable way to accurately split a community in two random subsets to see whether some institution works better than the ones we have today, then it makes sense to give up on that idea altogether and conceive of a different and less hierarchically organized taxonomy of experiments in democratic practice. This taxonomy is presented below along with the reasons why we did in fact make use of an RCT-like experiment for a preliminary implementation of a potential democratic innovation.

However, for the very reason that we grant this point, i.e. that no control group makes sense for actual democratic innovations, we might be confronted with the serious issue of having to assess those innovations without reference to any counterfactual scenario, which is the main purpose of having a control group. These, in common language, are straightforward reforms. Having reforms as experiments, could however effectively lead down a path where experimental political scientists get to substitute for political philosophers enthralled by the platonic dream of a society developed around their ideas of what counts as justice, goodness, fairness (Walzer 1981). In fact, the only way to effectively experiment with democratic innovations would be to have a fairly blind sort of prior institutional support, one that would grant those innovations' output real bindingness regardless of the content of the output (unknown upfront). This kind of support, however, is only likely to happen when the interests of the experimenters and those of the institutions that support their efforts overlap quite substantially. But were this happens, however desirable, this would intuitively entail some degree of resistance to the uptake of information that goes contrary to a negative reception of the innovation itself. Already in 1969, Donald T. Campbell (D. T. Campbell 1969) very well summarized this concern in what I call the 'paradox of institutional commitment' of a democratic experimentalist framework. A paradox that is deeply entrenched in the institutional arrangements of representative democracy and one that still threatens the possibility that anything like genuine institutional experimentation will ever become a reality. With a slightly positivist overtone, Campbell claimed that "[t]o be truly scientific we must be able to experiment. We must be able to advocate without that excess of commitment that blinds us to reality testing" (D. T. Campbell 1969, 410). However, the area between excessive ideological commitment and insufficient institutional support seems very hard to single out neatly.

Also, it looks like a peculiarly small area: in fact, on the one hand strong and interested institutional commitment seems to be a requirement for experiments to have the highest external validity possible, i.e. we want these experiments to mirror conditions that would apply to actual political life, therefore granting the kind of political efficacy that we want these innovations to be provided with. On the other, granting support and the sort of political efficacy that we hypothesize for the institution entails that any undesirable result (both in terms of output and assessment of the merits of the procedure) will be more likely to be hidden and/or discarded as irrelevant or due to some alleged confounding factor. In a nutshell, it is more likely that the experiment will be used instrumentally to some ideological purpose. Within this thin area going from ideological blindness to institutional disinterest ought to move any proper democratic experiment, and the experiment we set up was no exception. Its methodological structure depends mostly on the degree of institutional commitment that we managed to muster prior to the experiment, and that was compatible with the scientific, experimental purpose of the initiative. In the remainder of this cautionary premise I try and define the kind of experiment that we put in place, highlighting its strengths and weaknesses.

The kind of experiment we performed and why

Even though deliberative democracy had become, according to Dryzek “the most active area of political theory in its entirety” (Dryzek 2007, 237) already in the early 2000, it is only in the last few years that empirical claims have gained full citizenship within deliberative democratic theory. Our experiment adds to this fairly new tradition, trying to measure the effect of a specific online institutional arrangement on the realization of values central to deliberative democratic theory. Our attempt can effectively be construed as an effort to set up the kind of mixed discursive sphere that, following Hendriks (2006) was presented in introduction as a political device meant to bridge the gap between debates hosted in formal loci of governance and those entertained within informal spaces inhabited by ‘the public’.

To better understand what our study aims for, I now briefly reconstruct a taxonomy of experimental methodologies in political science and explain which one we deployed and why.

McDermott provides a taxonomy of methodological approaches to experimental political science which very much overlaps with the one presented by Druckman and colleagues in introducing their *Cambridge Handbook of Experimental Political Science* (Druckman et al. 2011a). She distinguishes between

laboratory studies, field studies and field experiments (McDermott 2002). The first are experiments proper, in which the experimenters make sure that no condition other than the treatment changes between groups. However, in these studies external validity is generally little, due to the constraints introduced to have treatment and control groups with the least differences possible. Field studies, instead, lean clearly on the side of external validity, in that they “typically look retrospectively at the effect of naturally occurring events” (McDermott 2002, 32). Of course, the identification of causal mechanisms in field studies can only be tentative, provided that no control group exists for the natural events that occurred. Field experiments try and strike a sort of trade-off between concerns for internal and external validity, affording some control over the conditions but also sacrificing some degree of generalizability from the experimental to the natural setting. Each type of experiment has specific advantages and drawbacks and, as I said, their use can only be assessed pragmatically, i.e. relative to the needs of the experimenters.

In our case, the kind of investigation we wanted to conduct, given the scarce institutional support we had, had to be a preliminary analysis of the technological merits and limitations and of the values that can be realized using an e-democratic tool to address ethical issues arising from specific instances of biotechnological progress. We however also wanted to preliminarily track the magnitude of the interest that similar initiatives might arise and the kind of people that could be drawn to these. In order to combine these two needs we opted for a field experiment. We tried to maintain the higher control possible over the treatments to which members of the various groups were exposed, therefore implementing an RCT-like structure, but in as much as we had little control over the recruitment of the sample of participants, what we conducted was really *only* a field experiment.

In what follows I introduce the theoretical background of the experiment and describe in full detail the pipeline of its design and construction. Then I proceed to describe and comment on the results.

“bioeticadeliberativa”

Democratic theorists and practitioners alike, have grown interested in the possibilities opened up by a class of innovative technologies that might have supported the longed for shift towards digital democracy (Coleman and Shane 2012; Coleman and Blumler 2009; Fung 2003; T. Davies and Gangadharan 2009). This alleged shift, ideally supposed to be happening thanks to ICTs, has been consistently suggested as a potential solution to renown issues that affect representative democracy as we know it: essentially legitimacy and trust issues revealed, for instance, in low electoral turnout rates and recurring popular outcries. These technologies, at least so the promise goes, would ameliorate or even defeat completely those issues. The technical grounds that they create for genuinely novel participatory practices, would be capable of easily scaling up to an entire polity, therefore amending distrust in democratic institutions and allowing for more radical forms of democracy.

This promissory landscape, however, has so far remained mostly what it was in the very beginning: somewhere to look forward to. The democratization of the public sphere that would follow the technological disruption of the media system has proven hard to be empirically supported. In fact, some years ago, a relatively young scholar, Matthew Hindman, showed that, regardless of whether it *might* have done so, the impact of the Web on the media had *not* resulted in the kind of narrowcasting of information (i.e. the unmediated generation and distribution of content by users, to users, as opposed to media outlets broadcasting the same content to mass audiences) that had been prefigured as a remedy to the domination of the public sphere by socio-economic élites. This very problem affects the newly shaped public sphere in the form of a “Googlearchy” or the “rule of the most linked” (Hindman 2009), in which big media outlets still dominate the scene and user-generated content only makes it to ‘the news’ when ‘the news’ decide to pick up on them. Moreover, influential individual political bloggers that might indeed make a difference—capturing broad audiences without anyone attending at and vetting what they decide to say—happen to be just new members of the old gatekeeping élite, e.g. upper-middle class white male, lawyers, Ivy League graduates, former journalists (Hindman 2009).

Jane Mansbridge has suggested that the public sphere (Mansbridge 1999) articulates along a continuum that goes from informal to formal loci. Smith’s definition of democratic innovations—i.e. “democratic devices that provide citizens with a formal role in policy, legislative or constitutional decision-making”

(Smith 2009, Introduction) roughly fits this latter category. These innovations, when they leveraged on ICTs, even in their best attempts, have failed to engage significant, and/or representative portions of the populace. Furthermore, since each initiative deployed a different design, their impact resulted hard to gauge and even harder to compare (Abelson et al. 2013). Projects such as Participedia⁹², for instance, have tried to remedy to this lack of systematicity, to the advantage of democratic practitioners willing to design participatory initiatives grounded in evidence. Unfortunately, so far, Participedia has had unclear results.

I previously presented my own reasons why the further democratization of politics, i.e. the continuous experimentation of new democratic institutions, is fundamentally desirable and why this progressive process of democratization concerns bioethics as well, as a political endeavor throughout. I also suggested the direction towards which a more democratic bioethics ought to go: competent bottom up participation. I maintain—and I previously showed some reasons why this makes sense—that ICTs still hold some promise if used properly and to tackle the right kind of problems, and have therefore suggested that using online tools to support deliberative democratic initiatives in bioethics, might be a way forward in a desirable process of democratization. Against the backdrop sketched above, which advises prudence and skepticism as to the existence of some sort of technological silver bullet, I argue that a properly deliberative democratic arrangement can fruitfully push forward the cause of democracy in bioethics.

In what follows I offer a rejoinder of the normative standpoint from which the participatory process is supposed to be seen and then proceed to present the details of its implementation.

The normative standpoint: a reminder

John Dewey first published his *The public and its problems* (Dewey 1954, 31) in 1927. It was a direct reply to Walter Lippmann's *The Phantom Public* (Lippmann 2011). Lippmann had voiced serious reasons for a radical form of skepticism in democracy. Oddly enough, the reasons for concern in democracy that Dewey was trying to counter back then were very similar to the ones that characterize elitist and technocratic stances on democracy today: a disquietingly low voter turnout, widespread indifference to

⁹² Participedia is meant to bring together democratic theorists and practitioners. Its outspoken purpose is to gather data about a range of initiatives, to construct a public repository of knowledge about democratic practices to be used by policy-makers and activists. <http://participedia.net/> (last access August 7th 2014).

politics, disaffection with it, the swiftly changing preferences of the public and their the uninformed emotional outcries, the detachment of candidates' electoral fate from their political expertise, the influence of "Big Business" on electoral outcomes and on enacted policies. This had to be seen as coupled with the mounting complexity of matters that were starting to become part and parcel of what is today known as science and technology policy-making. Looking at both trends jointly, apparently made (and still seems to make) a forceful case for some form of technocratic government of those complex issues.

Dewey himself lamented the disrupting impact of "[s]team and electricity"—standing metonymically for industrial progress—on traditional modes of social cooperation (Dewey 1954, 141)⁹³. This was the hardest way to object to technocratic and elitist drifts: sharing Lippmann's premises, to prove him wrong about his conclusions. In fact, Dewey went on to argue that the solution to the disarray between technological progress and social practices, institutions included, was not the further removal of policy-making from the subjects of political authority, but rather the nurturing of a more progressive public sphere, better prepared to generate collectively binding rules in this unprecedented societal context.

Of course, simply assuming that having more representative democracy would suffice to remedy the problems of representative democracy itself was naïf and ill-posed. Dewey himself was convinced that suggesting "the evils may be remedied by introducing more machinery of the same kind as that which already exists, or by refining and perfecting that machinery" (Dewey 1954, 144) was preposterous. The suggestion that Dewey put forth was rather that of reforming the "Great Society" brought about by technological changes (a society with increasingly specialized and secluded classes of cognitive workers and with an unheard-of wealth of differing moral views) so as to have it resemble a "Great Community" in which people belonging to sparse groups with differing and conflicting interests and values, ought to share their views respectfully.

Nowadays, liberal democratic theorists such as Nadia Urbinati charge the Web with having compromised the normal course of public opinion formation. As she provocatively recently put it, new media apparently disfigured Western democracy, deforming one of its essential phenotypic traits, i.e. the workings of traditional mass media, with certified gate-keepers and properly working bottleneck

⁹³ As I recall below, Dewey suggests that the problem is clearly not with pace of technological progress, but rather the failure of democratic institutions to take up such progress and evolve, thus letting ideas and ideals lagging way behind technology.

organizations such as political parties, trade unions and the like (Urbinati 2014, 16). Indeed, it has to be conceded, today's talk in the public sphere seems affected by evils peculiarly similar to those that affected democracy between the two world wars: loud public outcries, scarce participation and a drought of political engagement in general. Dewey's proposal thus looks as promising today as it did almost a century ago. In fact, the failure of recent attempts at fostering a more participatory kind of democracy might be due to the misdirection of the efforts that genuinely motivated activists, institutions and practitioners. They are being misguided into what can be recognized, with Dewey's words, as an attempt at "introducing more machinery of the same kind as that which already exists". In fact, even when they have been deemed successful (sometimes rightly so, in terms of absolute numbers of participation), initiatives to merely consult the population have failed to gain traction due to their scarce representativeness of the participants.

The most astonishing example, in Italy, was the recent *partecipa*⁹⁴: launched within the agenda of the Monti cabinet⁹⁵, it mustered more than 200'000 surveys about a relatively complex issue, i.e. how to reform our constitution. These surveys, essentially multiple-choice questions accompanied by information materials, were all filled and submitted online. The consultation was widely advertised and financially supported by the Ministries involved⁹⁶. Once handed over to the highest political offices the thorough report summarizing its results, though, had negligible impact onto actual constitutional policy-making.

One of the reasons why this might have been the case, seems to me clearly linked to the nature of the consultation: in its essential traits, it did not differ significantly from a standard market survey, meant to provide 'demand' input, into political 'supply'. Framed in this commercial terms, the unrepresentativeness of the sample (and its modest size as compared to the entire population with voting rights—more than 45 million people⁹⁷) might have given rise (and rightly so) to complaints by those who disagreed with the outcome of the consultation itself. And this is in fact what has happened

⁹⁴ <http://www.partecipa.gov.it/> (last access August 10th 2014).

⁹⁵ The initiative ended after the government had been replaced by Enrico Letta's premiership.

⁹⁶ The report is publicly available at http://www.partecipa.gov.it/assets/PARTECIPA_Rapporto_Finale.pdf (last access April 4th, 2014).

⁹⁷ As measured for the latest political elections. Data can be found here:

http://www.interno.gov.it/mininterno/export/sites/default/it/assets/files/25/2013_02_07_Guida_alle_Politiche_Servizio_elettorale.pdf (last access April 4th, 2014)

in some notorious cases such as the “GM Nation?” consultation in the UK (S. Campbell and Townsend 2003; DTI 2003; Horlick-Jones et al. 2007).

The composite and articulate nature of political legitimacy that I have outlined does not offer a simple answer to what would have yielded more legitimate outcomes (and, in a relevant sense, this is a question that does not make sense asking in the abstract within the framework I built). However, the introduction of some mechanism to allow for the horizontal, peer-to-peer exchange of reasons that ground some course of action over some others within these consultive initiatives might have helped. Their implementation is of course crucial for a number of reasons I showed following Thorpe’s critique (Thorpe and Gregory 2010; Thorpe 2010). However, I also presented arguments supporting the view that competent deliberation by anyone concerned with the issue might be worth some more tries. Upstream deliberative engagement, in a sense, can be a way to provide representative institutions with the reasons that ought to be taken into account, and ideally *formally* accounted for, whenever public choices are taken vis-à-vis some form of more or less radical moral disagreement. This is obviously compatible with democratic innovations aimed at fostering a sense of ‘Deweyan’ communality. It is also complementary to the kind of democratic innovations—counterdemocratic in nature—that might render descriptive legitimacy more immediately visible and offer a chance to veto illegitimate decisions, however deliberatively reached.

ICTs are an intuitive solution to the issue of cost-containment of such democratic experiments and they also provide immediate access to every citizen, anywhere, when he/she has time (even though, as I will show below, it is controversial to what extent this is true both in theory and in practice). Furthermore they can create an unconstrained (online) space for large communities to develop. These advantages have been proven hard to attain in democratic experiments, but fairly little is known as to why and what went wrong in the few cases in which online deliberation in asynchronous forums was attempted. This last part of my thesis tries to contribute to this knowledge and to provide some insights as to the direction towards which these experiments should move.

Dewey would write that “[t]he creation of adequately flexible and responsive political and legal machinery has so far been beyond the wit of man” (Dewey 1954, 31), apparently trusting that one day such experimentalist governance would be within the reach of the wit of mankind. We submit it that today it is indeed the case that experimentalist forms of governance are an ideal to which we can

approximate in practice. But this is only if we act upon the belief that institutions are devices through which we cast hypotheses as to what can enhance democratic legitimacy.

Our online instrument was supposed to enable the sort of mass, collaborative and deliberatively discursive finalized efforts that might ameliorate some of the ills of contemporary democracy when faced with scientifically and ethically complex issues. Whether it could do in practice was an empirical question that we therefore preliminarily asked empirically.

In what follows I describe the organization involved in the project, the process that led us to the actual design of the tool (both as it ideally ought to look like and as it was actually implemented) and the strategies for recruitment.

The working team

“bioeticadeliberativa” was constructed as a joint venture between *Scienza in Rete*, an online magazine devoted to the popularization of science in Italy, the research group in Biomedical Humanities belonging to the department of Experimental Oncology of the I.R.C.C.S. IEO (European Institute of Oncology), the Genome Function Unit of the San Raffaele Scientific Institute and the Laboratory for Civic Informatics of the department of Computer Science of UNIMI (University of Milano).

The working team was structured in subgroups with different non-overlapping functions. This structure of governance was made publicly available throughout the consultation (and it still is as of June 2014) on the website that hosted the initiative⁹⁸. Here each of these subgroups is introduced in its functions and their components briefly presented.

Advisory panel

The advisory panel was meant to oversee both theoretically and scientifically the project and to provide, once the project had been closed and the report prepared, the proper kind of institutional impact. The decision not to appoint any politically relevant figure to the panel was deliberate and aimed at characterizing the initiative as little as possible in terms of political belonging. This was also an attempt at conveying the message that everyone was more than welcome to participate. Such an attempt was also pursued at recruitment stage, when deciding through which channels to advertise the initiative (see

⁹⁸ In Italian, here: <http://bioeticadeliberativa.scienzainrete.it/chi-siamo/chi-siamo.html> (last access June 17th 2014).

below). Members of the panel were Giuseppe Testa, head of a research group focusing on the epigenetics of tumor and deputy director of the Biomedical Humanities group, both at the department of Experimental Oncology at the IEO; Matteo Mameli, reader in Philosophy at King's College London, who has a specific interest in the Ethics of Science & Technology and has recently joined a lively debate on the democratic import of populisms in Italy; Luigi Bobbio, professor of Political Science at the University of Turin, expert in the field of analysis of public policies and of the relationship between local and central governance, whose main research interest is in deliberative democracy; and Damien Lanfrey, Visiting Lecturer at City University, London, who acted as a consultant to the Monti cabinet for a number of e-consultations (amongst which the highly successful *partecipa!*⁹⁹) and currently advisor to the “Amministrazione Regionale dell'Emilia-Romagna” for innovation policy.

Scientific-technical group

In the scheme, i.e. the UML-compliant activity diagram presented below, this second subgroup goes by the name of “Board of experts”. These are the professionals responsible for the scientific integrity and the accessibility of the contents uploaded on the website. They were also supposed to provide support in answering the doubts and perplexities of participants and give reasons for the way contents were formulated and framed and, in case it was deemed appropriate, help participants rephrase and integrate specific passages. The group featured Paolo Maugeri, PhD, researcher at Università degli Studi di Milano, teaching bioethics in a number of universities, Michele Loi, PhD, currently Post-Doc at the Universidade do Minho in Portugal and part of the Citizen's Health through public-private Initiatives: Public health, Market and Ethical perspectives (CHIP ME) COST Action network¹⁰⁰, Elia Stupka, PhD, head of the Genome Function Unit at the San Raffaele Scientific Institute, Cristina Gaviraghi, professional popularizer of science and scientific journalist and Luca Carra, co-director of Scienzainrete. I was also personally involved in the drafting of materials and I provided responses to questions, prompts and queries by the participants.

⁹⁹ *Partecipa!* is an online public consultation held by a team of experts supporting the Minister of Constitutional Reforms, Gaetano Quagliariello, in the set up of a process of thorough reform of the institutional architecture as outlined in the Italian constitutional provisions. The project, however successful in garnering widespread and diverse participation failed to have any traction on the actual policy-making, also as a result of the discontinuation of the Ministry. A summary of the consultation, in Italian, can be found at <http://partecipa.gov.it/> (last access June 17th, 2014).

¹⁰⁰ The description of the project can be found at http://www.cost.eu/domains_actions/isch/Actions/IS1303 (last access June 17th, 2014).

Project responsibility

Prof. Giovanni Boniolo, head of the Biomedical Humanities at the department of Experimental Oncology at the IEO, prof. Fiorella De Cindio, head of the Civic Informatics Laboratory, Roberto Satolli, president and founder of Zadig and Elia Stupka, head of the Genome Function Unit at the San Raffaele Scientific Institute were jointly responsible for the project.

Design of the tool

The deliberative process

A UML-compliant Activity Diagram (Fowler 2003) describes the ideal deliberative process that we planned to deploy. The structure of the diagram (and thus of its underlying workflow) represents the revision and expansion of the theoretical precepts laid out as a set of deliberative criteria by Boniolo, and Boniolo and Di Fiore (Boniolo and Di Fiore 2010; Boniolo 2012) articulated in Part II. In particular it embeds directly in the technological support a requirement for scientific competence and ethical reasoning. I already provided an argument why this is believed to enhance the discussion rendering it democratic and deliberative in a genuine and proper sense.

Colors in the diagram below refer to different categories of actors (blue for the owner of the process, green for both the board of scientific and ethical experts and red for participants), whereas the shape of the boxes is used to signal actions (rectangles) and objects (circles). Cylinder-shaped boxes denote pools of data collected at specific time points from specific sources.

The process as it is described in this section is presented as an abstract model of the participatory workflow that does not take into account technological limitations that emerged later on while designing and implementing the actual platform. This one time experimental purposes as well are not accounted for in this design, which is therefore meant to explain how the process should abstractly work. This is why below I review existing technologies and subsequently describe the *actual* functioning of the online environment supporting our experimental deployment of the process making use of the technology we chose. This distinction between an ideal process and its experimental counterpart will become clearer as we define the experimental design, which informed some additional desiderata.

Participation to this ideal process is articulated in two consecutive stages: the first in which the agenda for online consultations is set, the second in which the actual deliberative participation takes place.

Each of the stages is further divided in a series of phases. Another conceptual clarification is in order before tackling the details of the workflow: in what follows we rely on this conceptual partition: *topics* are broad areas of interest (e.g. abortion), *issues* are problems falling within specific topics (e.g. whether abortion is permissible after the 14th day since conception) and *questions* are relative to proposals tackling one issue or another (e.g. “Ought we to use embryos for the derivation of stem cell lines for research purposes?”).

Prior to both stages, all participants, when registering on the platform, are asked (but not required to) report on their essential socio-demographic traits such as gender, age, geographic area, income, and education. This rudimentary and rough profiling of those who participate differs from the more in-depth attempt at describing the sample of our experimental subjects recounted below. However, giving up completely on profiling participants seems undesirable even at later stages of experimentation for each participatory initiative is always meant to be informative of future implementations.

The whole ideal process is hosted in an environment completely open for participation to anyone who wishes to join. Because of this, some difference in the participating population might be lost as compared to the overall population (self-selection bias will play a role in case participation is left open). There are reasons why also this effect is undesired: first, like-mindedness of the group might polarize decisions, leaving people with more extreme opinions than they had before the encounter (Sunstein 2009), second, minorities, whatever their nature, might be *de facto* excluded while having formal access to the environment in that disempowered to participate effectively, finally, the important *deprovincializing* effects associated to ‘hearing the other side’ (Mutz 2006, 68) might get lost along with the differences. Such undesired effects of openness need therefore to be countered by attempts at what Archon Fung among others calls *selective recruiting* (Fung 2006, 67). This process consists of specific efforts targeted at the recruitment of traditionally disengaged and unfairly excluded populational subsets, e.g. the young and the elderly, ethnic minorities. For our experiment we tried, within the limits of our best efforts and with very limited results, to selectively recruit the young and the Catholics: the former with a current low engagement rate in politics and the latter assumed to be suspicious of our project due to the sponsorship of “Scienza in Rete”, a magazine advocating pretty outspokenly for laicism.

A further worry associated to an open online forum is that it is indeed online, which might act as an additional barrier to participation, further affecting the already worse off. It is worth noting in passing that one of the most intriguing arguments against open participation to forums that are exclusively online submits it that the formal openness of the forum cannot make up for some subsets of the populace's lack of proper skills for participation¹⁰¹. There are two ways to interpret this argument: the first interpretation focuses on the lack of infrastructures (in this case household internet access), that affects some strata of society; the second interpretation points to people's insufficient individual skillsets, regardless of the availability of the infrastructure. I take the nature of both these objections very seriously, and am convinced that they both imply that whomever experiments with online participation has to do their best to involve *bona fide* targets of systematic exclusion providing both skills and infrastructures. However, this means primarily that public engagement initiatives ought to pursue infrastructural and educational purposes along with their other explicit goals and not so much that one ought to postpone engagement initiative, waiting until the whole population is technologically enabled and has the proper skillset for participation, whatever that may be. In particular I believe that forgoing the opportunity for online democratic participation experimentation for bottom-up input into policy making on the grounds that some people do not have access and/or cannot browse the Web properly would be somewhat akin to arguing against universal suffrage on the grounds that some people cannot read and write properly. Reading and writing can indeed be regarded as minimal requirements for the meaningful expression of one's preference. At the beginning of the XX century, in Italy, there have been institutional sources claiming (*Suffragio Universale E Analfabetismo. Appunti Statistici* 1911) that extending the franchise without educational thresholds would cause mayhem as a result of the vote of the illiterate part of the constituency (back then a consistent part—more than 40% of men older than 21 were illiterate—of the overall population). More specifically the argument put forth was that regardless of the actual capacity of these voters to understand whom they were voting for or why, their meaningful participation was threatened by their lack of access to information sparse in the public sphere and only accessible to those who enjoyed some degree of literacy. Seen in retrospect, this kind of arguments look pernicious in that it deliberately delays the extension of fundamental rights on the grounds that the state has so far proved incapable of furnishing everyone

¹⁰¹ While presenting this project within and without our research group, I got this provocative question a lot.

with the best tools for the proper enjoyment of those very rights. The situation in Italy in 2013 as to Internet access and Internet use resembles in relevant respects that of reading and writing skills at the turn of the century. Only the 54.8% of people aged 6 or older have accessed the Internet in Italy according to the last data available (2013) through ISTAT¹⁰². Although this figure does not convey a dire picture, the inequality in the distribution of this resource, with an impressive North to South gradient (58.9% in the North of Italy and 47.7% in the South) and a similar gradient along income distribution (a fork of 17 percent points, in 2012, divided families whose main source of income came from enterprise or freelance work, from working class families (ISTAT 2012)) makes the portrait more worrying than it may appear at first.

A more equal and widespread distribution of Internet access is arguably one of the most fundamental targets for the development of our country. In part also because this might work as an enabling factor for e-democratic forms of engagement. Nonetheless, the worry that people might participate unequally as a result of the current unfair distribution, must not stop our attempts at experimenting with forms of online participation which might realize the kind of democratic values that we strive for. Essentially, as I argued, this issue should not justify postponing democratic efforts, just like illiteracy ought not to justify not extending voting rights to the whole population.

1. Agenda setting

1.1. *Selection of the topic(s)*

Participants cast votes on their favorite topics for consultation (they are selected from a given list of items and participants have a chance to add new items to the list, which will then become available as options to other participants). The possibility to have an open agenda for discussion is both crucial to the legitimacy of the deliberation, and crucially vulnerable to undesirable effects. In particular the salience of issues might be unduly distorted by the influence of leading mainstream sources of information (also known as the *agenda-setting effect*) whose incentive to give voice to existing popular concerns is unclear. Furthermore even though broadcast media's persuasive powers, i.e. their capacity to mold and actively change attitudes towards specific

¹⁰² All data referenced to ISTAT can be obtained querying the relevant database at <http://dati.istat.it/> (last access June 8th 2014).

subjects, have been substantially contested and progressively underplayed by some (as reported, for instance, by Zaller (1996)), their effect on the urgency that the public perceives as attached to specific issues is held to be direct, sizeable and uncontroversial (it is well-documented since at least the 1970s, see for instance (McCombs and Shaw 1972)). Counteracting this class of potential undesirable effects is a goal that cannot possibly be accomplished by the means of a single institution (or class of institutions for that matter) only, for they are the consequences of phenomena inherent in and dependent on the distribution of power within our society.

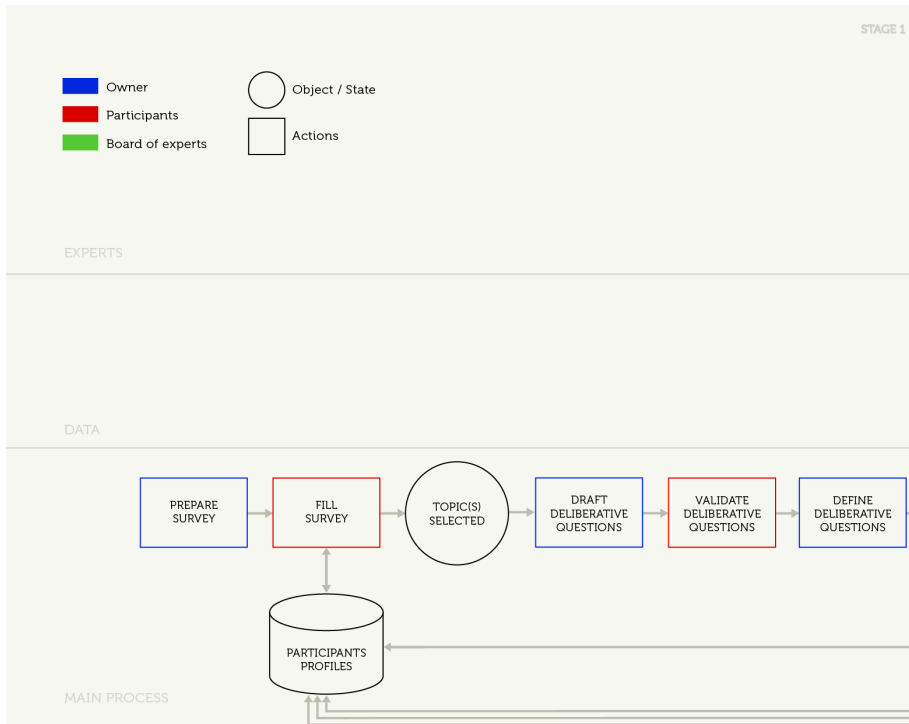


Figure 9 Activity diagram outlining the ideal participatory process: stage 1.

Previously we argued, following Mark Warren (2012), that it makes very little sense to conceive of competing and mutually exclusive models of democracy from which to derive an abstract institutional architecture that would best suit the model’s normative assumptions. Instead, we proposed that it is reasonable to deploy a sort of problem-based approach to democracy, one that singles out democratic devices that seem to suit the specific democratic shortcomings that need to be addressed resorting to some specific democratic remedy. Along these lines, the issue of the influence of mass media on the perception of the ‘current’ agenda for politics ought to be addressed, but it would be unfair to put the burden of correcting potential distortions on the democratic participatory device that we are presenting here. The possibility to instruct the agenda for discussion from the bottom up, has on the other hand the indubitable merit that, given a

roughly well-ordered public sphere (including a media communication system that works properly and is not systematically subjected to undue pressures by elites or influential minorities), it grants citizens a chance to have a say on the very issues that they want to discuss and/or be discussed publicly.

1.2. *Validation of the question(s)*

The most voted for topics are selected for consultation and, concerning each of those topics, a scientific committee isolates relevant issues, drafting a number of relevant *deliberative questions* about each issue. This first formulation of the questions might be biased, partial or unclear. Furthermore, some relevant questions might have been unduly left out (it does not really matter, for our purposes, whether these two mistakes happen deliberately or accidentally: the procedure is meant to screen out both biases independently of the committee's will). Thus, participants are asked to provide feedback on the formulation of specific deliberative questions provisionally drafted by the scientific committee and concerning the issue(s) belonging to the topic(s) selected for consultation. The bottom-up input into the formulation of the questions is allocated a given span of time. After that the committee needs to rewrite the questions presenting them in a new form: this is supposed to take explicitly into account any doubts and perplexities voiced by participants in the previous phase. The consultation is then set up around those questions, in this form.

2. Deliberative participation

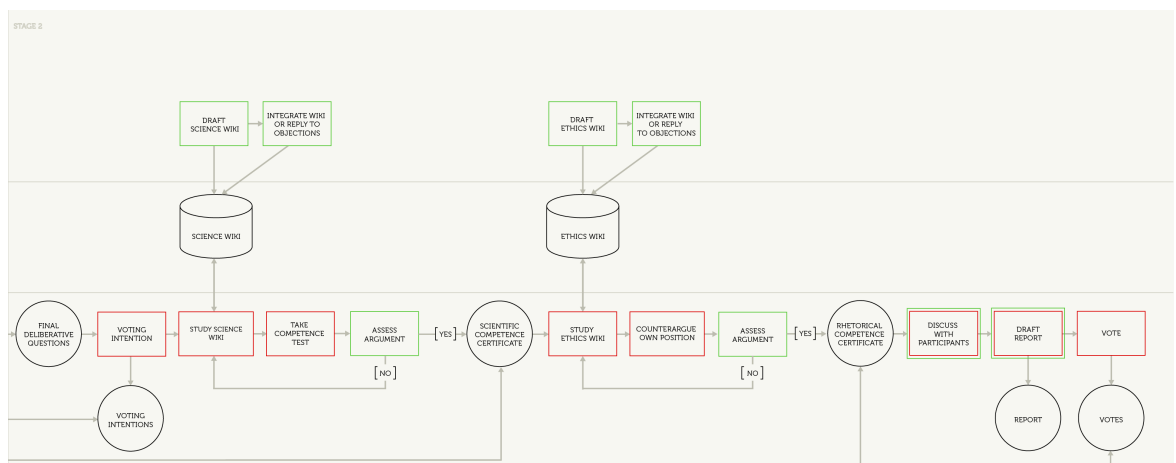


Figure 10 Activity diagram outlining the ideal participatory process: stage 2.

2.1. *Uninformed preferences*

Deliberative questions are introduced to participants (note that participants who did not contribute to the selection of the topics or to the validation of the questions can still participate now) by scant information about the issue the question is relative to. The information puts the question in context and highlights the overall relevance of the topic. It also points to the problematic nature of the issue. Participants are always faced with ‘digital’ Yes/No questions. To these questions they can give answers ranging from “Completely agree” to “Completely disagree” on a 4-point Likert-like scale. Each answer is attributed a score ranging from 0 to 1, where 0 is complete disagreement and 1 is complete agreement and partial agreement and disagreement are .75 and .25 respectively. No neutral answer is allowed for reasons that are articulated in the description of phase 2.2.2.

2.2. *Information*

Once expressed their ‘intuitive’ or uninformed preferences, participants gain access to a section in which more detailed information materials are available. These are divided in the two large sections described here: the science of the issue, and the ethics of the issue. Although science and ethics tend to intermingle substantially when it comes to complex issues, the two are presented apart for the purpose of clarity.

2.2.1. *Relevant science*

The scientific committee drafts information materials pertaining to the issue being discussed. Asynchronous online forums in a sense both grant *and* entail longer spans of time¹⁰³ will be allowed for participation. Anyone can contribute at any time, but this also means that participation will be somewhat spread over time. Taking the naturally longer timeframe as a resource, information material is constructed so as to be dynamically adjusted in the form of a crowd-sourced wiki to which participants are able to contribute and within which they might challenge assertions put forward by the scientific committee.

¹⁰³ James Fishkin’s deliberative opinion polls (Fishkin 2009), for instance, normally stretch over weekends, whereas online asynchronous forums can afford spans of time that can extend possibly for months.

Access to the next phase is conditional to answering a small set of basic questions concerning the information provided in the material. Given that the content of the materials can potentially change as a result of users' contributions, in case questions relate directly to contested or controversial claims (i.e. contested as controversial in the wiki), the test can itself be revised to accommodate new questions. It must be stressed that these tests can be taken by each participant as many times as they like, until they manage to pass on to the next section. This is because the test is only supposed to screen out prospective participant who fail to recognize the need to participate competently as a matter of reciprocity towards those who will be affected by the decisions taken upon the guidelines produced in the forum described below.

2.2.2. *Relevant ethics*

Participants are presented with a plain-language review of the main arguments tackling the ethical implications of the issue. Again, the material is only a starting point for further collaborative gathering of information and feedback. Once ready, each participant will be asked to present a principled counterargument to a randomly chosen argument presented in the material as supporting the position he intuitively subscribes to. This is meant to test whether the participant is so ideologically committed to his own position as to be unable to conceive of reasons that go against his own point of view.

Whereas the competence test used for phase 2.2.1 can roughly be automatized, screening for proper arguments is still a fairly non-algorithmic activity, which therefore needs to be performed by humans. This problem subtracts from the potential scalability of the method, in case actual masses convene to deliberate. Such issue can however be tackled devising this test so as to have it become an automated analysis of the formal structure of the argument itself, either via sophisticated natural language processing instruments or, more realistically, having semi-structured submissions. There exist already software tools that rely on a conceptually sound definition of what counts as proper argumentation. These generally employ some version of Toulmin's model of argument (as presented, for instance, in *An Introduction to Reasoning* (Toulmin, Rieke, and Janik 1984)) according to which a properly structured argument must display these essential traits: (i) a clearly stated

claim, (ii) some grounds supporting the claim, (iii) the warrants for those grounds, i.e. some principle or set of principles that grants deriving the claim from the grounds and that may “take the form of laws of nature, legal principles and statutes, rules of thumb, engineering formulas” (Toulmin, Rieke, and Janik 1984, 26), and (iv) some sufficient backing for the warrants. Examples of argumentation tools of this sort are presented below and, if satisfactorily implemented, might heavily reduce the burden of manually adjudicating the acceptability of participants’ submissions.

2.3. *Goal-oriented discussion*

Participants then earn the possibility to access an asynchronous forum, ideally structured following a logical blueprint, with contributions being answers to the deliberative question(s) and replies to answers being claims supported by evidence in favor or against the proposal. Members of the committee are allowed to participate to the forum, without any privilege: essentially all participants, irrespective of their status outside of the forum, act here as peers. The forum essentially functions as a support for the discussion of a report containing recommendations to be handed over to a public decision-maker. The entire work is allocated a reasonable amount of time depending on the scope and extent of the question(s) being discussed.

Having an explicit goal set for the consultation renders the collection of pre and post-deliberation preferences less vulnerable to the sharp critique that Habermas, as reported by Neblo, moved to Fishkin’s Deliberative Opinion Poll™ claiming how ironic it is to ask people for their (informed or uninformed) private preferences and then call it a *public* opinion poll (Neblo 2014, 8). Participants in our initiatives are asked to reach a genuinely collective decision, one to whose *wording* they are asked to contribute directly. If the public sphere is “the sphere of private people come together as a public” (Habermas 1991, 27), I cannot imagine how one could approximate more closely public decision-making than we do.

2.4. *Second screening of preferences*

Finally, participants express their preferences a second time. This happens at different times depending on whether people are willing to spend more time discussing and contributing to

the drafting of the report or not. Data concerning the participating population, their attitudes and how they transformed as a result of the process, just like it happens for socio-demographic information, are attached to the report itself and are used for future implementations of the institution.

Making it real

Developing a solution that would support the workflow just described, matching each of the features required by the process revealed both costly and complex. The project lacked resources and access to the proper core (programming) skills. These limitations notwithstanding, in what follows I present an experimental design that was developed to match what was available and the theoretical interest we have in e-democratic solutions to legitimation crises in bioethics. The experiment provided some insights into the actual attainment of the values underlying the participatory workflow. I report on all of these.

First I describe the questions that informed the experiment and the reason why they are interesting questions to ask. Then I explain how—implementing an adjusted version of the ideal process described above—we planned to go about providing answers to those questions. Finally I summarize the data that we managed to gather and describe the kind of import they have as to the normative proposal outlined in Part II.

The experimental design

Smith and colleagues (Smith, John, and Sturgis 2013) argued that, in spite of the centrality of asynchronous forums for the online translation of deliberative initiative that could influence policy-making, not nearly enough attention has been devoted to the systematic study of this kind of participatory environments. This, they claim, is particularly unfortunate given that a lot of political institutions are using such kind of forums to engage with the public and would therefore very much appreciate to have some evidence base on which to ground their use. Quite the contrary, however, studies on e-democratic deliberative tools focused almost exclusively on what are known as synchronous forums (see for instance the summary of results presented in Fishkin (2009, 106–50)). These are basically online live chats (which, according to the experiment, can either be in voice and/or text mode) that remove the constraint of physical presence, allowing participants in deliberative workshops to attend ‘remotely’. These online substitutes for deliberative workshop are however no

solution to the issue of scalability that generally affects deliberative initiatives. Synchronicity demands limited numbers of participants, in order for everyone to be able to listen carefully and voice their views. Thus, synchronous forums must be seen merely as partial attempts at removing the constraints of local access and testing how far the benefits of deliberation can extend beyond the geographical scope of the workshop.

Asynchronous online forums seem, at least *prima facie*, to be able to scale up more easily extending access in space *and* in time. The intuitive reasons why public policy-makers have started to rely consistently on this kind of solution are: (i) that they entail fairly low costs in terms of workload of those involved (moderation need not be exclusive and focused, because moderators can be alerted whenever messages are posted on the forum) and (ii) that building a proper infrastructure to support the initiative also is relatively cheap (the costs of setting up an online asynchronous forum are contained). Hence, we opted for this kind of online environment.

Two of the core values that democratic deliberation is meant to attain, for reasons that were made explicit in Part I, are factual inclusion and considered judgment. Our study aims at fixing the requirement for competence in order to measure how far this is compatible with the value of inclusion in online deliberative consultations that make use of asynchronous discussion forums. Factual inclusion can be measured both as the extent to which renown inequalities in political engagement were mirrored in the study, and as the association of individual traits, within the participating sample, to non-compliance with the treatments. Considered judgment can instead be conceptualized as the degree to which preferences change directionally as a result of some mechanism postulated by normative democratic deliberative theory. For reasons detailed above, we decide to test these three hypotheses via a non-blinded four arms RCT (whose recruitment was selective and open). This experimental design¹⁰⁴ was thus supposed to provide an answer to the following questions:

- a) Are there inequalities in participation to this online system (measured both at the time of recruitment and as non-compliance to treatment)?
- b) Do individual preferences change as a result of participation?

¹⁰⁴ The design has been adapted from (Smith, John, and Sturgis 2013).

- c) Do information, discussion and goal-oriented discussion have differential effects on these changes in preferences?

Furthermore, we deemed it relevant to investigate whether people who participated in a process such as the one outlined above took this process to possibly enhance the legitimacy of decisions taken vis-à-vis some degree of moral disagreement. Therefore, as discussed above, the study looked for tentative reasons to pursue further the project given its prospective potential to increase empirical legitimacy, even without directly testing the empirical legitimacy of its output. This led us to add a fourth question to which we wanted to find an answer, that is:

- d) Do people involved in the process perceive it to be legitimacy-enhancing?

To provide an answer to these four questions, the deliberative process described above has been adapted and somewhat simplified. The most evident simplification was the isolation of one issue concerning one topic, regardless of the input to the agenda provided by participants during stage one. This was done for merely pragmatic reasons: in particular we chose to consult people about the permissibility of direct-to-consumer (DTC) distribution of genetic tests of susceptibility to medical conditions because part of the funding that was used for the development of the platform came from a COST action grant to which members of the working team participated. The input to the agenda that we nevertheless collected will be used for further consultations, at this stage only prospective. The results of the mock agenda setting stage are anyway analyzed below.

Participants to this first experimental deployment needed to register to Moodle (an LMS presented further on) and fill an initial survey meant to profile everyone interested in participating for standard socio-demographic traits and self-reported political attitude¹⁰⁵. At the end of the survey, prospective participants were asked to provide feedback as to the partiality and intelligibility of the question, which was formulated in advance for the sole reason that the committee knew the topic and the issue before the kickoff of the consultation. Comments to the formulation of the question were then analyzed and fed into a reformulation.

¹⁰⁵ We used a validated six-item questionnaire (Choma, Busseri, and Sadava 2009) meant to assess liberalism and conservatism separately.

The question in this new form was then presented to the same group of participants divided in four subsets. Users were randomized to three treatment groups and one control group. These are associated to letters for reasons of brevity: (a) is the control group, (b) is the information group, (c) is the non-goal-oriented discussion group and (d) is the goal-oriented discussion group. The activities in which they were involved are described below. We expected the sample to be affected by a significant self-selection bias¹⁰⁶. This turned out to be true, confirming that setting quotas on the sample would reveal impractical. The deliberation was launched on the platform once this phase was over.

Each group's members were asked to provide some input. The demand entailed by the input asked for increased from group (a) through to group (d), with members of group (a) invited to answer only one single question, twice: the first time the question was prompted as the consultation was launched, and the second once the consultation was deemed closed; members of group (b) were instead asked to provide an answer to the same question at the beginning of their workflow, but, before answering the same question again, were also asked to go through materials and competence tests that assessed their understanding of the materials and their capacity for ethical reasoning; members of group (c) had the chance to comment on, directly revise and ask for revision of information material they were provided access to. They also were required to prove their scientific and ethical competence and were eventually granted access to a forum in which they had a chance to discuss horizontally, i.e. peer-to-peer, about the reasons in favor or against one answer to the question or the other. Both this and group (d)'s forums were lightly moderated; members of group (d) were asked to do everything members of group (c) did, with one essential difference: their lightly moderated forum was given the explicit goal of drafting a report to be submitted to a generic public decision-maker¹⁰⁷.

¹⁰⁶ See the description of the sample below. There are however also theoretical reasons why representativeness of the sample is not one of the goals for this kind of consultative initiatives. I explore some of those reasons in Part II.

¹⁰⁷ An additional resource concerning the canons of argumentation was available to every participant.

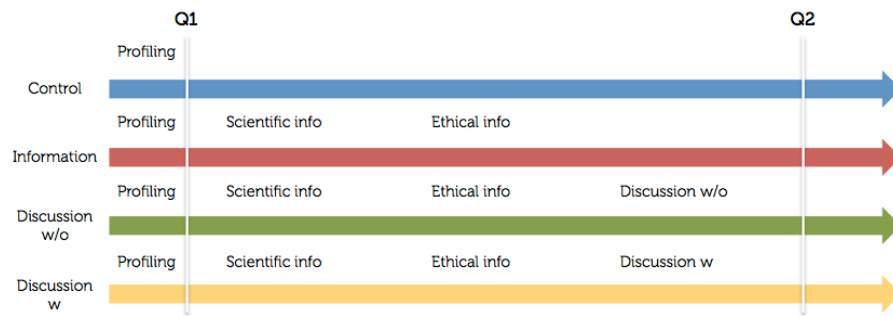


Figure 11 Timeline of the experiment for different groups. Q1 identifies the first time the question is asked, while Q2 identifies the second time the same question is asked.

We submitted a post-test survey to groups (a), (b), (c) and (d). Only to the subset of the sample that effectively used the tool we asked to highlight its pros and cons, e.g. how intuitive the graphical user interface was, how demanding the consultation was, how interesting they found the topic etc. This survey is reported in the Supplementary materials, while its results are discussed below.

Relevant endpoints

Socio-demographical traits of the sample were compared to those of the Italian general population as presented in the latest censuses conducted by ISTAT, the Italian national institute for statistics. In particular I compared age, gender, area of residence, education, marital status, number of family members, income and Internet use of our participants to those of the general population in Italy. This provided a way to corroborate the hypothesis that advantaged (either economically or culturally) strata of the populace tend to engage more in active citizenship practices. It also allowed for a reasonable assessment of the outreach of the initiative. To measure this last variable we also asked participants to report by whom or from where they were referred to the website.

We hypothesized that religious belonging and self-reported liberalism and conservatism might be somehow linked to the individual preference for the discussion of topics that roughly fall in the class of standard topics in bioethics (euthanasia and abortion) as opposed to those topics more linked to very recently developed biotechnologies. We therefore tested this hypothesis looking for correlations between individual traits and topics selected for the agenda of the consultation.

The measure of drop outs, best defined as non-compliers to treatments, in different groups provided an answer to the question whether information or information combined with non-goal-oriented discussion, or information combined with goal-oriented discussion do have differential effects on the

degree of engagement of citizens as to the specific bioethical issue for which participants were consulted. We expected the rate to be higher, the higher the demand put on the participant for their participation. We also checked whether individual traits were associated with the likelihood that participants would not comply with the treatments to see whether these had any significant effect on compliance.

A shift in individual policy attitudes was measured as well. We tried and gauge whether there was a link between the transformation of individual preferences and participation in the discursive deliberative activities of the two forums (against the backdrop of a control group). Following in Luskin, Fishkin and Hahn's (2007) footsteps we had individual policy attitudes range from 0 to 1 on a 4-point scale in which complete agreement would give a score of 1 and complete disagreement a score of 0, while partial agreement and partial disagreement were attributed .75 and .25 respectively. Change in attitude was measured simply as the difference between post-test and pre-test attitudes. To put it more formally $c = X_{i2} - X_{i1}$ where c is the change in attitude, i is the participant and 2 and 1 stand for the times at which attitudes were measured. We proceeded to calculate the mean value for each of the groups (essentially averaging individual changes within groups). We then also compared individual changes to see whether we could detect any sizeable difference between groups considering compliance and non-compliance to the treatments.

Finally, a post-test survey provided an answer to the fourth question, asking participants to claim to what extent they did or did not believe this kind of democratic innovation might have a legitimacy-enhancing potential.

In the next section I present a review of existing technologies to support the experimental design just outlined. Each technology is described in some detail and reasons why they have not been chosen are stated.

A review of existing technologies

What follows presents a review of the existing technical solutions that could have been employed in order to support our deliberative process. The workflow outlined above was used as a benchmark to single out all of the activities that we needed our platform to cover. These activities had to be supported by some online technology: we therefore proceeded to the evaluation of existing tools,

trying to see whether there were any of those that could satisfy the requirements implied by our ideal workflow. We set up our review via commonsensical preliminary steps:

- i. First, we isolated relevant technologies. This was done attempting to be as inclusive as possible, overviewing any existing technology that might support one or more of the features we were looking for.
- ii. Then we split this lump class of technologies into 3 subsets that would highlight features decisive for specific chunks of the workflow:
 - a. Argumentation tools;
 - b. Deliberative platforms;
 - c. Learning Management Systems (LMSs).
- iii. We finally made our requirements or *desiderata* subset-specific, meaning we tried to fit them within one or more of the three categories just listed.

These efforts resulted in a list of 15 viable instruments. Both the analysis of the technologies and of the process by means of which we isolated them followed the framework constructed by Wenger et al. (Wenger et al. 2005), which outlines four levels of analysis for the development of technologies for communities:

“The configuration of technologies that a community and its members use [...]

The platforms into which vendors and developers package technology [...]

The tools that support specific activities (e.g. a discussion board), or bridge between types of activities [...]

The features of tools and platforms that make them usable or differentiate one offering from another” (Wenger et al. 2005, 8)

For there was no community engaging through a technology existing prior to the set up of the experiment, we did not address level one in the process of designing our technology. It might make

sense to take level one into account for further experiments in case the technology starts supporting some sort of ongoing community.

The taxonomy is presented in detail below. Three tables summarize the relevant features for each of the three subsets of technologies.

Argumentation tools

Tools within this class were reviewed in that they could support and structure interactions within the peer-to-peer discussion forum to which participants gain access after going through the competence certification phase. Such tools might be thought to support also the argumentative test in phase 2.2.2.

- Deliberatorium¹⁰⁸

The Deliberatorium is an argumentation tool developed by Mark Klein at the Massachusetts Institute of Technology (MIT). It provides users with a platform for the asynchronous online discussion, in the form of a so-called “deliberation map”, of topics organized in questions. Each question can be given a series of answers, which are either supported or countered by arguments, supposedly presenting some evidence. This architecture of participation is supposed to foster collective wisdom and harness it towards collective decision-making on controversial issues, such as global climate change. The main intuition behind this articulation of the participatory flow is that the usual organization of participation by time works poorly in organizing knowledge and making progress towards some desired end. Time-centric systems have a number of disadvantages that range from scattered content, hard to retrieve and with a high risk of redundancy, the “soapbox problem, a bias advantaging without any justified reason the last who speak, and logically flawed argumentation¹⁰⁹. In order to redress these issues the Deliberatorium proposes to organize user-generated content according to the structure I described above.

Though its structure indeed accommodates a perspicuous representation of the logic of a debate, thus defeating the first two issues mentioned above, and encouraging the presentation of arguments supporting one’s proposed solution, the whole way it is implemented does not

¹⁰⁸ <http://cci.mit.edu/klein/deliberatorium.html> (last access August 7th 2014).

¹⁰⁹ These issues are presented and discussed in Mark Klein’s 10 minutes introduction to the Deliberatorium, which can be found here: <http://cci.mit.edu/klein/videos/concepts-intro.mov> (last access June 22nd 2014).

deliver. In particular, the graphical user interface has a very old touch to it and makes it very hard for a fairly skilled user to work his/her way around.

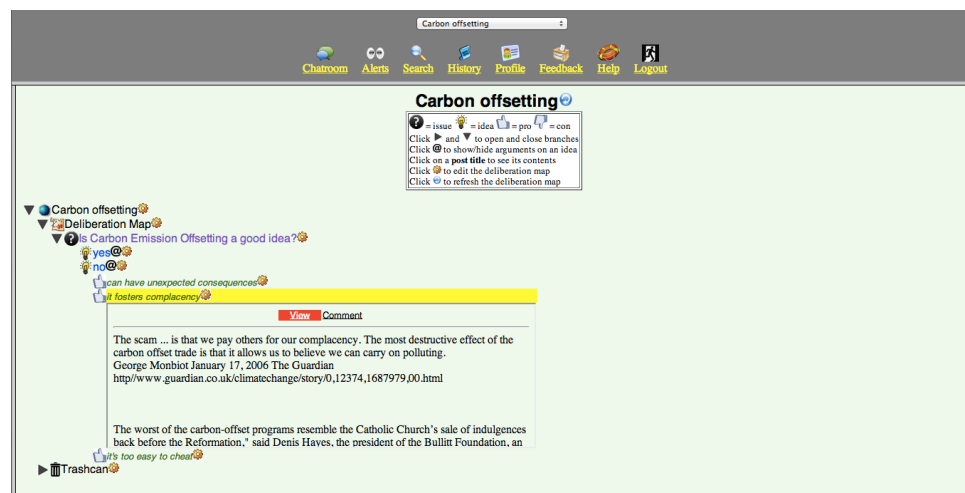


Figure 12 An example of a deliberation map in the Deliberatorium. In this example the issue of carbon emission offsetting is discussed.

Further limitations of the instrument arose as soon as we tried to assess how feasible it was to actually make use of the tool: first, installing the software required contacting directly Mark Klein and his team, and working on its GUI would have impeded progressing with the implementation, which was clearly incompatible with our time constraints. Secondly, a high degree of moderation is required to operate the Deliberatorium properly and this was inconsistent with our tight budgetary constraints and lack of manpower. Lastly, but more importantly, the argumentative structure proposed, however compelling the arguments in its support, seemed to be ‘stiffening’ our participatory workflow, which was already hampered by a number of filters to incompetent participation.

– Compendium¹¹⁰

Compendium is a dialogue mapping software tool developed by the Compendium Institute, an open forum for the development and dissemination of the software itself. Among the institutions contributing to its development, a prominent role seems to be played by the Knowledge Media Institute (KMi) of the Open University, in UK, with Simon Buckingham Shum leading a research group advancing the core and design of the software, which partly assumed new forms such as the Evidence Hub, presented below. The main idea behind the

¹¹⁰ <http://compendium.open.ac.uk/institute/about.htm> (last access August 7th 2014)

Compendium is that of providing a visually compelling representation of argumentatively ‘wicked’ problems, in the hope that this might at least help solve the issue. The way problems are conceptualized and subsequently visualized is pretty much the same that the Deliberatorium employs with both its advantages and disadvantages.

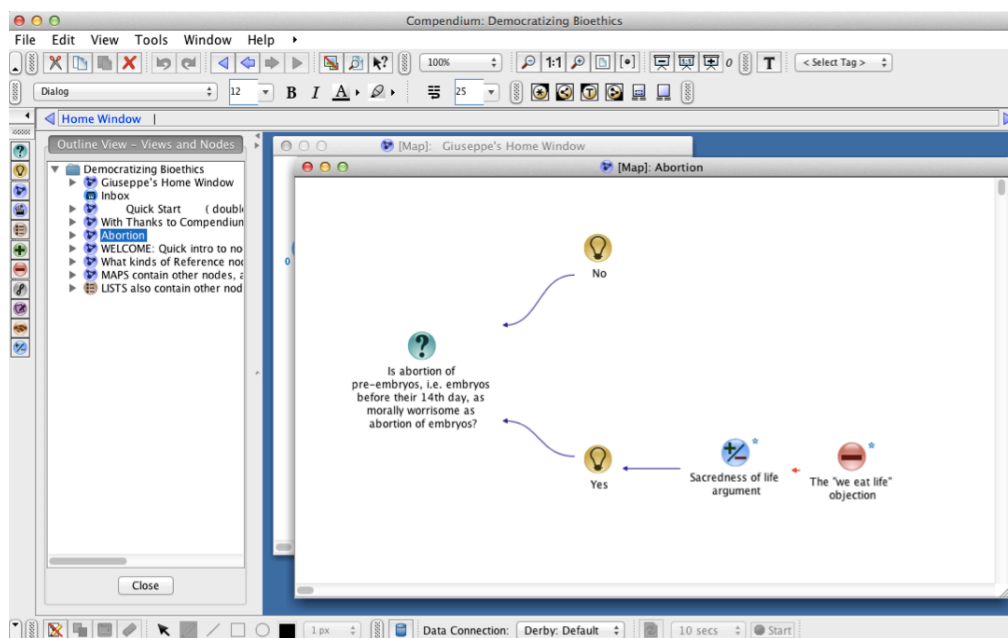


Figure 13 Compendium. An example of the tool used as a local implementation to discuss the issue of abortion.

As **Figure 13** shows, the GUI is still cranky and its 1990s origin is still apparent. Also, the Compendium Developer Community, a Yahoo group supporting anyone willing to use and/or contribute to the Compendium source code has been inactive since at least December 2013, thus suggesting the project has been losing traction. In fact, recently the project has moved towards a new phase called CompendiumNG¹¹¹ (NG standing to Next Generation). The new version of the software adds features to its original core (e.g. nodes can be tagged, pictures and documents can be added to the map, icons can be personalized). It however subscribes essentially to the same logical structure for the visualization of the debate. Installing this new version of the software on a Mac OS, though straightforward for savvy users, is still too articulate a process for the average user (e.g. it requires launching a script from terminal). The community supporting development of this new version of the application still seems to be unpopulated: the forum, launched longer than one year ago, has, as of July 2014, only 24 posts with less than a hundred replies. All of these are minor issues compared to Compendium’s

¹¹¹ <http://www.compendiumng.org/> (last access August 7th 2014)

main drawback, which lies in the current unavailability of a version of the software designed to run online, i.e. installed on a server, therefore defeating the purpose of having ubiquitous accessibility and making this application a poor candidate for our project.

– The Evidence Hub

The Evidence Hub, developed by the KMi, is “a collaborative knowledge-building (specifically evidence-building) web platform”¹¹². It is undoubtedly the most complete tool for considered argumentation, in that it integrates a vast array of features, which can accommodate essentially any request as to the needs communities might have to support quality debates. The logical backbone along which debates are constructed in the Evidence Hub is essentially identical to that used in Compendium and in the Deliberatorium. Users can contribute to a list of what are called “key challenges”, each challenge gives way to a number of “issues”, for each issues there can be competing “potential solutions”, which are essentially claims as to what is the best way to proceed in one particular respect, and every claim/solution can (and should) be backed by “evidence” supported by some explicit reference.

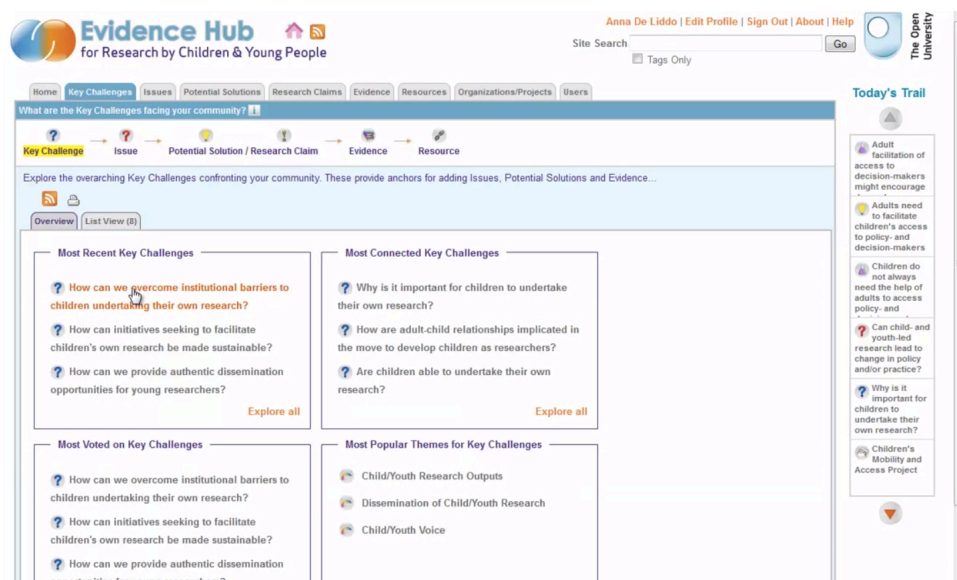


Figure 14 The Evidence Hub. Overview visualization of key challenges. The example is drawn from a group dealing with "Research by children and young people".

The visualization of this structure differs substantially from the ones we have seen so far, in particular allowing for multiple visualizations of the same node. Before choosing which of the

¹¹² <http://evidence-hub.net/about/> (last access July 23rd 2014).

“key challenges” one would like to explore further, one can visualize all available challenges either in a plain list, browsing the list according to criteria, e.g. recency of the post, or in a so-called overview mode, which already ranks them according to common-sense criteria such as popularity, number of connections between the challenge and other challenges and the like.

Within each key challenge, there are three ways to visualize every dependent node: a “linear view”, a “widget view” and an “evidence map view”. When looking at a challenge, the most fruitful standpoint is the second one: the widget displays three collapsible windows, one listing issues related to the challenge, the other available resources to tackle the challenge and the last one the groups and projects working on the challenge.

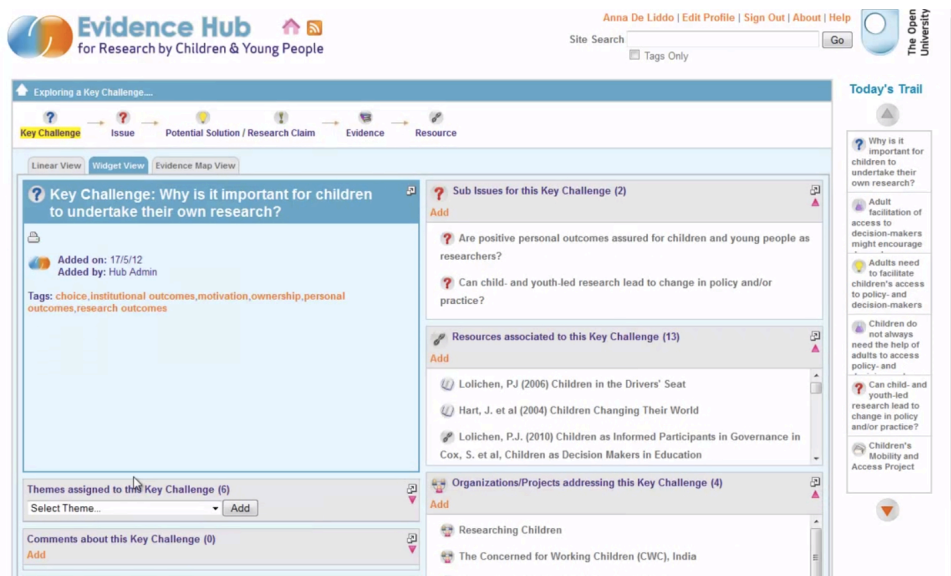


Figure 15 The Evidence Hub. Within challenge widget view.

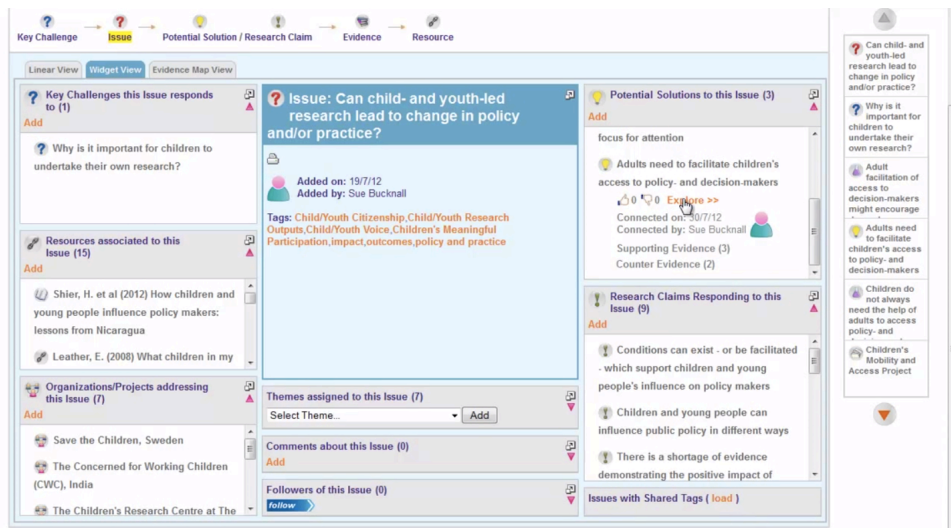


Figure 16 The Evidence Hub. Within issue widget view.

Going one step further in the workflow, picking one specific issue, the widget view centers, in a wholly non-metaphorical sense, the entire screen on the issue and wraps it around with its relations to other challenges, resources, potential solutions and research claims.

Potential solutions appear in pretty much the same way issues do, but are related to supporting and counter evidence, which can be further explored to look for the details of the source that allegedly supports the evidence in favor or against the solution.

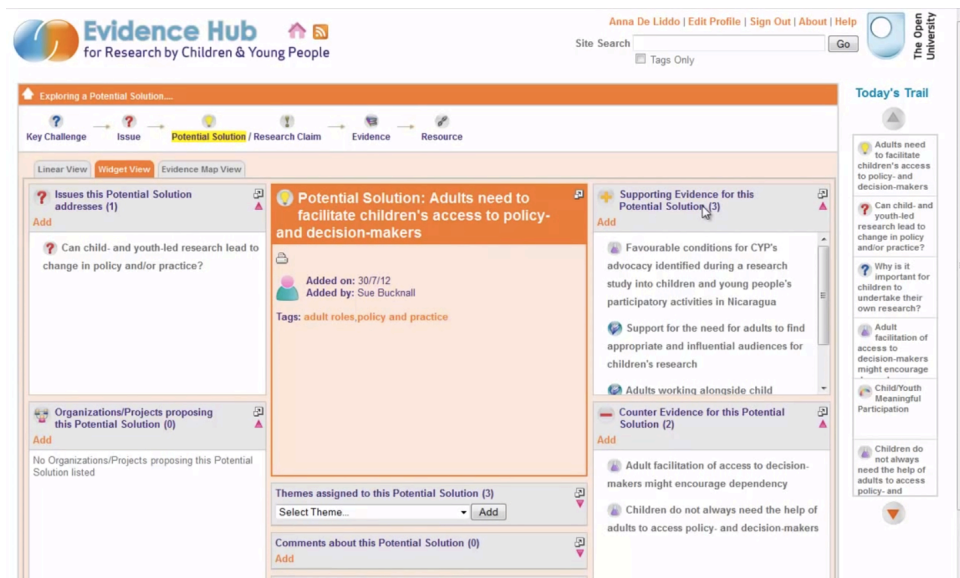


Figure 17 The Evidence Hub. Within potential solution widget view.

As apparent from the series of figures, to help users recognize immediately the part of the chain of argument they are at—in addition to the menu on top each page—background colors of pages are used to signal that one is progressing through from top level challenges and issues

(blue), to specific solutions (orange), to evidence supporting or undermining the solution (purple).

The linear view shows a line by line summary of the entire chain of argument one is looking at, whereas the “evidence map” view visualizes graphically relationships between nodes. Since this representation is pretty much the same Debategraph uses, I provide some illustrative figures below only.

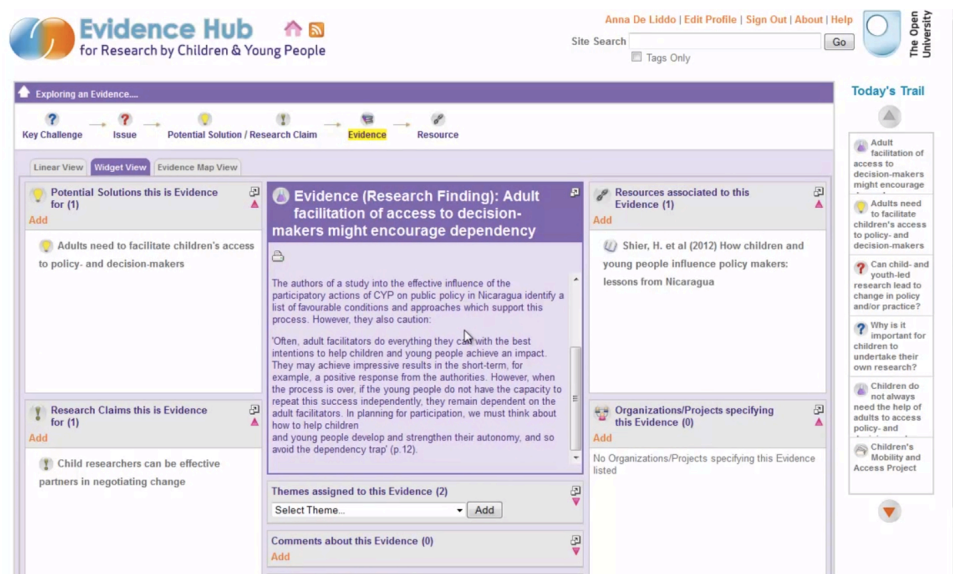


Figure 18 Within evidence widget view.

As of today, a number of institutions are already using the Evidence Hub to coordinate work on their own projects trying to address what they regard as key challenges. There is no available evidence as to the actual impact the tool has had so far on the efficiency of the work of these communities and I look eagerly forward to the making of this evidence.

As to our own purposes though, however complete and compelling the argumentative structure of the environment, it did not seem to fit reasonably well with our core goal of certifying competence and only then let people discuss. The debate within the Evidence Hub is highly constrained by design, but anyone willing to submit to those constraints could potentially make reference to evidence that does not qualify as such according to shared standards (say, for instance, scriptures), therefore potentially derailing the debate. This does not imply that our own solution addresses this issue more satisfactorily, but it seems to suggest that the entire Evidence Hub environment was built with in mind the idea of a class of highly

skilled, competent participants, willing to come up with the best scientific evidence available in support of some specific policy-making recommendation. Recruiting experts' participation was not amongst our aims. Quite the contrary, we wanted to include the highest number of motivated people possible, filtering out incompetent participation. We asked Anna Deliddo, one of the people in charge of the project at KMi, whether we could have some competence certification tool plugged into the Evidence Hub. Unfortunately, it turned out there was no ready-made LMS (see below) plugin for the platform and the joint project had to be aborted. We therefore decided not to use the Evidence Hub, regardless of its technological and theoretical merits.

– Debategraph

Debategraph is a web tool for argument visualization/mapping. It is meant to enable groups and communities to debate, decide and deliberate about complex issues.

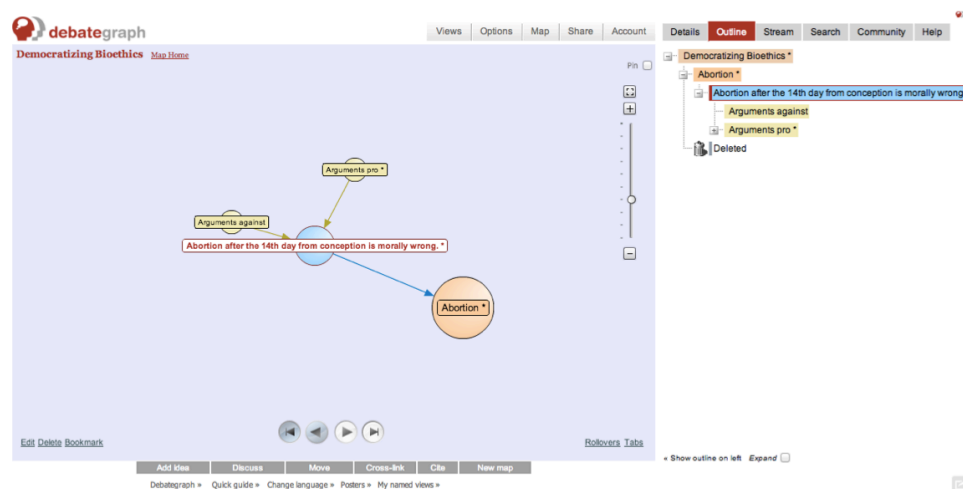


Figure 19 Debategraph. An example of a map of argument concerning abortion.

Anyone allowed to can contribute to a map and make his/her voice heard and represented. The tool promises to make shared understanding more effective and to avoid “unnecessary repetition and ad hominem attacks”¹¹³. The platform is also always readily available to the input of new evidence and ideas. The argumentative logical structure underlying the representation does not differ significantly from the ones we have seen so far: issues or

¹¹³ Description of the tool found at <http://debategraph.org/Stream.aspx?nid=65027&vt=bubble&dc=focus> (last access July 26th 2014).

questions give rise to potential solutions which can be supported or countered by arguments and evidence. In the map shown above, the proposed solution to the general issue of abortion is to regard abortion as morally wrong when operated after the 14th day since conception and two token bubbles represent arguments in support of and against the solution.

Debategraph is easily available online and only require users to fill in a brief form for registration before participating in a map. However, again, since we had deemed pivotal to prevent from participating those people who were not acquainted with the science and the ethics of the issue in advance of the discussion, we needed to adapt this solution and make it work together with some LMS. There was no such solution promptly available and we therefore decided not to resort to Debategraph.

– Reflect

Reflect is a tool for the online collaborative sense-making of other people’s written ideas. In the words of its developers, at the University of Washington, it is supposed to improve online discussions “through restatement”¹¹⁴. It comes as a Wordpress plugin, as a Mediawiki extension or as a Greasemonkey—i.e. a Firefox plugin that operates on the webpage at the level of one’s own browser—script. Any of the three solutions allows for the highlight and rephrasing of specific sentences or sets of sentences. Reflect’s main purpose is to summarize long and cramped pieces of text, to make them more readable and to avoid long discussions due to misunderstandings. As shown in **Figure 20**, users can restate parts of what somebody said, and the original author can still retain the right to confirm or disconfirm others’ interpretation of his own message.

¹¹⁴ Brief description of the tool at <http://engage.cs.washington.edu/reflect/> (last access July 26th 2014).

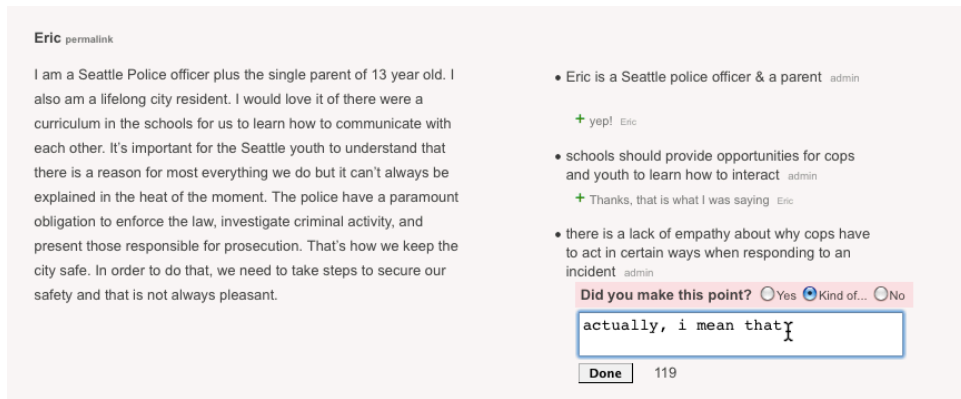


Figure 20 Reflect as a Wordpress plugin. Eric posted a long piece of text other fellows helped restate and summarize. Eric himself agreed with their interpretation of what he said.

This very promising and flexible tool will need to be considered for future implementations of our project, but it was incompatible with our workflow constraints: the participatory process could not be supported using Wordpress; integrating Wikimedia within Moodle, the tool we chose after careful consideration, was not straightforward and entailed programming efforts that extended beyond our capabilities; finally requiring the installation of a Firefox plugin script to all participants would have entailed dropout rates even higher than we recorded, for it would have commanded the use of a specific browser and some efforts and skills to actually get the script working.

The table below summarizes our rough analytical taxonomy of argumentation tools.

Argumentative tools	Deliberatorium	Compendium	Debategraph	Reflect	Evidence Hub
Aims	Deliberative mapping	Hypertext concept mapping	Debate mapping	Understanding via restatement	Collaborative knowledge building
Installation	Required	Required	Not required	Plugin/script	Not required
Features					
E-Learning
Polling
User layering
Info Material Attachment	.	√	√	.	√
Tags or similar posts	.	√	.	.	√
Argumentative structure	√	√	√	.	√
Tutoring Demand	High	High	High	Little	High
CONS	<ul style="list-style-type: none"> Highly constrained interaction Currently not working 	<ul style="list-style-type: none"> Awful GUI Not genuinely collaborative 	<ul style="list-style-type: none"> Reloads the entire map when centres on a node Rigid 	<ul style="list-style-type: none"> Only does one thing 	<ul style="list-style-type: none"> Complex workflow
PROs	<ul style="list-style-type: none"> Non-time-centric, logically structured contributions 	<ul style="list-style-type: none"> Link nodes to attachments 	<ul style="list-style-type: none"> Periodic digests of the map Link claims to web sources 	<ul style="list-style-type: none"> Listening is core to deliberation 	<ul style="list-style-type: none"> Very complete

Deliberative platforms

These tools were initially thought to be able to provide the range of features that might support the entire deliberative workflow as described above. All of these implement some specification of a space for discussion and voting about issues. However, as it turns out, it was hardly the case that any of these could in fact provide the kind of progressive workflow with which individuals are supposed to be engaged in our ideal process.

- LiquidFeedback

LiquidFeedback is an open-source software enabling “proposition development and decision making”¹¹⁵. Originally conceived to support the internal activities of the German Pirate Party, its scope was progressively extended and came to be used by movements, civil society organizations and local communities alike (Domanski 2012). Regardless of its growing popularity as a tool that might enable a moderate reform of representative democracy complementing it with elements of direct democratic expression of popular control over parties and bottleneck institutions, there is still scant scientific insight into whether and to what extent it yields the output it promises to. In fact, the most recent reports from LiquidFeedback original developers’ deployment seem to raise doubts as to the extent to which the tool lived up to its promises: the German Pirate Party lost most of its traction and was essentially politically dissolved. This was partly the result of the ‘liquidity’ of the technology that supports the Party’s internal operations: its members in fact revealed incapable of reaching conclusive decisions on even basic issues such as the very procedure with which to decide upon issues (Chiusi 2014, 127–139) and this led to some sort of perpetual stall and a definite drop in the Party’s popularity.

LiquidFeedback can be thought of as a deliberation platform that proceeds stage-wise within issue specific forums. Each stage can be very finely tuned to fit the needs of the owners of the platform. Within each issue, every participant can formulate a proposal. Each proposal needs to be supported by a given proportion of the total number of participants (this quorum can be

¹¹⁵ As described on the official website’s homepage. <http://liquidfeedback.org/> (last access July 26th 2014).

set by the owner). If and once the proposal has been supported by a sufficient number of users, it gets to be discussed for a set number of days (again the details are filled in by the owners). Discussion is articulated through counterproposals, which can be seen as hints on how to reformulate the proposal so as to capture more votes and obtain a larger support. Each counterproposal can in turn receive suggestions. The discussion, so structured, then results in a 'frozen' reformulation of the proposal, which then needs to be supported by a minimum number of participants in a given lease of time (this second quorum is usually higher than the first, with a shorter span of time available, but again these parameters can be tweaked by the owners of the process). In case this frozen proposal musters a sufficient amount of supporters, the proposal is subsequently put to a vote.

LiquidFeedback's most distinctive feature, however, is the possibility to use so-called proxy-voting procedures, i.e. direct and revocable delegations that are specific to one proposal. Theoretically this was thought to work as a way to provide people with the chance to be endorsed in case their expertise in some specific area was recognizable and appreciated. In a sense, this would have meant that recognition of experts or leaders would be devolved to participants entirely. However, as it turns out, this feature has consistently gone unused, for a number of reasons, the most intriguing one being that at least a quarter of the few people who do decide to participate are not willing to give up their vote to someone else (De Cindio and Stortone 2013, 154).



Figure 21 LiquidFeedback as used for Umberto Ambrosoli's candidacy as governor of Lombardy. See below.

A formal member of the institutional network that developed “bioeticadeliberativa”, i.e. the Laboratory for Civic Informatics, was also involved in the test of LiquidFeedback on which the study I just mentioned reports. Hence our team had a privileged angle from which to assess the feasibility and desirability of using it for our experiment. The study highlighted several limitations of the platform, in particular showing that no matter how important “to build an effective participatory government” or “useful to generate valid, reasonable and shared proposals” (De Cindio and Stortone 2013, 156) participants deemed LiquidFeedback (more than half the respondents rated LiquidFeedback along these two dimensions above 5 on a scale of 1 to 6), a large number of them took the pain to write down in the open suggestion form of the post-test survey, that its GUI was not nearly as friendly as one might expect of an instrument meant to be used widely and for political purposes.

Furthermore, participation to Liquid Feedback could not be qualified within the platform, with users classified according to whether or not they had passed the scientific and ethical competence tests. For these reasons we decided not to rely on Liquid Feedback as the technological solution to support “bioeticadeliberativa”.

– IdeaScale¹¹⁶

IdeaScale is a proprietary software for online idea gathering. The process of idea gathering as construed in IdeaScale consists of three essential steps: first any user submits his/her own idea concerning a given problem/issue.

¹¹⁶ <https://ideascale.com/> (last access August 7th 2014)

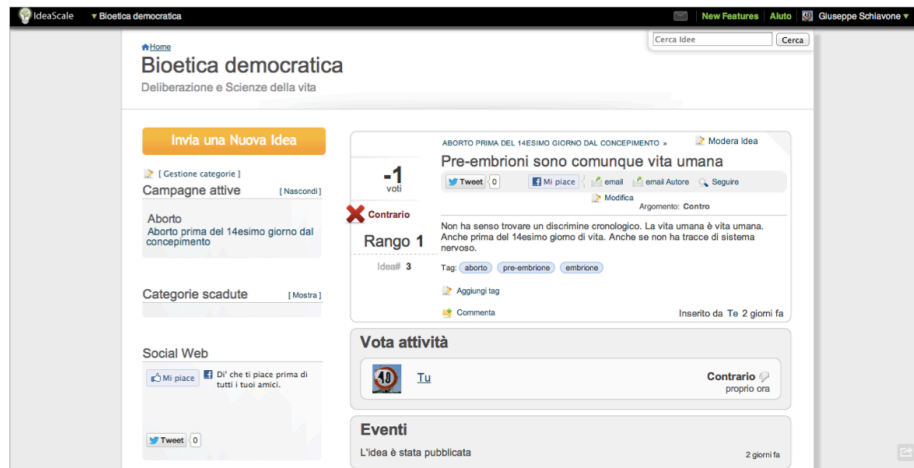


Figure 22 IdeaScale. Front-end demo of ideas concerning the issue of abortion.

Secondly, the rest of the community can comment on and agree or disagree with the idea, thus voting the idea up or downwards.

Finally, voted ideas are changed status and assigned to a community of interested participants which can take action upon the idea and deliver some outcome ideally solving the problem/issue.

The whole vision of IdeaScale revolves around the idea of empowering innovation within specific communities. This vision is specified in a huge number of features that can be tweaked via a very user-friendly administration panel, which requires only limited programming skills. However, most of these features only come as “premium”, which entails a fairly high price. A price anyway higher than could be afforded within the budgetary constraints of “bioeticadeliberativa”.

Though often used by local government and for public services, the core concepts of IdeaScale are very much the same that are used for users’ input into corporate innovation. The instrument is therefore better able to account for the refinement of existing services and for the streamlining of services to be.

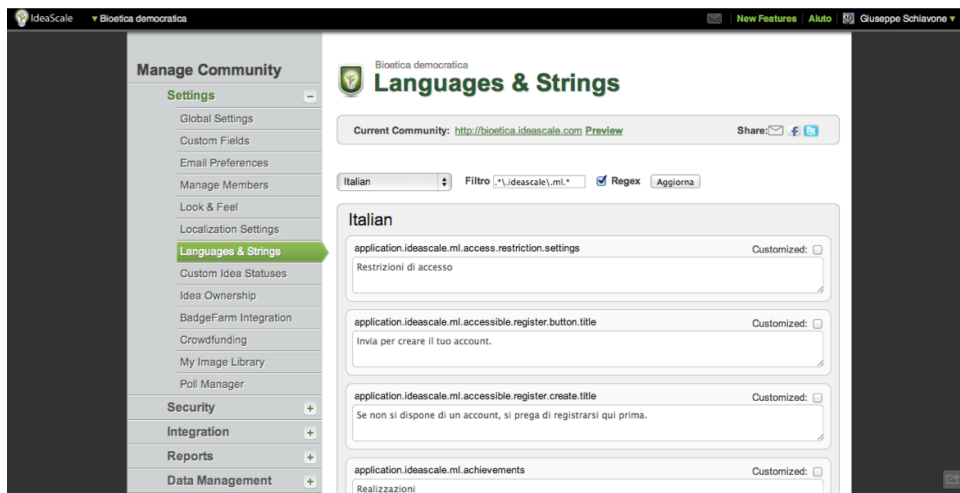


Figure 23 IdeaScale. Administration panel.

Regardless of the price it comes with, then, IdeaScale is not the tool of choice for an environment meant to host competent reason-giving and was therefore discarded from the list of potential solutions to technologically support “bioeticadeliberativa”.

– Airesis

Airesis is a project for direct, participatory, open-source online democracy developed by a team of Italian volunteers¹¹⁷. The software is continuously evolving as a result of the work that is being constantly done by the developing team. The version of Airesis I am describing and commenting upon here is the one online at the end of July 2014. When we conducted our first technological review, approximately during the summer of 2013, some relevant features described below were still unavailable and convinced us that the platform could not perform as we needed it to. As of today, most of those features are in place and, especially taking into account the results of our experiment concerning participation to the actual formulation of the guidelines, it would make sense to try Airesis out.

The platform comes with a very nice contextual tutorial, which, on a user’s first access to a specific kind of page, highlights all the relevant areas of the page, defining concepts and explaining how to work one’s way through.

¹¹⁷ The group of people developing the project is described here, in Italian only: <http://www.airesis.it/chisiamo> (last access July 30th 2014).



Figure 24 Airesis. Tabs listed below are in the blue area on top. This is an empty board. The left-hand side bar shows notifications clustered in categories (no notification is visible in this screenshot).

Each group, which can be easily created in a couple of steps and is hosted directly on Airesis' servers, has roughly five internal tabs:

- A "Board" onto which the problem supposed to be tackled can be described and concerns about the use of the platform and the scope of the initiative can be voiced.
- A "Proposals" tab that collects every proposal to solve the issue put forth by any of the authorized users.
- A "Calendar" in which events and votes can be scheduled by those users allowed to do so.
- A "Documents" section in which up to 50MB of materials can be stored and rendered available for anyone to download and use.
- And a "Forum" tab with configurable areas for discussion.

Areas can be hidden in case they are unwanted or pointless in some specific group. The left-hand bar shows Google icons displaying notifications that are user-dependent, i.e. notifications that concern activities performed specifically by the logged-in user.

The most interesting of the areas, which is also central to the whole idea of Airesis, is the one containing proposals. I will briefly outline how proposals are structured in Airesis so as to show the merits the structure has.

Proposals go through three stages: discussion, voting and voted. The first two are live phases, while the third only serves as a record of the process. Each proposal in the discussion stage has to be introduced by a description of the problem/issue. A list of the aims and goals of the proposal must accompany this description. Then, one solution can be outlined. A certain amount of time is allocated to this phase. At this stage, comments to the proposal and contributions to its formulation can be given.

The screenshot displays the Airesis 'Spazio Comune' interface. At the top, there's a navigation bar with 'GRUPPI', 'Spazio Comune', 'PROPOSTE', and 'CALENDARIO'. The main content area shows a proposal titled 'Abolizione di coltivazioni OGM e tutela del territorio con la vendita a Km 0'. On the left, a sidebar indicates 'Valutazioni 47' and 'Maturità 94%'. Below this, it says 'Dibattito in corso' (discussion in progress) and provides details like 'Creato da: 19 Mar 2013 alle 18:46' and 'Aggiornata da: 31 Mar 2013 alle 14:49'. The proposal text includes a warning: 'Il dibattito proseguirà finché non avranno partecipato almeno 82 persone. La proposta andrà in votazione se avrà una maturità superiore al 60%, altrimenti verrà abbandonata.' The 'Problematika' section lists five points: 1) risks to human health and environment, 2) patentability of genetic material, 3) biodiversity reduction, 4) favoring multinationals (like Monsanto) over local agriculture, and 5) favoring large industries over small farmers. The 'Obiettivi' (objectives) section states 'Risolvere i problemi sopra elencati'. The 'Soluzione 1' (solution 1) section is also visible. On the right, there are icons for document, calendar, and user profile.

Figure 25 Airesis. A proposal concerning the use of GMOs in agriculture during the discussion phase.

Most importantly, though, participants assess the so-called “maturity” of the proposal voting whether it looks ready to pass through to the voting stage or not. Maturity seems to be computed as the proportion of people who rated the proposal as ready for a vote to those who rated it as worth more discussion. How mature a proposal must be to pass on to the next stage is a parameter that can be fixed by the proponent. Once this stage is over and the proposal has been deemed mature enough, participants can contribute to the actual drafting of a more formal version of the proposal. Each proposal can come with more than one solution, which must anyway be uploaded by the administrator of the proposal. Each solution that gets to be voted must be unbundled in a series of paragraphs to which anyone can contribute. Every paragraph can be commented so that its owner can update the content, if he thinks it makes sense to do so. The proposal can also be commented upon by anyone. The administrator can then set a date (or a range of days) to let participants vote on the proposal. Subsequently, results of the voting session are published in the “Voted” section.

Airesis, as it is apparent, has a number of merits. In particular it allows for the kind of goal-oriented interaction that we wanted to foster for “bioeticadeliberativa”. Furthermore, the flexibility allowed by the platform in the creation of classes of users enjoying different privileges could have been used to manually filter out users who had not passed the competence tests, ideally hosted on some LMS. This process would not have been very easy to streamline, but, given the numbers of our participation in this first experimental deployment, nothing would have made it unfeasible. There are however other obstacles, which would have made Airesis unsuitable to our experimentation even in case the features just described were in place when we first set out to plan the experiment itself.

Unfortunately there are no data available as to actual use of the platform and there are still very basic functionalities supporting analytical efforts in this respect by those who would like to experiment with it. This means that I cannot draw sweeping conclusions as to how the tool has been used so far. However, scoping through publicly available groups, what is immediately clear is how little the “Write a contribution” to texts feature is used. I was able to spot only one direct contribution to a text (a fairly unarticulated one, to be true¹¹⁸). This seems to suggest that the problem we highlighted and quantified in our experiment is common to other e-democratic initiatives: participants do not fancy contributing directly to the drafting of texts, but had rather comment on the text itself and the issue thereby presented.

A more systematic attempt at having the workflow organized and handled by a team of experts might make up, within Airesis, for part of the issues highlighted and, as anticipated, it is therefore sensible to consider testing the platform as a tool for the democratization of bioethics.

– openDCN

The DCN in openDCN stands for Deliberative Community Networks. OpenDCN is a configurable software environment to support online participation and deliberation. It has been and still is developed jointly by the Foundation RCM (FRCM) and the Civic Informatics

¹¹⁸ A user suggested that the problem at stake—whether and how to give up on cash money in Italy—would not have been perceived as a problem by “foreigners”, in that they are used to using “electronic money only”. See <http://www.airesis.it/proposals/5136-eliminazione-contante> (last access July 30th 2014).

Laboratory (LIC) of the University of Milan. The tool makes use of three different kinds of spaces, which can be considered as the building blocks of platforms developed relying on openDCN. First there is a community space, devoted to the free interactions among participants. This, in the words of its developers, is “aimed at fostering public dialog on civic issues and facilitating the rise of mutual trust”¹¹⁹. This area is managed via a tool the developers call “Informed Discussion”, which is essentially a threaded forum, with the possibility of attaching files and link to outside resources.

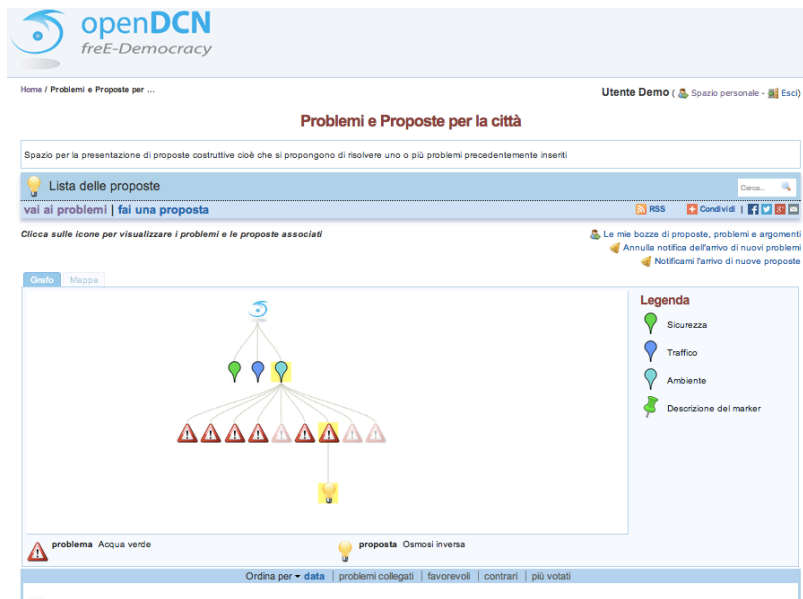


Figure 26 openDCN. A map view of problems and proposals divided in thematic areas. This comes from a freely accessible online demo, available at <http://demo.opendcn.org/> last access July 30th 2014.

Secondly, one can introduce a deliberation space, which can resort to three different tools: “Problems and proposals”, “Certified Citizen Consultation” and “Online Ordered Meeting”.

As to “Problems and proposals”, bottom up contributions by participants are organized in issue-specific, or thematic areas. Within each thematic area, participants can point out problems, which are then linked to proposals for a solution to the issue. Problems and proposals are displayed in a map-like fashion (as shown in **Figure 26**). Each solution can be backed or countered with arguments in favor or against respectively.

This part of the environment enables groups to get closer to an agreed upon solution, which is also the result of structured argumentation and therefore considered judgment. In fact, within

¹¹⁹ <http://www.opendcn.org/index.php/en> (last access July 30th 2014).
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this space, openDCN also allows for certified consultations, whereby certified, the developers supposedly mean consultations whose participants are identified via some method less prone to manipulation such as verified email addresses. Consultations of the participating population, are essentially ways to poll, according to the needs of the owner of the platform, the opinion of the environment's userbase. OpenDCN further grants the possibility of having finalized interactions in synchronous discussion forums, which are suitable for deliberation in small groups.

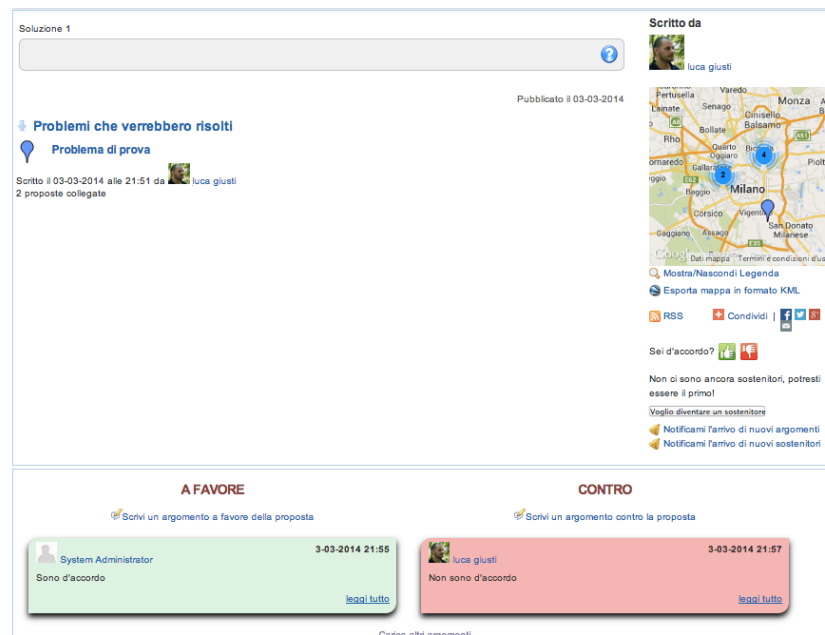


Figure 27 openDCN. Arguments in favor and against a specific proposal for the solution of some existing problem. This comes from a freely accessible online demo, available at <http://demo.opendcn.org/> last access July 30th 2014.

Finally, openDCN affords some personal space to each participant, in which participants can manage their own history on the platform and decide how to present themselves.

Once more, the wide array of functions that an environment as wide in scope as openDCN can cover, was both too broad and too narrow: it was too broad in that it supports features which we did not need, e.g. synchronous discussion, and it was too narrow in that it does not support knowledge certification in any formal way.

– Loomio¹²⁰

¹²⁰ <https://www.loomio.org/> (last access August 7th 2014)

Loomio requires an introduction somewhat similar to that given for Airesis: it is an ongoing project and some huge steps forward are likely to have been made once this dissertation is discussed. More precisely, after successfully crowdfunding, Loomio 1.0 will be launched around the end of year 2014. Once more, then, it makes sense to update this part of the review in that what is true today of the private beta implementation of the software might not be true of its public 1.0 release.

Loomio is a “better way to make decisions together”¹²¹. Very much in the vein of most other platforms described in this paragraph (with the notable exception of IdeaScale), it is free and open source software available for anyone to allow for participation in their own community. I beta tested the platform and report on its features in what follows.

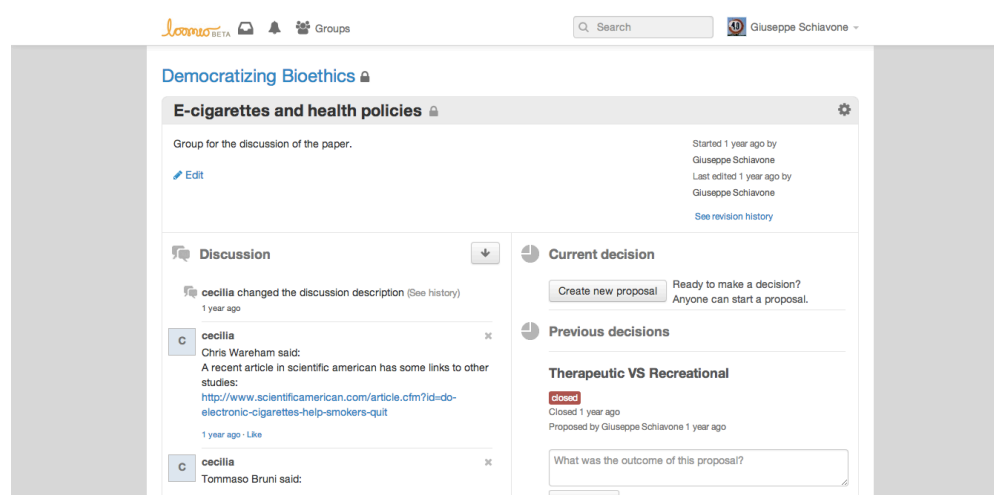


Figure 28 Loomio beta. An assay of the GUI within discussions. On the right comments are displayed chronologically. On the left decisions are displayed chronologically.

Each user has his/her own homepage welcoming him/her right after logging in. This displays a list of the discussions to which he/she has been or still is participating. Every discussion comes with a brief summary of what it is about, to be drafted by the author of the discussion, a board for the actual discussion, which is pretty much a list of threaded comments on the right hand side of the page and a list of decisions concerning the discussion. Every member of the group can vote each decision, agreeing, disagreeing, abstaining or vetoing the decision. Once the decision is closed, which happens according to the needs of the proponent of the decision, an outcome has to be published summarizing the decision that is being made.

The main idea behind Loomio beta is to have only essential features and let users define the conventions or rules by which their group runs. The details of one group's own decision making procedures is the most compelling example in this regard. Administrators cannot set a quorum on the number of participants to consider a decision valid. Whatever the number of participants who actually voted as a proportion of the members of the group is, that number is always visible and the proponent of the decision can deem a decision closed regardless of that proportion. This structure stresses the potential for self-regulation within communities, but also falls very short of the attempt at certifying scientific and ethical competence that is at the center of our deliberative democratic project. Therefore the tool was not considered for implementation.

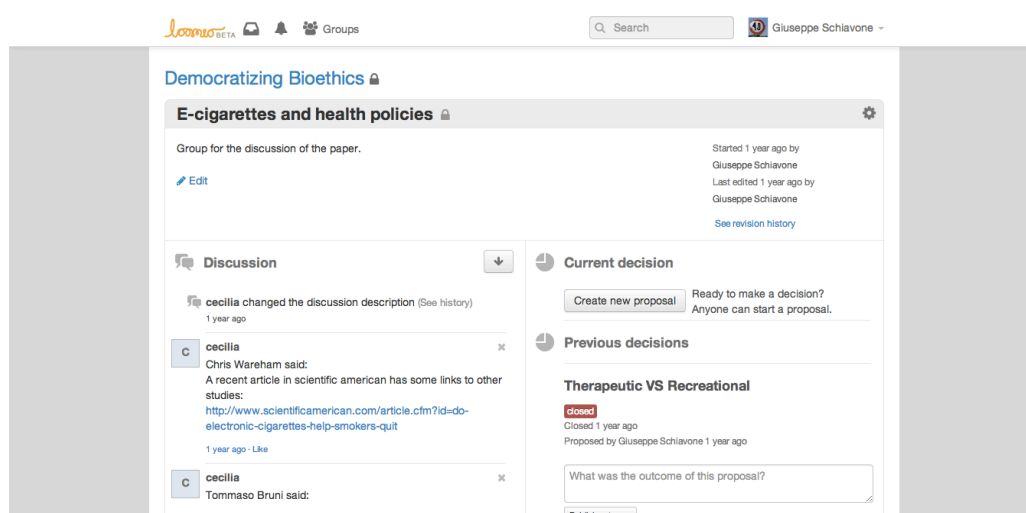


Figure 29 Loomio beta. The screenshot shows a discussion on how to go about drafting a paper concerning the issue of electronic cigarettes and taxation. This was actually used by members of our PhD program and eventually resulted in a publication coauthored by Cecilia Nardini and I. See Nardini and Schiavone (2013).

The table below summarizes our rough analytical taxonomy of deliberative platforms.

Deliberative platforms	Liquid Feedback	IdeaScale	Airesis	OpenDCN	Loomio
Aims	Open democratic governance	Community engagement	e-democracy social network	Complex decision-making	The Wordpress of e-democracy
Installation	Required	Not required	Not required	Required	
Features					
Polling	√	√	√	√	√
User layering	.	Premium	√	.	.
Attachments	√	√	√	√	√
User profiling	√	√	√	√	√
SN integration	?	√	√	√	√
Reputation	√	√	√	√	.
Tags or similar posts	.	√	√	√	.
Argumentation	.	.	√	√	.

	Analytics ¹²²	·	√	·	·	·
Hosting			√	√	·	√
Moderation Demand	High		Fair	Fair	Configuration-dependent	Little
CONs	<ul style="list-style-type: none"> - Articulate participatory flow - Unfriendly GUI 	<ul style="list-style-type: none"> - Proprietary software - Costly 	<ul style="list-style-type: none"> - Non-argumentatively organized posts 	<ul style="list-style-type: none"> - Inflexible user layering 	<ul style="list-style-type: none"> - Private beta release as of July 2014. 	
PROs	<ul style="list-style-type: none"> - Free - Widely used 	<ul style="list-style-type: none"> - Big - Multipurpose 	<ul style="list-style-type: none"> - Flexible user layering 	<ul style="list-style-type: none"> - Entire array of activities 	<ul style="list-style-type: none"> - Wonderful GUI - Flexible and complete 	

Table 3 Deliberative platforms. Feature-wise summary. Hosting refers to the availability of some online space dedicated to one's community directly on the platform's website.

Learning Management Systems

LMSs were one of the essential points of reference given that our process relies primarily on the certification of competence to instruct a phase-wise progression of the participatory flow.

- Just Learn It! (JLI!) and Ariel 2.0

JLI! and Ariel 2.0 are the two main tools used by the University of Milan to support their education online (they are actually the only ones officially available to the entire Athenaeum). They both have very rudimental functionalities and are used essentially to distribute class materials and to perform tests online when needed for courses.

It is beyond the point here to go through each and every feature of the two LMSs. Suffice it to say that, as compared to Moodle, there are at least three respects in which the two compare very unfavorably.

First, the array of activities that can be performed within JLI! and Ariel 2.0 is very little, in that limited to those activities that might be of some use for undergraduate courses. Secondly, within each activity, the number of parameters that can be changed to fit the administrators' purposes is fairly limited, i.e. the tools are not flexible and can hardly be adapted to goals other than the ones for which they were originally conceived. Finally, the community of developers and users of both JLI! and Ariel 2.0, again, in comparison to Moodle's community, is negligible.

¹²² When installed on one's own server, log files are obviously available. No analytic tool to track participation is however provided. This holds true of Airesis, LiquidFeedback and OpenDCN. Analyses on the use of these two platforms must make reference to logfiles of the owners of the process.

UTENTE COLLEGATO: SOSSAVONE GIUSEPPE
CORSO SELEZIONATO: 2012-2013 INTERAZIONI SOCIALI IN RETE

ES.1: SITI WEB VS AMBIENTI DI INTERAZIONE SOCIALE IN RETE - SONDAGGIO: SCELTA MULTIPLA

Per ciascuna delle seguenti domande seleziona il distrattore corretto (solo uno può essere corretto). Puoi effettuare un salvataggio intermedio delle risposte per completare il modulo in un secondo momento cliccando sul pulsante "Salva". Clicca sul pulsante "Terminato" quando pensi di aver terminato il modulo.

Questo esercizio prende spunto da una questione emersa nella lezione di venerdì 23 novembre e ha lo scopo, per me, di avere il polso della situazione nel suo insieme, e per voi l'auto-valutazione; quindi è bene che il confronto con le risposte date da altri (lo faremo a lezione o sul sito del corso) venga dopo aver formulato autonomamente la propria.

1 Vorrei inoltre verificare se e quanto le risposte alle domande che seguono, sono influenzate dall'essere stati o meno presenti alla lezione di venerdì 23 novembre in cui la questione si è posta.

presente
 assente (occasionalmente)
 assente fisicamente (non frequento o frequento poco in aula, ma seguo regolarmente online)
 assente stabilmente (non ho frequentato oppure ho smesso di frequentare)

Il corso si intitola Interazioni Sociali in rete e finora ha trattato di un approccio alla progettazione di ambienti di interazione sociale in rete.
La lezione di venerdì 23 si intitolava: Strumenti per la realizzazione di siti Web: i CMS.
Quindi l'ambito di attenzione è leggermente diverso: in un caso i siti web, nell'altro gli ambienti di interazione sociale in rete.
Sia SW l'insieme dei siti web e ISR l'insieme degli ambienti di interazione sociale in rete, dire in che relazione stanno ("c" denota il simbolo di inclusione)

2

SW c ISR
 ISR c SW
 SW ↔ ISR

Figure 30 Just Learn It! An example from the course in Online Social Interactions.

Ariel 2.0
 Il portale della didattica online di Unimi

Benvenuto nel Portale Ariel, il portale dedicato all'e-learning nel nostro Ateneo. Il Portale contiene siti didattici degli insegnamenti, dei corsi post laurea, dei progetti di accertamento delle competenze in ingresso, test online e molto altro.

Se sei uno studente o un docente Unimi esegui l'autenticazione con il tuo indirizzo di posta elettronica di Ateneo e relativa password e consulta le pagine e i siti a te dedicati, se sei un esterno puoi registrarti al Portale tramite l'apposita procedura.

Il motore di ricerca e le categorie dei progetti ti possono aiutare nella consultazione.

Ricerca siti didattici **Cerca** **Elenco completo**

E' possibile eseguire una ricerca inserendo: una o più parole presenti nel titolo dell'insegnamento, il cognome del docente, oppure il codice dell'insegnamento. Per affinare la ricerca accedere alle opzioni della Ricerca avanzata. Per tornare alla visualizzazione iniziale cliccare "elenco completo".

Siti didattici / 1605 siti online **Per Facoltà o Scuola / A-Z**

- Giurisprudenza / 60 siti didattici
- Medicina e Chirurgia / 222 siti didattici
- Medicina Veterinaria / 98 siti didattici
- Scienze Agrarie e Alimentari / 155 siti didattici
- Scienze del Farmaco / 184 siti didattici
- Scienze della Mediazione Linguistica e Culturale / 111 siti didattici

I progetti speciali

- TFA - Tirocinio Formativo Attivo**
 Percorso finalizzato al conseguimento dell'abilitazione all'insegnamento
- Test online**
 Progetti per consentire agli studenti di verificare il proprio grado di preparazione
- Corsi di recupero**
 Progetti di Facoltà per verificare, integrare e migliorare le conoscenze matematiche di base
- Laboratori online**
 Laboratori dedicati ad argomenti specialistici di discipline scientifiche ed umanistiche
- Progetti di valutazione**
 Progetti per raccogliere opinioni, suggerimenti e osservazioni su specifiche tematiche
- SSRonline**
 Corso di laurea online in Sicurezza dei Sistemi e delle reti informatiche
- Progetti per le scuole**
 Progetti dedicati ai docenti e studenti delle scuole superiori

Elenco progetti:
 seleziona...
 Selezione un progetto per accedere alla scheda

Figure 31 Ariel 2.0. Welcome page of the University of Milan most commonly used LMS.

This entails difficulties when it comes to solving issues with the configuration of the software and paucity of materials available to guide administrators step by step in the configuration itself. In addition, even though the two LMSs might have been familiar to users coming from the University of Milan, their 'peculiar' User Experiences (UXs) would have required quite some effort to newcomers in order to work out how the platform worked.

– Moodle¹²³

Moodle is the most widely used system to handle and manage learning online for a number of organizations. It has progressively become established as some sort of Wordpress of the

¹²³ <https://moodle.org/> (last access August 7th 2014)

LMSs¹²⁴. The open source software developed collaboratively by the community that engages with Moodle is available to anyone for free alongside a huge amount of materials guiding educators and administrators through its installation and management. The community of developers is led and coordinated by an Australian headquarter which receives financial support by a sizeable number of companies that deliver services linked to Moodle worldwide. Its core functionalities, localized in most languages, can be complemented by a series of plugins covering even more functions. New versions of the software are constantly released (e.g. when we developed, in 2013, the stable version available was Moodle 2.4, Moodle 2.7 is, as I am writing, the most recent stable version). Just like Wordpress, Moodle has a basic structure, which, once installed, can be modified according to one's needs via the installation of themes, i.e. the features that account for how the website running Moodle looks like, and plugins, i.e. additional features that work on specific themes performing functions not present in the basic core of Moodle. Our implementation made use of one plugin only allowing for registration via social networks identities (Facebook and Google+)¹²⁵. Moodle also allows for the installation of so-called additional modules, which are, in Moodle's jargon, supports for activities, which are not provided in the basic configuration of Moodle, e.g. surveys were not available in Moodle 2.5 as a default option, thus we installed a module covering that specific function.

- Khan Academy and OilProject¹²⁶

Khan Academy, just like OilProject (which, contrary to Khan Academy, is in Italian and is a for profit initiative), are basically public repositories for free online courses. Content is generally prepared by teachers and subsequently vetted by some sort of editorial team of the website. Anyone can join in Khan Academy as a coach, but this only means that he/she can recruit people for participation to existing courses. There is no way, for coaches, however, to constrain users to their own courses. OilProject does not offer the chance of participating as a

¹²⁴ Wordpress is the most widely used Content Management System worldwide. Its modular structure and the open source nature of its core code allow for countless implementative possibilities.

¹²⁵ This plugin also caused some troubles with users trying to retrieve passwords they never set in the first place given that they had logged in via their Facebook or Google accounts.

¹²⁶ <https://www.khanacademy.org/> and <http://www.oilproject.org/> (last access August 7th 2014)

coach, thus excluding also that one could simply log in and manage a course with some analytics available.

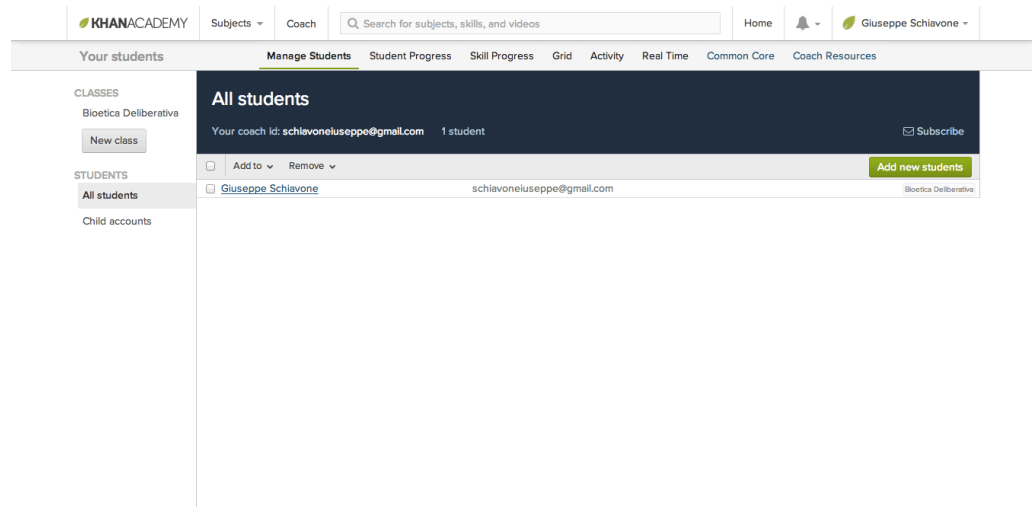


Figure 32 Khan Academy. An empty coach's dashboard, offering analytical tools to manage classes taking existing packaged courses.

Regardless of the merits of the high-end GUIs of these websites, the lack of a proper way to upload and manage one's course posed a serious problem for the configuration of our bounded workflow for participation consisting of more than one stage. Unless we directly asked one of the two enterprises to join our team, the chances that anything like the consultation we set up was developed were nil.

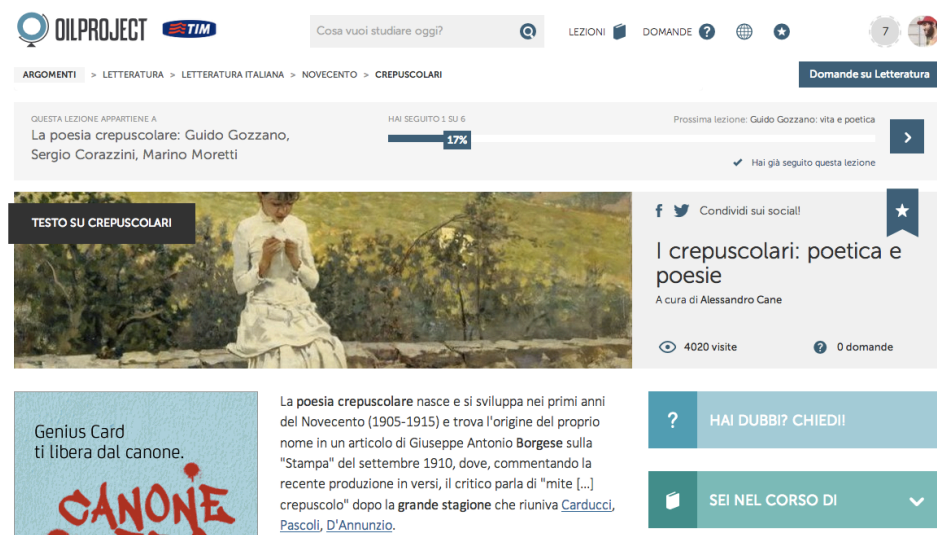


Figure 33 OilProject. How a course about Guido Gozzano's poetry looks like.

Other desired features were also lacking in both these tools: no collaborative drafting of materials module was available, which defeated two of the central purposes of the experiment:

(i) having two different groups with information materials that could be changed and adjusted to participants' perplexities by participants themselves and (ii) having one group drafting their own guidelines collaboratively. Moreover, and even more importantly, none of the two solutions had any part of the environment specifically dedicated to issue specific peer-to-peer discussion. This, along with the need to actually agree with administrators about the upload of the consultation on their website (which might have resulted in some compromise concerning the content) and with some doubts about the perception that hosting a participatory consultation on systems developed deliberately and explicitly for learning might have stimulated, made us discard these two solutions altogether.

The table below summarizes information concerning the LMSs analyzed.

e-learning tools	Just Learn It!	Moodle	Ariel 2.0	Khan Academy	Oil Project
Aims	UNIMI e-learning	The Wordpress of e-learning	UNIMI e-learning	e-learning	e-learning
Installation	Not required	Required	Not required	Not required	Not required
Desired features					
Discussion forum	.	√	√	.	.
Analytics	√	√	√	√	.
Directed workflow	√	√	.	.	.
Collaborative wikis	.	√	.	.	.
Quizzes	√	√	.	√	√
Material Attachment	√	√	√	.	.
Gamification	.	√	.	√	√
Languages	ITA, ENG	ALL	ITA, ENG	ENG	ITA
CONS	– Bare GUI	– No argumentative structure	– Vast and confusing	– Unconstrained interaction	– Sponsored and difficult to publish a course
PROs	– Integrated w/ OpenDCN	– A whole established environment – Easy SN login	–	– Cool UX	– Cool UX

Table 4 e-learning tools. A feature-wise summary.

With this (by no means exhaustive) classification available we were confronted with the choice whether to bundle together two or more tools (which would have required substantial programming efforts) or to sacrifice some of the relevant features, with particular reference to a properly argumentatively structured environment for discussion, and configure one tool in order to have it comply with the majority of our desiderata, most importantly the set of a lower bound for competence for participation. We went for the second strategy due to mostly pragmatic reasons, i.e. tight budgetary and time constraints. Eventually we picked Moodle and turned it into our tool of choice.

At some point along the process of designing the environment, we explored the option of having one technology ‘stitched’ onto another without having to give up on any of the desired features. However, as time passed, it became progressively clearer that such a possibility, though theoretically reasonable, was practically unmanageable given the tight budgetary constraints by which we operated. Essentially no developing effort exceeding the mere installation and configuration of one tool could be supported. The analysis of how to fit tools together has been therefore removed from this chapter.

Moodle’s modular structure and extreme versatility allowed for the implementation of the mix of education and discussion that we needed, without requiring any developing effort other than the actual configuration of activities from the administration panel. The manpower needed in order to set up the consultation this way was really little and this consideration might be taken to have a bearing on the efficiency of such kind of initiatives.

Once singled out the technology, we installed Moodle on our deployment server (*Scienza in Rete’s* servers hosted it), tested the environment in its configured form and started planning for recruitment. The next section reports on our recruitment efforts.

Recruitment

We officially launched the online system on March 26th with a formal presentation held at the *Acquario Civico* of Milan. The presentation was also streamed online on *Scienza in rete’s* website. During the meeting the tool was introduced, described and critically examined by a panel of discussant, made of both academics and journalists. Representatives of the Municipality of Milano attended and spoke out their interest in the initiative.

Stage one of the process described above unfolded during the month of April, while stage two kicked off in May.

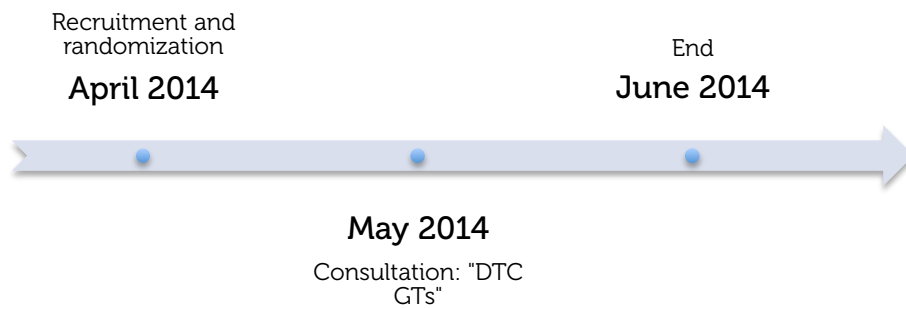


Figure 34 Timeline for the consultation

The recruitment of 300 people was set as the target for the earliest phase following the formal kick-off of the project. In the remainder of this paragraph I will present some tentative reasons why setting up this lower bound for the sample made sense, given the information we had prior to the launch of the consultation. Then, I will list the recruitment channels that we tried to open up. This allows for a more accurate estimate of the number and kind of people that were addressed. This estimate was subsequently double checked surveying participants in order to gather who referred them to the website.

Setting a lower bound for recruitment

Smith, John and Sturgis (2013) reviewed the main publications analyzing or reporting data concerning the use of ICT solutions for online deliberation. The overview was mostly focusing on asynchronous online forums. As I said already, even though, according to the review, most top-down civic engagement initiatives already resort to this kind of technical solution, the scientific literature has been focusing overwhelmingly on synchronous forms of participation (regardless of the fact that these seem intuitively to share some of the technical shortcomings of offline deliberative forums). Two significant exceptions are the abovementioned paper that presents the overview itself alongside a RCT testing an online forum, and a paper by Rhee and Kim from 2009 (Rhee and Kim 2009). The experimenters in Smith, John and Sturgis (2013) recruited their sample through an IPSOS-Mori online panel, which was made up of 370'000 subjects. 51'500 were selected setting quotas on and subsequently invited to participate in the forum. Of these 51'500 subject only 6'009 accepted the invitation and were randomized to 3 groups (two treatment groups and one control group): this means the panel had a response rate of about 15%. Participation to this online forum was economically incentivized (reward points were offered for participants that would be about 100 times the size of points rewarded for

filling an average survey). Rhee and Kim's article presents data concerning the Daum Deliberative Democracy project. This is an experiment conducted in South Korea, where daum.net¹²⁷, a website offering online services that range from e-commerce, to media content, to online searching, hosted a deliberative forum for the 2004 political elections. In 2004 the website was the most visited website in South Korea. Publicizing the initiative on daum's homepage the authors managed to recruit 36'485 people. Once they would sign in the "Discussion Plaza", users were randomly assigned to one of 8 treatment groups. I will not delve here into the details of these treatment groups (a series of hypotheses about factors that contribute to the deliberative quality of participation were tested). The interesting bit for us here lies in the post-test survey response rate: the survey was sent via email to more than 2 million registered users and the 2.4% of these completely filled the survey.

Contrary to what happens for citizens' juries and deliberative polls, for which oversized samples entail the degradation of some desirable outcomes, fixing an upper bound to the size of the sample for participation in an asynchronous forum would not make much sense: in fact, there is possibly no limit to the number of participants that might effectively and properly take part to deliberation as hosted on asynchronous online forums.

The reason why 300 users was set as the lower bound for our recruitment was instead essentially pragmatic and depended on the outreach we could realistically aim for relying on our advertising channels. In order for the sample to be randomized properly to the 4 groups, the total number needed to be known in advance (we did not have the technical means to automatically randomize users as they signed in). Hence we could not afford to keep the recruitment open over time (specifically after the first users had started their consultation). The experimental pipeline was therefore divided in two distinct moments: (i) recruitment and randomization and (ii) participation. The duration of the first moment, again, had to be defined as a function of the effectiveness of our advertising campaign (the sooner we filled our minimum sample size, the earlier the recruitment campaign could potentially be closed). Below is a list of our advertising channels' outreach, building upon which I give an estimate of the response rate that would be required to fill the minimum sample.

¹²⁷ http://en.wikipedia.org/wiki/Daum_Communications (last access June 1st 2014).

Fondazione Rete Civica di Milano. The *partecipami*¹²⁸ network alone has more than 3'000 registered users and a monthly average of 12'000 individual visitors. This pool of registered users has been said to have a fairly high response rate (comparable to that of the IPSOS-mori panel mentioned above).

Scienza in Rete is an online magazine devoted to the discussion of science and technology issues. It has a newsletter with more than 5'000 subscribers and its website receives about 1'500 individual visitors every day.

Cognitive Science and Decision-making Processes students. UNIMI gave permission to resort to the list of institutional email addresses of students enrolled in the masters degree in Cognitive Sciences and Decision-making Processes. For the year 2013/14 325 were enrolled in the program and the program had been open since 2008.

Adding up the users belonging to these three networks and assuming a negligible degree of overlapping between them, we cast a prudential projection of a 3% response rate and assumed it would allow pretty safely for a sample size of 300 users. Hence this lower bound was set as a realistic goal to achieve.

The actual recruitment

Though this rough calculation provided some clue as to the time to be allocated to recruitment and as to a reasonably sized sample, there was no guarantee that those channels would be sufficient. Hence, the initiative was advertised through any channel that was accessible to the network of the working team, and thanks to the support of *Scienza in rete* professionals, IEO and San Raffaele press office workforce, it managed to get a fairly wide outreach. This, as I will show, was not however immediately translated in participation by those reached through these media. In the following paragraph I list all the instances in which the initiative was mentioned and more or less directly advertised, qualifying the source with explicit reference to those sources contacted in an the attempt at fostering the highest degree possible of inclusion.

- Well in advance of the launch of the initiative, on February 5th, *La Stampa* published a piece¹²⁹ written by Giovanni Boniolo, outlining the democratic method for deliberation in the Life

¹²⁸ <http://www.partecipami.it/users/listmembers> (last access August 10th 2014).

Sciences already presented in his *The Art of Deliberating* (Boniolo 2012) and in the abovementioned paper published in the *Journal of Medical Ethics* and co-authored by Pier Paolo Di Fiore (Boniolo and Di Fiore 2010). The article presented textbook success stories of bottom-up deliberative-democratic efforts in the governance of the Life Science (i.e. the HFEA consultation on cytoplasmic hybrids (HFEA 2007) and the Oregon Health Plan deliberation) and hinted at the forthcoming consultation hosted by *Scienza in rete*, thus calling for participants.

- *Il Sole 24 Ore* is a daily business newspaper, formally owned by *Confindustria*, the Italian association of employers with a moderate readership of slightly more than 1 million people. It has a Sunday special that deals specifically with cultural and scientific issues. Some participants reported having heard of the consultation through *Il Sole 24 Ore*, however no one in the working team published anything, nor are we aware of any mention of the initiative in the newspaper.
- *Scienza in rete* of course contributed greatly to the advertisement of the initiative sending out a call for participations to the subscribers of its newsletter, publishing a series of articles¹³⁰ making explicit reference to the initiative and having a banner sitting on their homepage throughout the entire recruitment phase.
- Pietro Greco, an Italian medical doctor and science popularizer, is one of the hosts of *Radio3 Scienza*, a science daily that broadcasts on Radio 3 RAI. The show goes live, every weekday, from 11:30am, until 12:00am. On March 26th prof. Giovanni Boniolo was interviewed for an episode of *Radio3 Scienza* entitled “Vital dilemmas”¹³¹. Boniolo presented both the book that was about to be released (Boniolo and Maugeri 2014), a handbook in bioethics edited by Paolo Maugeri and him whose chapters are authored by most of the members of my own PhD program in Biomedical Humanities, and the launch of the online consultation.

¹²⁹ A copy of the article, entitled “When England overcame their fear of hybrids” (in Italian “Quando gli inglesi vinsero il terrore degli ibridi”) and published only on paper can be found here:

http://www.scienzainrete.it/files/quando_gli_inglesi_vinsero_il_terrore_degli_ibridi.pdf (last access June 8th 2014)

¹³⁰ See, for instance <http://www.scienzainrete.it/contenuto/articolo/giovanni-boniolo-luca-carra/conoscere-deliberare-anche-online/marzo-2014> (last access June 9th 2014).

¹³¹ The title is a pun, in Italian, for “vitale” means both concerning life (and therefore biomedicine) and essential. The episode can be streamed at: <http://www.radio3.rai.it/dl/radio3/programmi/puntata/ContentItem-7036a4b5-b209-4e42-afc7-7319021d09d6.html> (last access June 8th 2014).

- Anna Alberti, head of the “Health” section of Marie Claire, published an article tackling the specific issue of testing for genetic predispositions via Direct-to-consumer services. This piece¹³², mentioning the consultation calling it an “online survey”, reported the author’s experience of filling in the first questionnaire and the doubts that the topic cast. The contribution was unfortunately released only online and a few days after the recruitment phase was closed and it therefore is very unlikely to have contributed to the actual recruitment.
- Nexa for Internet & Society at the Politecnico di Torino is “an independent research center, focusing on interdisciplinary analysis of the force of the Internet and of its impact on society”¹³³. An invitation to participate to the initiative was extended to subscribers of Nexa’s newsletter.



Figure 35 Chiara Lalli's piece published on Wired.it

- Chiara Lalli, who sat as a discussant during the kick-off conference held on March 26th, decided to promote the consultation writing a piece that was published both on the online version of Wired Italia¹³⁴, the Italian version of a monthly magazine devoted to science and technology from a distinctively pop angle. The same article was also posted on Lalli’s and Giuseppe Regalzi’s blog¹³⁵.

¹³² The article is available online at <http://www.marieclaire.it/Benessere/Fare-o-non-fare-il-controllo-genetico-La-parola-a-quattro-esperti> (last access June 8th 2014).

¹³³ Nexa short presentation, <http://nexa.polito.it/nexafiles/Nexa-short-presentation-English.pdf> (last access June 9th 2014).

¹³⁴ <http://www.wired.it/scienza/medicina/2014/04/01/bioetica-deliberativa/> (last access June 9th 2014).

¹³⁵ <http://bioetiche.blogspot.it/2014/04/bioetica-deliberativa-come-discutere-di.html> (last access June 9th 2014).



Figure 36 bioeticadeliberativa advertised through a banner on the top-right corner of each page of *Bioetica* <http://bioetiche.blogspot.it/>, a collective thematic blog updated by Chiara Lalli and Giuseppe Regalzi.

- Cristina Tognaccini, scientific journalist and contributor to Linkiesta¹³⁶, an online only newspaper, interviewed me and Giuseppe Novelli, renown geneticist and currently dean at the Università degli Studi di Roma Tor Vergata. She presented the consultation in my own words and introduced both a bullet point reconstruction of the origin of bioethics and of the issues concerning the DTC distribution of genetic tests in Novelli's words.



Figure 37 Linkiesta published a piece explaining the consultation and its topic, i.e. DTC genetic tests.

- Paolo Maugeri and I, in a deliberate attempt at recruiting the very young, presented the consultation to three high school classes in Melegnano. The lecture, interactive and educational in nature, tried to introduce the idea of rational adjudication of moral claims via argumentation, underlining its importance in the management of moral disagreement at the societal level. Then we introduced both the topic of DTC genetic tests highlighting their

¹³⁶ <http://www.linkiesta.it/bioetica-deliberativa> (last access June 9th 2014)

promises and their actual and current downsides and explained the functioning of the platform.

- A lecture of the course in Bioethics for students of biotechnologies at the Università degli Studi di Milano was devoted to the introduction of the controversy over DTC genetic tests and to the presentation of the platform.



Figure 38 I nipoti di Maritain post advertising the consultation.

- In order to try and involve explicitly catholic participants, we reached out to openly catholic groups. Within this category falls “I Nipoti di Maritain”, which is a blog deliberately trying to provide Catholics with intellectual guidance and a space for open discussion of cutting-edge issues. Lorenzo Banducci published a post¹³⁷ calling for participation by their readership on April 11th. Another openly confessional group whose collaboration we asked for and obtained in order to secure some degree of variety in religious affiliation in the sample is an informal newsletter group used by a catholic fringe of the Milanese Partito Democratico. Thanks to Anna Scavuzzo we managed to reach out to its subscribers.
- In September 2013 the Laboratory for Civic Informatics of the Università degli Studi di Milano organized and hosted the “I Codici (Software) della democrazia” workshop. This workshop was meant to strengthen links in the network of Italian academics and practitioners engaging with e-democracy in the broadest sense. The consultation was presented at the workshop, during its conclusive session, and an invitation to participate was extended to all of the participants via the website that was used for discussion during and after the workshop.

¹³⁷ http://nipotidimaritain.blogspot.it/2014/04/bioetica-deliberativa.html#.U7vqUo1_vN8 (last access June 12th 2014).

Towards the end of March I personally published a post inviting participants of the workshop to attend the kick-off presentation on March 26th and also to fill in the first survey¹³⁸.

- PartecipaMI advertised the consultation both on its forum and on its Facebook page. It also sent out an email inviting subscribers to its newsletter to participate.
- We also sent out two emails inviting students enrolled in the Cognitive Science and Decision-making Processes master course to join in the consultation.

During the first week of May, recruitment was successfully closed with 310 properly profiled prospective participants.

Results

Summary

The sample that was recruited was not representative of the Italian population. In particular, it was slightly younger than the overall population (with a median age of 44 years as opposed to 48), and with an uneven age distribution (very few people from 35 to 45 were enrolled). Participants generally had a high socio-economic status (SES) as measured by income and education and were men in the 55.3% of cases. In particular, less than the 1% of the sample held a junior high-school diploma or lower degree, whereas, in this same category falls the 53% of the Italian population.

Men in the sample were single in a rather significant proportion of cases, while both women and men divorced in our sample were more than three times the proportion of divorced women and men in Italy overall. Participants, as one might expect, accessed the Internet with a very high frequency (almost everyone did more than once a day) and were less likely to be Catholic than the general population, although the definition of the rate of Catholics to non-Catholics in Italy raises some methodological difficulties. The overwhelming majority of participants came from the Northwestern part of Italy.

Participants were on average very liberal and not very conservative, with a specific peak of liberalism concerning their attitudes towards economic policy (M=7.05 on a scale of 1 to 9).

¹³⁸ Here is the post I am referring to: <http://codicidellademocrazia.partecipate.it/infodiscs/view/112> (last access June 12th 2014).

Regardless of our efforts at reaching out to the most diverse range of participants (see above The actual recruitment), people were drawn to the consultation mostly through word of mouth.

We found no interesting correlation between self-reported religious/spiritual belonging, liberalism/conservatism and bioethical issues selected for discussion. This might be the result of a sample strongly affected by self-selection bias. Interestingly, however, long-standing 'classical' issues in bioethics, such as abortion and end of life, attracted a lot of attention across the whole sample, suggesting that these might still be regarded as viable candidates for consultation, probably in that perceived as morally controversial their longstanding legal adjudication notwithstanding.

Along the consultation, participants would log into the platform mostly after recall emails were sent out. The average time spent on the platform, per session, was rather high (9' 09"). The degree of engagement as measured via the number of users accessing the platform over time, did not decrease significantly over the course of the consultation, suggesting that it is indeed possible to maintain a fairly highly active participation through time in case the consultation has the sort of articulated workflow described above.

As to the compliance to the experimental treatments, relative to our control group, we find that no individual trait had a recognizable effect on compliance other than belonging to one of the experimental groups. In particular, as the burden of participation increased (from control upwards), the likelihood that people stopped engaging increased. Noticeably, however, both the coefficient for discussion without any explicit goal set for the discussion and that for information turned out to be lower (more in the negative: -2.20811 for group (b), -3.06627 for group (c) and -1.91055 for group (d)) than that for goal-oriented discussion. This link is interesting and deserves further investigation on a larger sample, in that it might suggest that tasking a group explicitly with a goal increases the chances that, regardless of whether they do accomplish the task (which in our case they did not), they are more motivated to participating as 'engagers' suppose them to.

As to the so-called transformative potential of deliberation, we found that deliberating has indeed some preference-changing potential, in that compliance to the three treatments has some effect on people's minds about the issue at stake (specifically, in our case, moving their opinions towards agreeing more to the practice of DTC GTs than they initially did). Investigating the mechanistic nature

of these changes, I found evidence that the both the inner-forum discussion of members of group (b) and the discussion held in both forums for groups (c) and (d) were of very high deliberative quality (as measured via 4 and 5-components DQIs (Steenbergen et al. 2003)). However, respondents to our post-test survey highlighted that they did not feel like participation to the forum made them change their view on the topic. This apparent inconsistency is discussed below and delved into in the last section of this work.

The sample and the population

A total of 310 people completed the pre-consultation survey described above. I report on the relevant traits that were singled out for the sample and, wherever possible, compare those traits with analogous features in the Italian population.

Gender and age

In this paragraph I first compare the gender and age of our sample against what we know about political engagement in Italy. I subsequently contrast the same information to the distribution of gender and age in the general population in Italy.

According to the latest data published by ISTAT, there are 13 men older than 14 in every 100 and 7.3 women older than 14 in every 100 that engage daily in political talk. Also, the 23.6% of men claim they “Never” talk politics as compared to the 40.8% of women. Taking talk about politics as a proxy for engagement, if we look at the stratification of these percentages according to respondents’ age, as shown in **Figure 39** and **Figure 40** below, we notice that the very young hardly ever talk about politics, suggesting they are effectively disengaged and that the percentages of people who never talk about politics tend to decrease as age grows and increase again, especially for women, in people older than 60. Naturally, those who report they talk at least once a day about politics display a somewhat complementary arrangement: very few young people actively engage in political talk, whereas approximately half of the men in their late 40s until their 70s talk daily about politics.

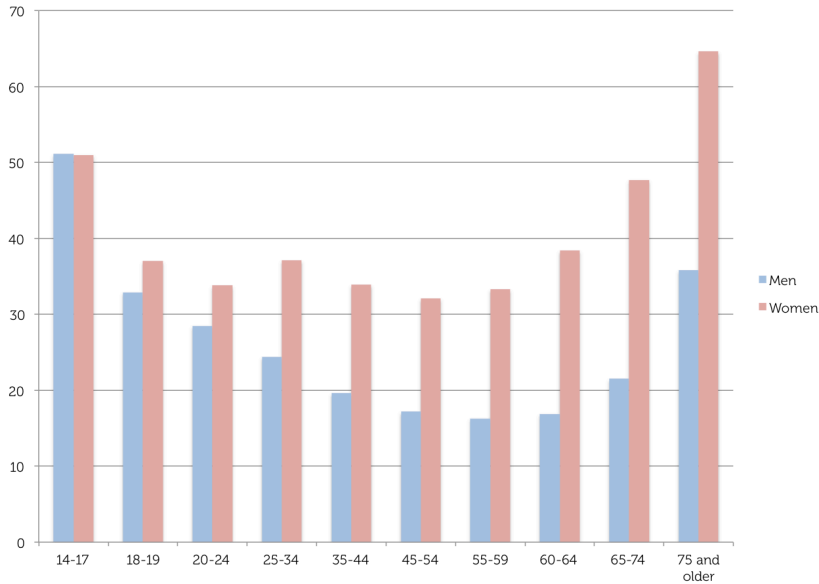


Figure 39 People who never talk about politics in every 100 people with the same characteristics. Men vs. women in age groups. Data are for the year 2010. Source: ISTAT

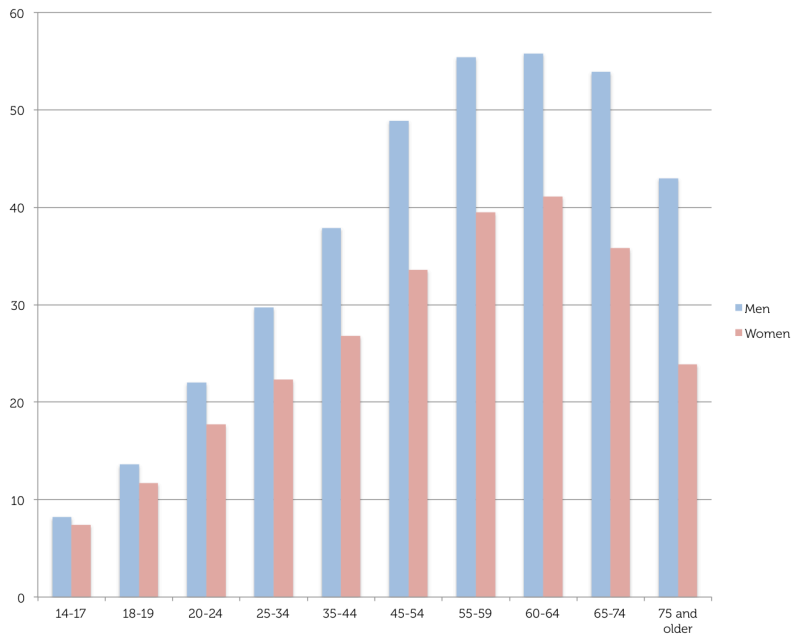


Figure 40 Men and women who talk daily about politics in every 100 people with the same characteristics. Men vs. women in age groups. Data are for the year 2010. Source: ISTAT

A similar trend applies to women, with a significant gap as compared to men. Geographically, Italy has what can be roughly defined a ‘gradient of political engagement’ that goes from North to South, with North-Western Italy having the 36.7% of people talking every day about politics, North-Eastern Italy

the 41.8%, the 37.7% in Central Italy¹³⁹ while only the 25.7% of people who live in the Southern part of Italy talk politics daily.

This information led us to informally forecast very low participation from the very young (younger than 20) and the very old (older than 65), also due the kind of recruiting strategies we deployed as to the former and the ‘technological’ barrier as to the latter. This was only partly reflected in the data we collected.

The median age of our sample is 44 years, with a slightly higher value for women (46 years old). The average age is instead 43.2 years old. In the Italian general population, considering only people older than 14, the median age is 48 years old, suggesting that the recruited sample does not differ dramatically from the population in this specific regard.

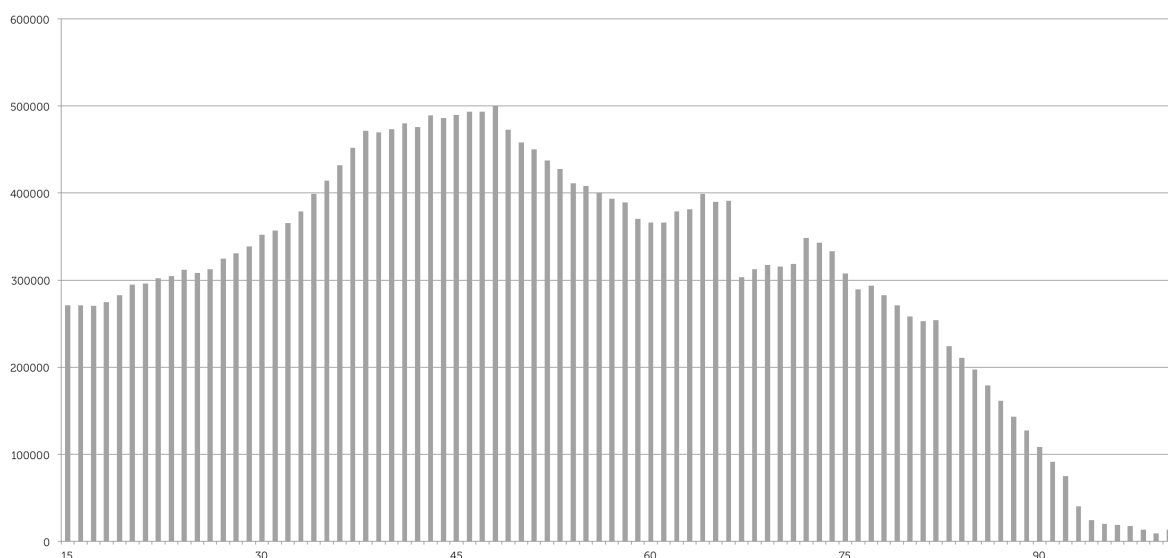


Figure 41 Overall age distribution in the Italian general population. Source: ISTAT

The overall rate of men to women in the participating population leans towards the side of men. A total of 171 men (55.3%) and 136 women (44%) successfully completed the pre-consultation survey (two people preferred not to disclose their gender and one failed to input a properly formed date). This skewedness partly confirms the hypothesis that men are more likely than women to engage actively with politics.

¹³⁹ Tuscany and Emilia Romagna contribute substantially to the high percentages of political engagement in the North-East and Central Italy respectively with 42.4% and 46.4% of people who actively engage daily with politics. These regions have traditionally had voter turnout rates slightly higher than all other regions, e.g. in 2008, when the average turnout was 75.2% for the lower chamber of the Parliament, in Tuscany the 79.2% of the population with voting rights voted while in Emilia Romagna the 82.1% submitted a valid preference. Source: <http://elezionistorico.interno.it/index.php?tpel=C> (last access: June 8th 2014).

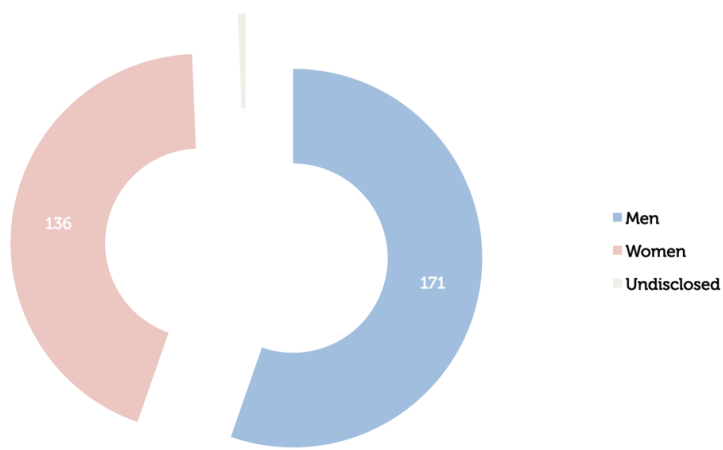


Figure 42 Overall rate of men to women in the participating sample

Somehow unexpectedly, however, the difference between men and women in the sample is reverted for older women. In particular, there are more women than men in the age group 50-54 and 55-59, which does not fit in the description of the politically engaged population outlined. In absolute terms, though, this difference has little impact in the gender distribution of the sample suggesting that the reversal in proportions might be due to chance alone.

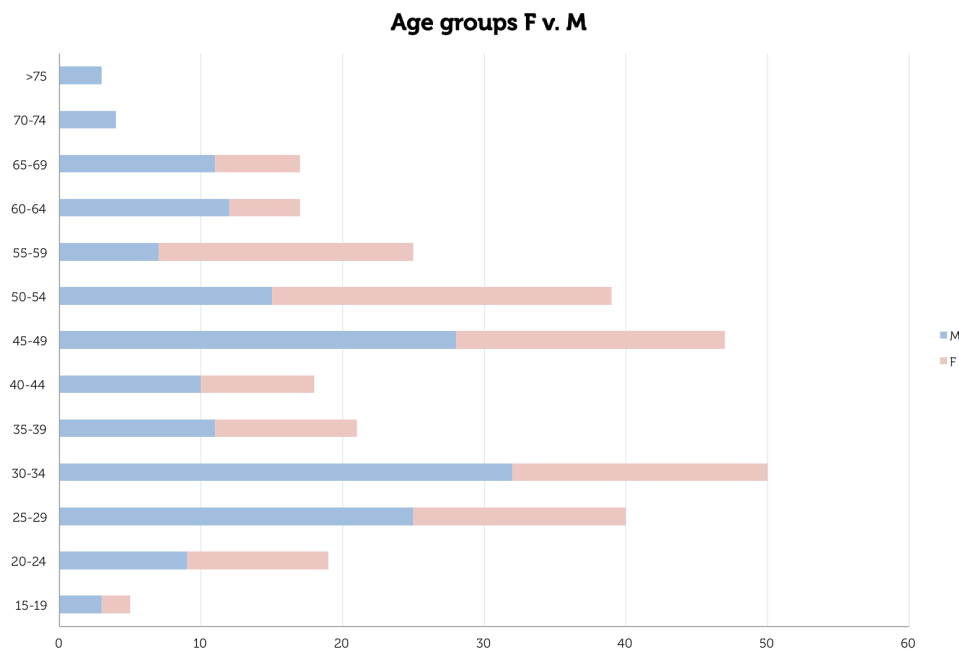


Figure 43 Age stratification of men and women in the participating population.

Considering now the aggregate measure of participation for age groups and comparing it to the Italian population, it is worth noting that, as of 2013, there are approximately 24.6 million (48%) men aged 15

or older in Italy and 26.7 million (52%) women in the same age span¹⁴⁰, with the age distribution illustrated below in **Figure 41**. The sample recruited is, in the light of what just said, highly unrepresentative of the overall population. The sample also departs from what one might expect the ‘engaged’ part of population responding to the initiative to be.

Geography

Within the sample, each part of the Italian peninsula was represented by at least a few individuals. The vast majority of people (198), however, reported they lived in the North-Western part of Italy. Only 44 people came from the North-East, 38 from central Italy, 13 from the South, 6 from the Islands (Sardinia and Sicily) and 10 people said they came from abroad.

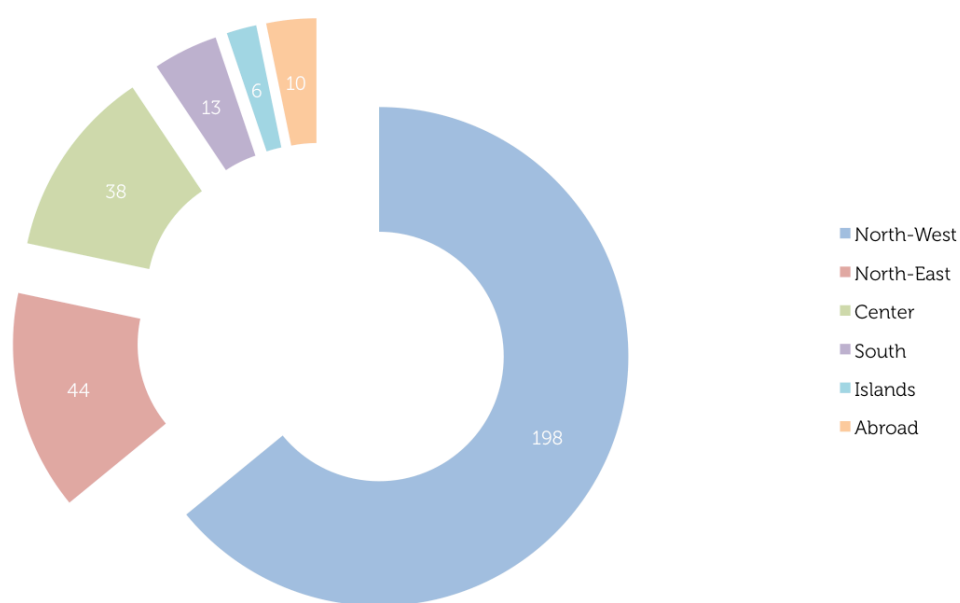


Figure 44 Distribution of the sample according to geographic area.

This distribution is already telling, but if we compare it to the percent distribution of the population in Italy, differences become even more striking. The North-Western part of the country was forcibly over-represented. This has an effect in the under-representation of each and every other part of Italy. Particularly noteworthy is the lack of participants from the Southern part of Italy. On the one hand, this part of the data is consistent with what we know from the most recent information published by ISTAT on the geography of political engagement in Italy. The South has clearly the lowest degree of

¹⁴⁰ The source for all statistics about the Italian general population is the latest ISTAT data available, if not otherwise stated.

political engagement with a mere 24.1% of the population talking daily about politics as compared to the 36.7% in the North-West, the 41.8% in the North-East and the 37.7% in the Center. More than the 32% of the people living in the Southern part of Italy claim they never talk about politics, as opposed to approximately the 23% for the entire Northern part of Italy and slightly more than 21% for the Center.

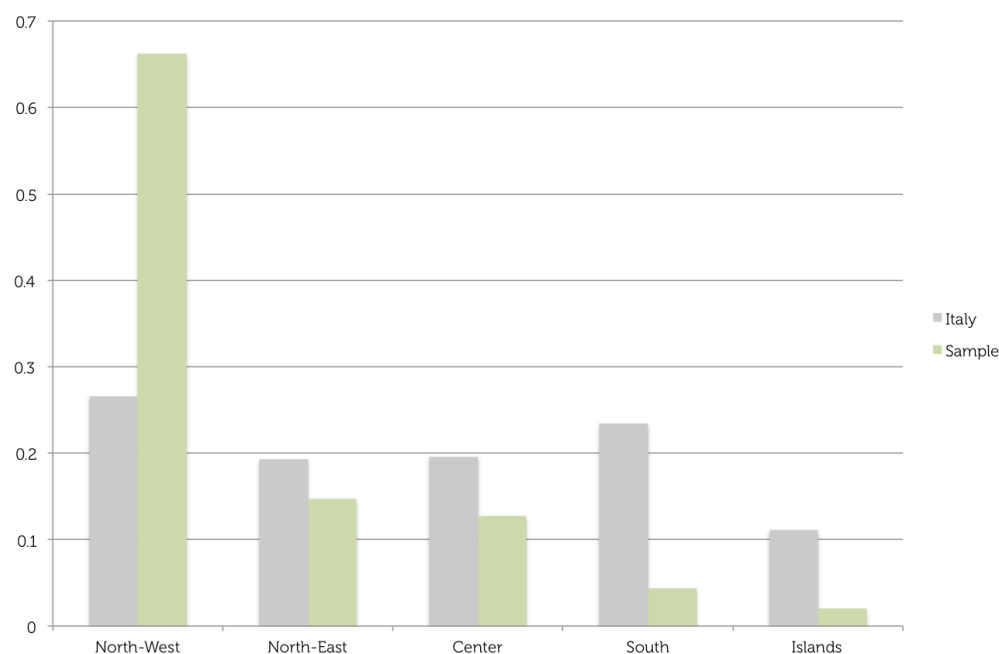


Figure 45 Geographical distribution of the population in Italy (in grey) as opposed to the sample (in green). Source: ISTAT.

On the other hand, however, there is a clear skewedness of the sample towards the recruitment of people from the North-West (especially when compared to the baseline engagement of people from the North-East). This is probably due to the fact that recruitment was initiated, for a significant part, by organizations that either make reference to the area of Milan because they are based in there (e.g. the University of Milan, the San Raffaele Scientific Institute and the IEO) or are specifically dedicated to issues concerning Milan (e.g. PartecipaMI). This trend might have been reinforced by the sort of word of mouth pattern that the recruitment seems to have relied upon (see below Referral).

Education

In 2010, Neblo et al. (2010), found that the worry that democratic deliberation, or democratic deliberative initiative were only interesting “for the small number of people who are already deeply involved in politics” who would use these new opportunities “to press their advantages” (Neblo et al. 2010, 1), was fundamentally misplaced. In conducting a large survey on the U.S. population they

discovered that people’s willingness to participate in hypothetical opportunities for deliberation was far higher and more widespread than previously thought. In particular, and more interestingly, contrary to what was regarded as commonplace in democratic theory, some traditionally disengaged clusters of the population revealed comparatively significantly interested in deliberation. “Younger people, racial minorities, and lower-income people expressed significantly *more* willingness to deliberate” (Neblo et al. 2010, 9). The authors then further investigated whether and to what extent this attitude would translate in actual engagement practice and set up a field experiment, recruiting a random sample of citizens from a number of U.S. districts to an online (synchronous) deliberative forum with participants’ members of Congress to discuss immigration policy. When they did so, they found that these findings were confirmed in practice, both as to the willingness to participate in the actual experiment and as to the likelihood that willing participants will successfully show up at the experiment.

Interestingly, however, the authors seem to overlook the link between willingness to participate and actual participation, and education. In both their field experiment and their survey, education showed a trend—though only marginally significant and only in the field experiment (when comparing those unwilling to participate and actual participants)—linking higher educational attainments and participation. This trend seems to be confirmed, and actually magnified, by recruitment to our experiment, which seems to have been able to draw mostly very highly educated participants.

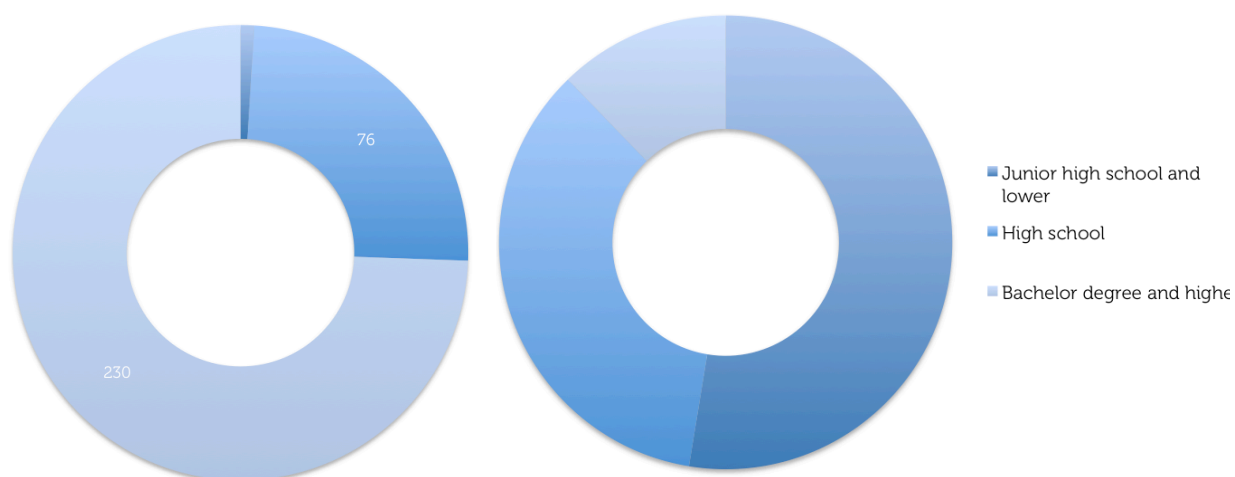


Figure 46 Education of the sample (left) and in the general population in Italy (right).

The two figures above show a pie chart of the relative distribution of our sample and of the general Italian population as to their education. The difference is remarkable. Even provided that most of our

sample comes from the North-Western part of Italy, whose population is slightly more educated than that in the rest of the peninsula, the difference cannot be underplayed. In 2013, in the North-West, more than the 50% of the people only held a junior high school diploma or less than that. This relatively less educated part of the Italian population went basically unrepresented in our experiment. The 74% of our sample, at the time of the consultation held a bachelor degree or higher qualification (versus the 12% in the overall Italian population). But the most impressive figure is represented by the apparent lack of participants with junior high school diploma or lower qualifications: in our sample less than the 1% of the people fell in this category, whereas in Italy, that accounts for the 53% of the population.

This skewedness might clearly be a reason for serious concern also for initiatives tackling similarly technical issues, in that they might be unable to reach out to interested parties with lower educational status.

Marital status

As of January 2013, the Italian population is composed, as a proportion of the overall number of men, by 49.8% of married men, about the 45.9% of single men, the 2.5% of widowers and by only a tiny minority of divorced men. In comparison, our recruited sample has a higher number of unmarried men (more than half of the men who filled in the survey reported to be single) and a lot of divorced men as compared to the ratio of divorced men to men in the general population.

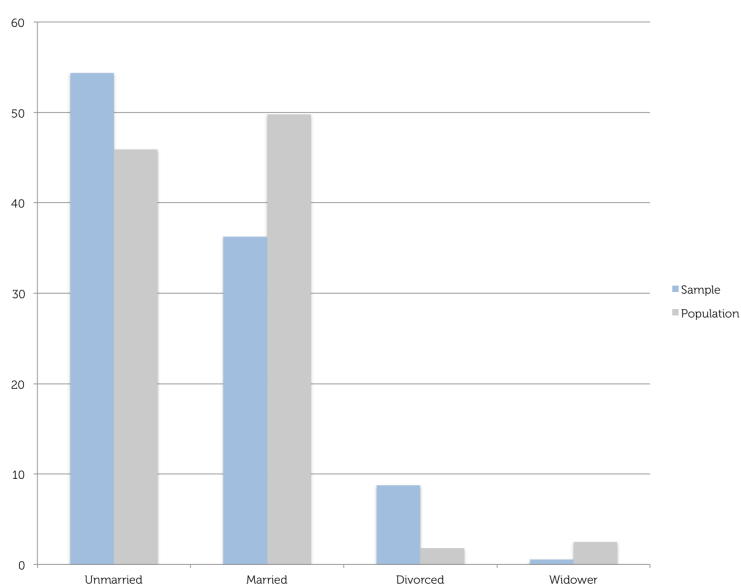


Figure 47 Marital status. Men in the sample and in the general population as a percentage of total number of men.

Similarly to what is true of men, the sample has, as a percentage of the total number of women, a proportion of unmarried women higher than that of the general population, and also a proportion of divorced women much higher than that one finds in the general population (11.7% vs. 2.6%). I can only hypothesize that this prevalence of divorced people in our sample might in part be due to the fact that the overwhelming majority of participants come from the North-Western part of Italy (see above Geography), where the rate of divorces per inhabitants is slightly higher than the average and more than twice the rate in Southern Italy (0.11% vs. 0.05%). Another, very tentative, reason, which could partly explain this divergence might be the overall degree of liberalism of the sample. I presume this degree to be higher than that of the general population. The degree of liberalism can in turn be said to stand in some relationship (positive correlation) to the likelihood of divorce. However this link is really only tentative and some recent research suggests that precisely the opposite correlation is the case in the U.S. The study shows how living in a state with a higher rate of religious conservatives, on its own, makes it more likely that one divorces (Glass and Levchak 2014).

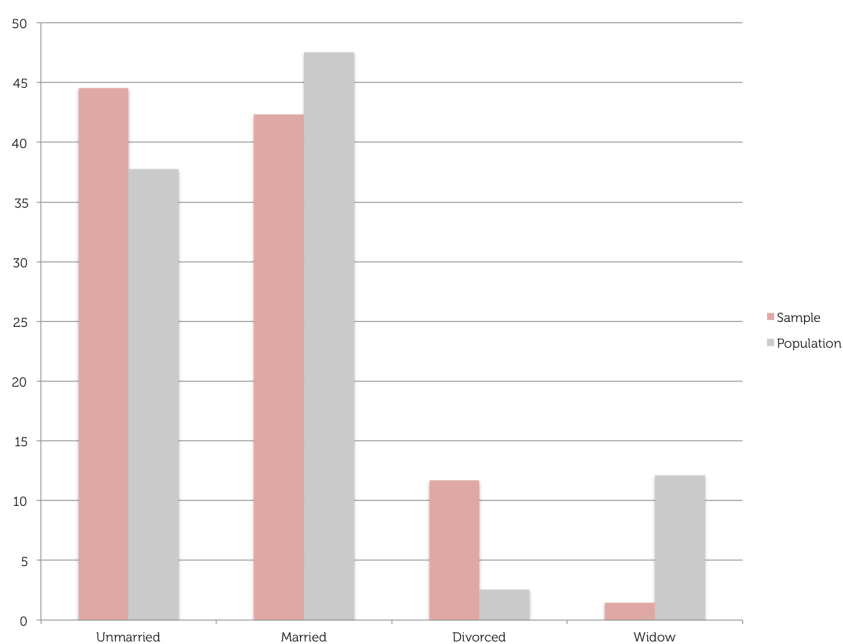


Figure 48 Marital status. Women in the sample and in the general population as a percentage of total number of women.

Members of the family

The average number of family members for Italy was 2.4 in 2011 and had been decreasing steadily for more than 4 decades. The Southern part of Italy has a higher average value (2.7 members per family) (ISTAT 2013). Our sample's average is instead 2.9 members per family. As shown in **Figure 49**, the relative majority of participants come from families of four members.

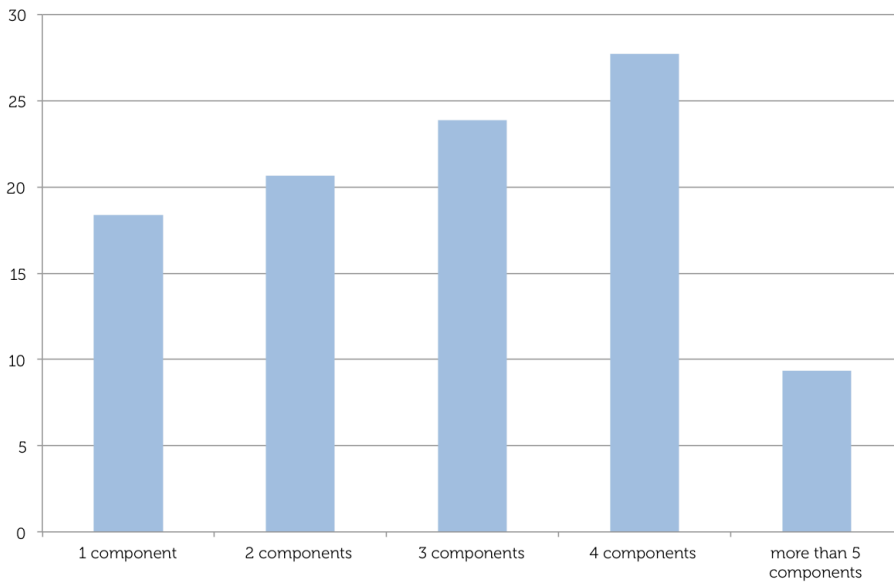


Figure 49 Number of family members for participants in the sample.

This information might have a bearing on the appraisal of the information about income distribution of the sample. Specifically, allowing for a downplay of the standard concern for over-representation of high-income strata of the population. In fact, according to the latest data that I have available, the net income of families depends directly on the number of family members, e.g. a family with four members has an average yearly income of more than €37'000, while a family with only two members earns, on average, €26.961 a year (ISTAT 2008, 4). This, as I will recall immediately below, also has a North to South gradient, which is relevant to the assessment of the sample's actual 'income status'.

Income

I set up this part of the survey deliberately so as to have an immediate readout of the distance of our sample from the population. To do so, I asked participants to self-report on the quintile of their family's net yearly income. **Figure 50** compares the distribution of net family income for Italy to the net family income distribution in the sample. As one might expect, families with low net income are less than they are in the general population. And families in the wealthiest quintile are proportionally more than in Italy overall.

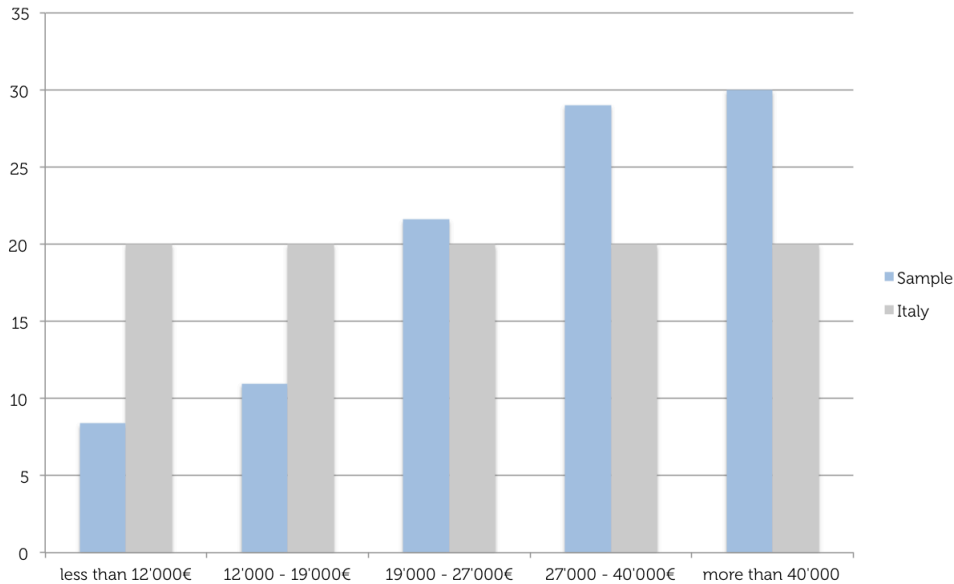


Figure 50 Income distribution for the sample and in Italy. Source: (ISTAT 2008)

However, as I pointed out above, this skewed distribution might be, at least partly, due to the higher average number of family members in the sample with respect to Italian families. More numerous families tend to earn much more than less numerous ones. Also, since most of our sample comes from the North-Western part of Italy, it makes sense to report that the median net family income, i.e. that half of the families make a year, for Northern and Central Italy is approximately €30'000, while in the South the value drops to €21.916, suggesting that our sample is only slightly wealthier than the population from which it was (not deliberately) drawn (ISTAT 2008, 9).

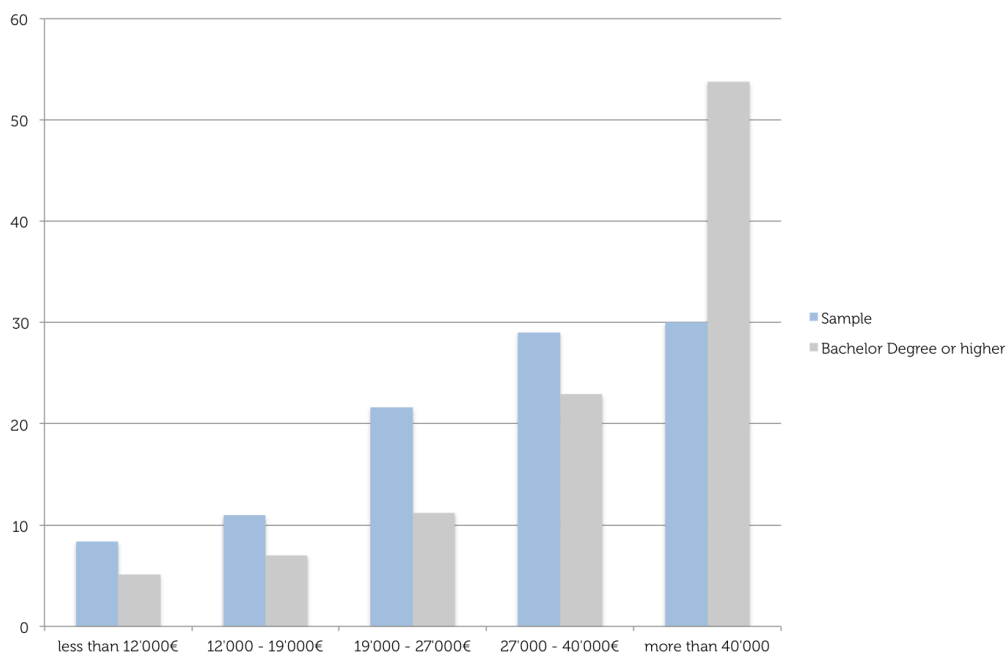


Figure 51 Income distribution in quintiles for our sample and highly educated people in Italy.

Finally, it is worth noting that plotting the income distribution in quintiles taking into account only the most educated part of the population, the differences between the sample and the population become less visible. Our sample has a very high prevalence of highly educated individuals. These individuals show a family net income distribution that is way more skewed to the right end than our sample's is.

Internet use

All of our participants were asked how often they used the Internet (irrespective of the purpose for which they do so). All of them claimed they used it at least once a day and almost everyone (296 people) reported to actually use it more than once a day. This is of course something one expects when setting up an online experiment. Even though the sample is, in this specific respect, particularly unrepresentative of the population (in Italy only the 33.5% of the population reportedly uses the Internet daily, with percentage as low as the 28% in the South), the experiment, in the light of a participation which can be assumed to be relatively skilled as to web browsing, ought to be regarded as particularly informative of the actual usability of the tool we deployed. More precisely, questions contained in the post-test survey in regard to the ease of use of the website must be adjusted taking into consideration the fact that this feedback comes from a particularly capable sample.

Religion

Overall, in Italy, interviewed in 2010, the 32% of the population aged 6 or older would say they go to church (or to some place of worship) at least once a week. The 19.2% would instead claim they never go to church (or to some place of worship) and the 30.6% that they attend church only a few times a year. Taking the yearly attendance as a proxy for religious affiliation—which is a fairly conservative estimate, given that there must be self-reported Catholics who do not go to church at all—I compare our sample's self-reported religious affiliation to see whether there is a higher or lower percentage of religious people. **Figure 52** breaks down the self-reported religious affiliations of participants. Self-reported Catholics account for roughly the 31% of the sample. Unless we equate self-reported religion with weekly church attendance, our sample only has roughly half of the people that would call themselves Catholic in a representative sample. Also, there seem to be way too many atheists and agnostics for the sample to be representative of the 19.2% of the population that never goes to church.

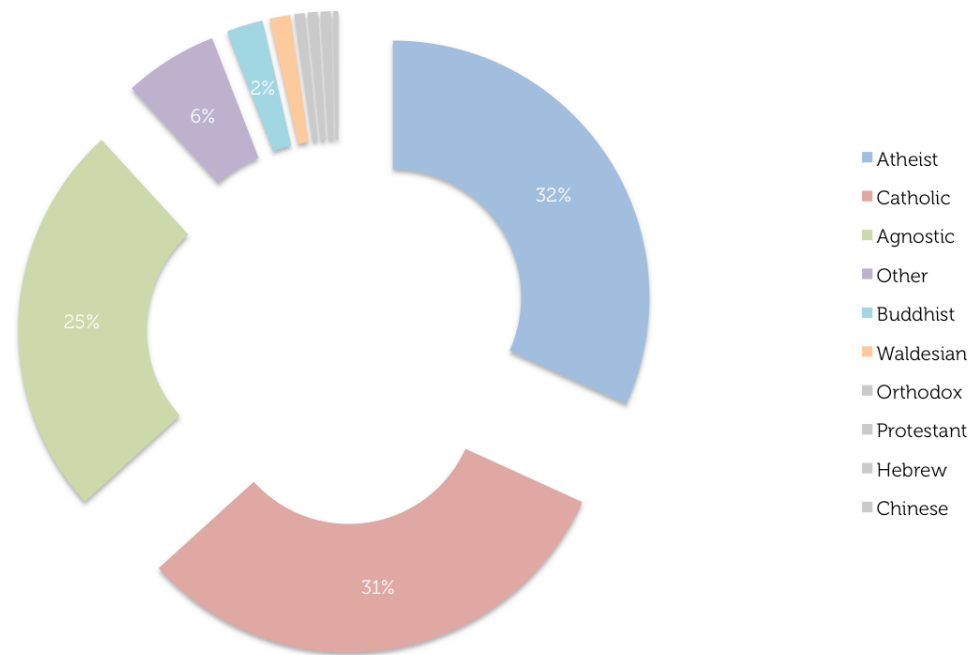


Figure 52 Self-reported religious affiliation of participants.

Liberalism and conservatism

There is no direct way to infer the degree of liberalism and conservatism of the Italian population and I am not aware of any published data in this regard. However it is interesting to have participants characterized according to whether and how liberal or conservative they are, in order to have a clue of the degree of ‘political’ variance within the sample.

We measured self-reported liberalism and conservatism of our participants using the scale developed and tested by Choma, Busseri, and Sadava (2009). Their scale uses a 9-point Likert scale to assess self-reported political belonging. The scale measures liberalism and conservatism separately and both along three different, but clearly non-independent, domains: liberalism and conservatism in general, liberalism and conservatism as to social policy, liberalism and conservatism as to economic policy. I report on the main descriptive statistics along these three axes.

General liberalism	M=6.69 (SD=1.43)
Liberalism in social policy	M=6.51 (SD=1.68)
Liberalism in economic policy	M=7.05 (SD=1.66)
General conservatism	M=2.97 (SD=1.6)
Conservatism in social policy	M=2.96 (SD=1.59)

Table 5 Liberalism and conservatism score along the three axes.

The recruited sample's mean value for general liberalism is 6.69 with a fairly high standard deviation (1.43). The mean for general conservatism is 2.97, with a 1.6 points standard deviation.

This suggests that the sample enjoyed some degree of variation but was decidedly leaning towards the liberal end of the spectrum. Both variation and tendency towards the liberal end of the continuum hold true for the social policy and economic policy axes, with the sample being especially liberal with respect to economic policy. The mean score for liberalism in social policy is 6.51 (with a 1.68 standard deviation), while the mean score for conservatism in social policy is 2.96 (1.59 standard deviation). In economic matters, the mean score for liberalism is 7.05 (1.66 standard deviation), whereas the mean score for conservatism is 2.74 (1.71 standard deviation). Averaging the individual scores for the three items one can appreciate how they are inversely correlated ($R=0.24$, $p=0.00003$), confirming that the instrument worked properly.

Interestingly, this self-reported liberalism did not translate directly onto the answer to our deliberative question. We expected the more liberal attitude towards DTC GTs to be leaning towards at least a partial agreement to the practice. Instead, as reported below, average attitudes towards the commercialization of DTC GTs in all four groups was below 0.5.

Referral

Given the fairly vast advertising effort, it makes sense to try and measure whether this had any visible effect in the way participants were drawn to the open consultation. In order to do so, we asked participants to report from whom or where they heard about the initiative. We found that a relative majority of the sample (136 people, 44%) claimed they heard about the initiative from a friend suggesting that our efforts were somehow vain.

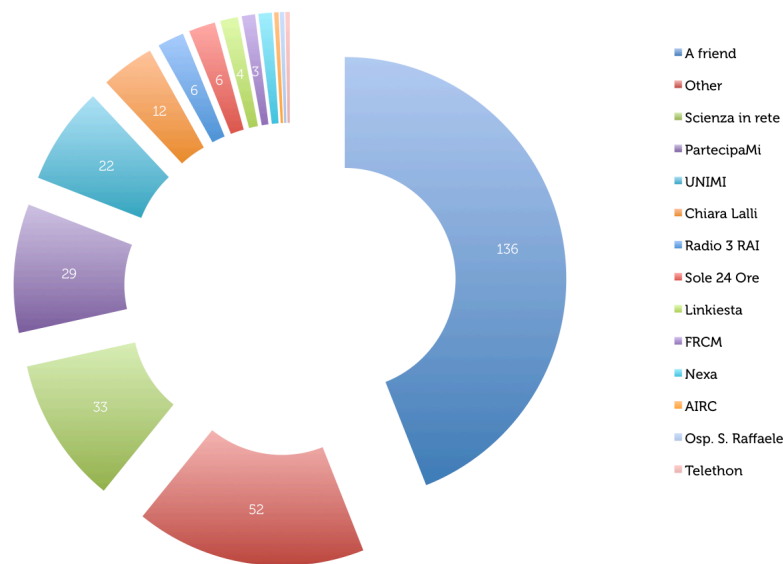


Figure 53 Absolute numbers distribution of referral. Most of our sample heard about the initiative thanks to a friend.

This finding might be further suggestive of the relationship between the kind of motivation that is required by these participatory initiatives, which is fairly high, and the sort of ‘calls’ that participants take action upon. Learning about the project, in this sense, might motivate people more effectively to participate when they are told by someone they trust or know, rather than when they see it or hear it advertised publicly.

The question: feedback and reformulation

One of the features of the process described above is the openness to revisability at multiple stages. The first stage at which the process provides revisable materials is at the first presentation of what I called the deliberative question. A panel of experts formulates the deliberative question first, and subsequently they reformulate it, taking stock of the feedback received by participants. In order to do so I analyzed users’ responses to the question: “Is the question «Is it right to commercialize genetic tests directly to consumers?» understandably and neutrally formulated?”¹⁴¹. Negative responses would prompt participants to reformulate the question so as to have it impartial and understandable.

78 participants said they found the question, in that formulation, not understandable or not neutrally formulated. These users then provided their own input for a reformulation. Open responses in surveys generally pose some degree of analytic challenge. In order to make sense of these responses, I

¹⁴¹ The Italian version was the following: “La domanda “È giusto commercializzare i test genetici direttamente al consumatore?” è formulata in maniera imparziale e comprensibile?”

proceeded to create a code to single out common threads in responses, and have a quantitative take on the relative distribution of these threads. Some questions were coded for more than one thread, in that they contained some reference to different issues.

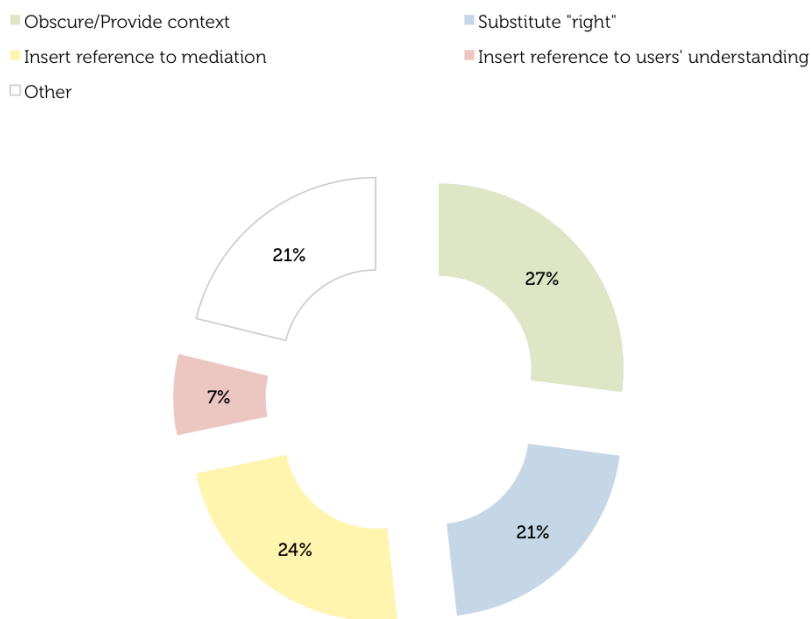


Figure 54 Relative distribution of suggestions on how to reformulate the question.

Common threads identified in the feedback that we received were: (i) first, some underlined their outright impossibility to understand the question, in most cases due to the lack of any context introducing the question itself; (ii) participants suggested that using the term “right” might be misleading and frame the issue explicitly in moral terms and relatedly recommended to substitute it with some, more neutral, term; (iii) they also highlighted the importance of some reference to the presence or absence of mediation for the question to be maximally perspicuous; (iv) some users asked that we inserted a reference to users’ understanding of the tests themselves. This latter suggestions was disregarded because mentioning the issue of consumers’ understanding in the question itself would have defeated the purpose of discussing whether or not commercializing genetic tests directly to consumers, without the mediation of professional expertise was acceptable and legitimate. Points (i) to (iii) were instead integrated in the new version of the question. The panel drafted and edited a 250 words plain language introduction outlining the relevance of the issue of DTC genetic tests and introducing the problem of DTC distribution of genetic tests providing medically relevant information.

The question was instead reformulated as follows: “Are you in favor or against the commercialization of genetic susceptibility tests directly to consumers without the mediation of health professionals?”¹⁴²

The sample's agenda

Participants could pick at least one and at most three issues out of a list. They could further insert one issue of their own choice in case it did not figure in the list. There were several issues receiving quite some votes, given the total amount of participants, but one issue clearly stood out of the crowd: that was “Abortion and end of life”. As shown in **Figure 55**, the second most voted issue received slightly less than 80 preferences, whereas 164 votes expressed a strong preference for the discussion of the issue of “Abortion and end of life”. This indicates that, contrary to our initial hypothesis, no matter however unrepresentatively liberal our sample turned out to be, still the issues that the vast majority of people wanted to discuss was the most prototypical example of classical bioethics. Speculating on this result, I hypothesized two, partly mutually exclusive, explanations for why this might have been the case: the first hypothesis assumes some degree of ignorance on the part of the sample. Participants might have simply, directly recognized the issue of abortion as relevant to bioethics and straightforwardly assumed it deserved discussion, irrespective of the long-standing debate concerning the topic (which participants might well have been unaware of). The second explanation takes it, instead, that participants felt like abortion was still an unresolved issue, which is as pressing nowadays as it has been all along the years in which it was debated. However, given the degree of education and the profession of a big part of the sample, I feel confident that people were aware of the extent to which the issue has been discussed and thus it is likely that participants share the impression that an issue typically looked at as settled—abortion and end of life—deserves further discussion than it is allowed today, in Italy.

¹⁴² The original formulation, in Italian, is “Sei favorevole o contrario alla commercializzazione di test genetici di suscettibilità direttamente al consumatore e senza l'intermediazione di professionisti sanitari?”

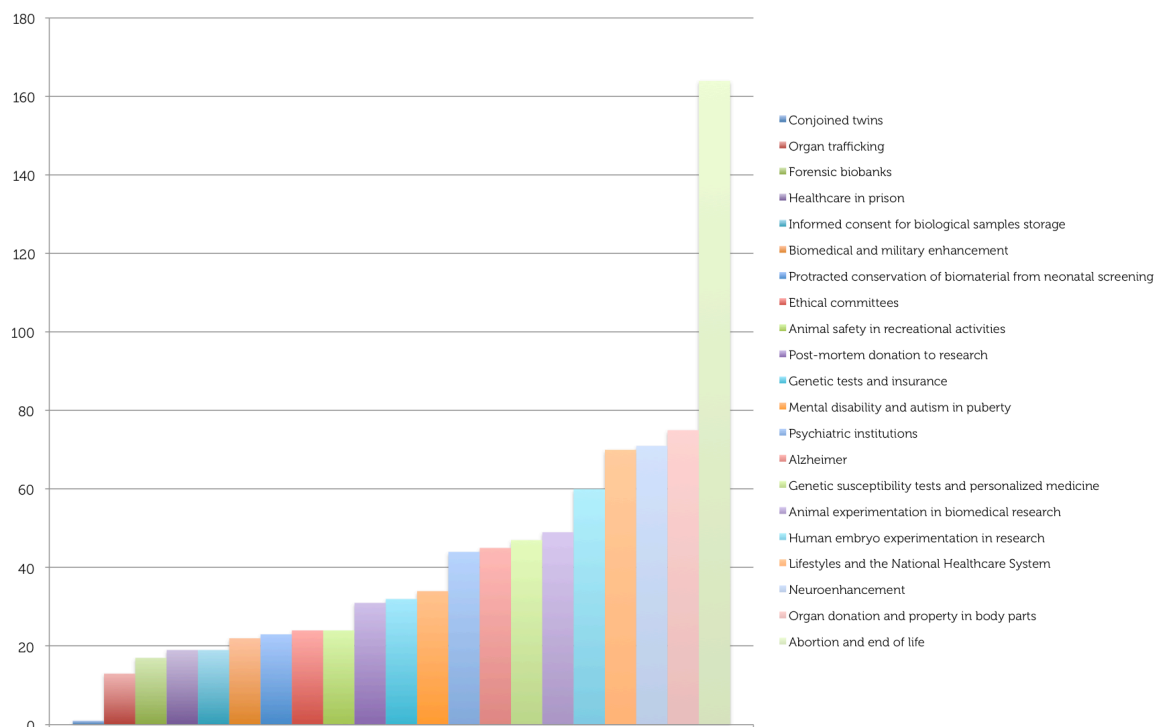


Figure 55 Issues and the amount of votes each received. On the right issues go from least to most.

To test further the hypothesis that there might be some trend towards clustering around issues according to one's liberalism/conservatism or religious/spiritual belonging, we produced¹⁴³ a heatmap visualizing the degree of correlation among issues and the two aforementioned variables. The map shows very little correlation between degrees of average individual liberalism and conservatism, religious/spiritual belonging and we also found no meaningful clustering among issues.

Slightly uninterestingly, the only significant correlations that we managed to single out properly were inverse correlations (in blue) between liberalism and conservatism, and between Catholicism (V24), atheism (V36) and agnosticism (V37). Essentially meaning that liberalism and conservatism are, at the individual level, inversely proportional, and that people who flag themselves as Catholics are very unlikely to also report on their atheism and agnosticism (religions were not mutually exclusive options in the survey).

¹⁴³ I would like to thank Pierr-Luc Germain, one of the alumni of our PhD program, and currently PostDoc bioinformatician at the IEO, and Daniela Bonzi for the invaluable help they provided in trying to make statistical sense of the data.

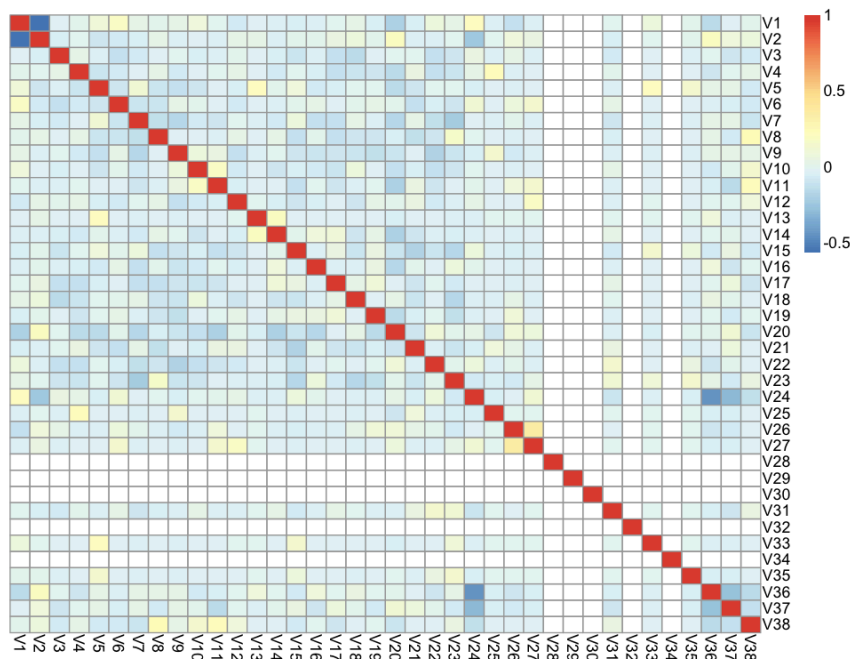


Figure 56 The heatmap shows correlations between self-reported political belonging (V1 and V2 are political conservatism and liberalism respectively), the selection of issues (V3 through to V23) and self-reported religious affiliation (V24 to V38).

Traffic to and on the website: users' behavior

Prospective participants to the consultation were welcomed by “bioeticadeliberativa”'s homepage. This page succinctly presented the initiative and its working team in five slides. The first one summarizing the scope and aims of the project, the second visualizing the ideal workflow of the consultation, the third describing, again via images, how the process of participation was articulated and the fourth and fifth asking users to participate and introducing the working team respectively.



Figure 57 bioeticadeliberativa. The second slide: describing our ideal workflow.

A pop-up would prompt first-time users to go straight to Moodle to register and enroll in the first experimental consultation. A Google Analytics script was implemented into Moodle so as to have a

real time and aggregated account of the traffic to and on the platform. Information about the behavior of users and the devices and systems they prevalently used to access the website is relevant to the development of future versions of the software that would integrate information collected in this first experimental phase.

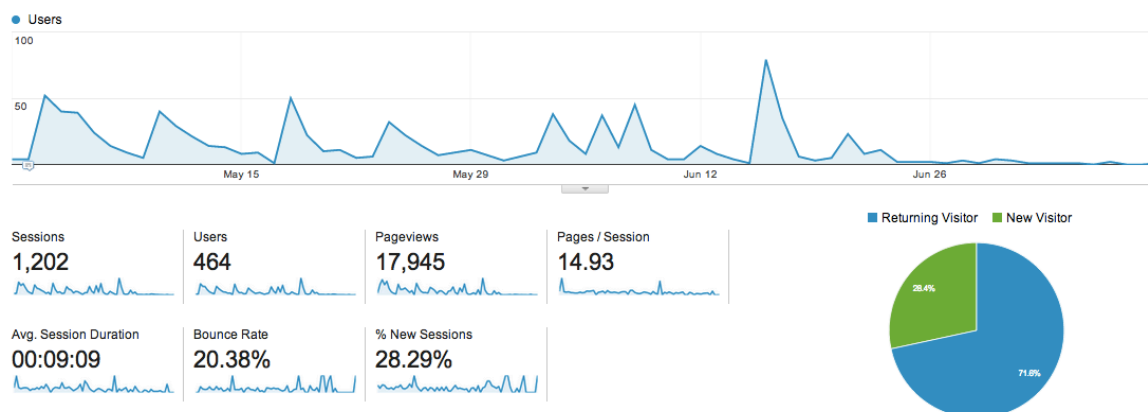


Figure 58 Traffic to <http://bioeticcedeliberativa.scienzainrete.it/moodle.php> and sub-folders. Users' behavior for the period going from May 1st to July 10th.

Typically, the traffic that the website would receive followed a recognizable pattern: any time a recall email was sent out to participants, traffic would spike, suggesting that people went to the website mostly when asked to do so, rather than spontaneously logging in. The number of users connecting after each recall did not seem to be decreasing over time, suggesting that the degree of engagement in such an articulated workflow does not necessarily need to be trending down over time. However, similarly to what De Cindio and Stortone (2013) found concerning users' engagement with LiquidFeedback, the contribution/input users provided decreased consistently over time.

The average duration of sessions was fairly high (more than 9 minutes), thus highlighting a fairly high degree of engagement with the environment and its content. Furthermore, the bounce rate, the percentage of people who get to the first page and then leave in a matter of seconds, was fairly low (20.38%)¹⁴⁴.

We deliberately decided to install a responsive theme on Moodle, so as to have content formatted conditionally on the users' device of choice. However, a large majority of the sessions (45.6%) were generated from Windows, the 29% from Mac OS, while very few of the participants accessed the

¹⁴⁴ A benchmark to these information is the average duration of sessions for the participal consultation, led by the government. On page 29 of the report, the authors claim that an average session duration of 9' 34" is "absolutely encouraging", subsequently mentioning the initiative's bounce rate (35%) and dubbing is "inevitably high" (Dipartimento per le Riforme Istituzionali 2013).

website via mobile (roughly the 20% of sessions were generated from iOS and Android combined). Noticeably, sessions on mobile were, on average, significantly shorter than on computers, again hinting at the scarce usability of the website on mobile. This might alert us to the fact that, in further deployments of the platform, we ought to put more effort into developing solutions specifically for mobile.

Operating System ?	Acquisition			Behavior		
	Sessions ? ↓	% New Sessions ?	New Users ?	Bounce Rate ?	Pages / Session ?	Avg. Session Duration ?
	1,202 <small>% of Total: 100.00% (1,202)</small>	28.37% <small>Site Avg: 28.29% (0.29%)</small>	341 <small>% of Total: 100.29% (340)</small>	20.38% <small>Site Avg: 20.38% (0.00%)</small>	14.93 <small>Site Avg: 14.93 (0.00%)</small>	00:09:09 <small>Site Avg: 00:09:09 (0.00%)</small>
1. Windows	548 (45.59%)	35.58%	195 (57.18%)	15.88%	12.97	00:08:41
2. Macintosh	348 (28.95%)	13.51%	47 (13.78%)	10.06%	24.45	00:13:12
3. iOS	134 (11.15%)	30.60%	41 (12.02%)	40.30%	7.60	00:05:05
4. Android	103 (8.57%)	36.89%	38 (11.14%)	48.54%	5.49	00:03:27
5. Linux	61 (5.07%)	21.31%	13 (3.81%)	19.67%	12.05	00:09:52
6. Windows Phone	8 (0.67%)	87.50%	7 (2.05%)	87.50%	1.12	00:00:10

Figure 59 Statistics concerning users' behavior disaggregated for operating system

Direct-to-consumer genetic tests

Information materials provided for the consultation were significantly edited, rewritten and integrated versions of the chapter on the issue from the anthology curated by Boniolo and Maugeri (2014). Information about the science of DTC genetic tests was provided in the form of either a static webpage, or a collaborative wiki. The initial text contained in the wiki was identical to the text submitted to group (b). Also, both kinds of information materials contained a video, produced by the University of Zurich¹⁴⁵ and kindly rendered available for the experiment, which presented the way in which tests are delivered to the consumer and what information is generally made available this way. The written material introduced the issue with a very brief historical overview, then a taxonomy of genetic tests would follow, and a short overview would present the most commonly used assessment method for genetic, but more generally clinical, tests (the so-called ACCE, evaluating the test along these four axes: analytic validity, clinical validity, clinical utility and ethical implications). Finally, some known limitations of the use of these tests, when sold directly to consumers, were highlighted.

¹⁴⁵ The video is also available on Vimeo: <http://vimeo.com/86036981> (last access June 21st 2014).

Il cittadino di fronte ai test genetici al consumatore

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 - L'etica dei test genetici
 - Controargomentazione
 - Il forum di discussione informata
 - Grazie!
 - Come la pensi ora?
 - Come la pensi ora?

La scienza dei test genetici

La questione scientifica

Introduzione



Nel 2008 *Time magazine*, stilando il consueto elenco delle cinquanta migliori invenzioni dell'anno, mise in cima alla lista i test genetici liberamente acquistabili dal consumatore. Tra le principali motivazioni della scelta vi erano l'enorme potenzialità di questa innovazione e il suo costo sempre più accessibile.

23andme, la più celebre tra le ormai numerose aziende che commercializzano questo servizio al consumatore, per soli \$99 fornisce oggi, a chi lo richiede, un esame del proprio profilo genetico, rilasciando, dopo una lunga controversia con l'FDA, solo le informazioni legate all'ascendenza genetica, oltre ai dati "grezzi".

In realtà i test genetici sono parte integrante della pratica medica ormai da decenni e i vari tipi commercializzati al consumatore ne rappresentano un sottoinsieme. La peculiarità di questi ultimi però, sta nella loro vendita "al dettaglio", direttamente a chi ne faccia richiesta, senza alcuna intermediazione di un professionista sanitario.

Tipi di test genetici

In base alle informazioni che forniscono e allo scopo per cui vengono eseguiti, è possibile suddividere i test genetici approssimativamente in otto grandi

Figure 60 Scientific information provision for group (b).

Ethical issues related to DTC genetic tests were presented again in a wiki and static format. At the outset the wiki contained the same text that featured in the information material and the form of the content had been vetted to have the lowest use possible of 'technical' jargon. The document presented three arguments against DTC sale of genetic tests. Each was followed by a counterargument. I sum arguments and objections up, so as to provide an overview of the actual content to which participants were exposed.

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 - L'etica dei test genetici
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 - Grazie!
 - Come la pensi ora?
 - Come la pensi ora?
 - Questionario conclusivo
- Le mie questioni

L'etica dei test genetici

L'etica dei test genetici al consumatore

La vendita diretta al consumatore di test genetici è estremamente controversa. Alcune implicazioni etiche generate dal ricorso a questo tipo di esami, come quelle legati alla *privacy* genetica, sono le stesse sia per i test somministrati in contesti sanitari, sia per quelli liberamente acquistati dall'utente. In quest'ultimo caso però, l'assenza di intermediari solleva altre e diverse questioni etiche. Il panorama dei servizi forniti dalle aziende di questo settore è però molto variegato e non sempre viene completamente escluso l'intervento di un professionista sanitario o di un consulente genetico.

In certi casi, per l'acquisto dei test è richiesta una prescrizione medica, accompagnata dall'assicurazione che i risultati verranno discussi in un contesto opportuno. A volte invece, i servizi di supporto sanitario sono presentati come prodotto acquistabile insieme al test, oppure è la stessa azienda a fornire la consulenza genetica attraverso il proprio personale o mediante l'intervento di società specializzate. Molti degli argomenti presentati di seguito dunque non si applicano indistintamente a tutte le aziende del settore, ma sono più o meno giustificati dal tipo di supporto offerto ai consumatori.

Tre argomenti contro la vendita diretta al consumatore di test genetici

Ecco di seguito tre argomenti contro la vendita diretta al consumatore di test genetici, ciascuno accompagnato da un controargomento, ovvero da un'obiezione, all'argomento stesso.

1. La vendita diretta al consumatore può danneggiare

Figure 61 A print screen of information materials concerning the ethics of DTC genetic tests as visualized by participants in group (b).

1. DTC genetic tests put a threat to consumers' autonomy. Consumers' autonomy, defined very roughly and stipulatively, as their capacity to make informed choices, can be harmed by DTC commercialization of genetic information, in that removing the mediation of health professionals might result in scarce comprehension of the information and subsequently in misinformed choices.

- 1.1. DTC genetic tests enhance consumers' autonomy. Quite the contrary, a right to access one's genetic information is warranted by DTC accessibility of genetic tests, therefore augmenting the scope of consumers' exercise of autonomy. Consumers can decide, through DTC commercialization, whether, when and how to access genetic information. Consumers can also make such choices unburdened by external sources of pressure.
2. DTC genetic tests can harm psychologically consumers. Getting to know one's genetic susceptibility can result in significant psychological distress (whatever form this might take). Psychological counselling is hence not only advisable, but rather a requirement for these tests not to generate harm.
 - 2.1. Psychological harm is an issue, but not for DTC genetic tests. Even though the risk of psychological harm must not be underplayed, some studies have shown that this risk is negligible and that typically, DTC genetic tests purchasers do not experience psychological distress.
3. Genetic determinism can be promoted by DTC genetic tests. The way these tests are sold and advertised seems to underlie some sort of genetic determinism, defined as the belief that one's genetic make-up will determine some features of their future. The further DTC commercialization of these tests ought therefore to be prevented.
 - 3.1. Private companies' duties concerning their consumers' beliefs do not extend limitlessly. It is true that privately held companies hold some duties concerning their consumers' beliefs. Consumers' belief in genetic determinism does not seem to be one such belief. Furthermore, a link between promotional strategies used by DTC genetic tests companies and the spread of genetic determinism must be established.

Contributions to wikis

One of the distinguishing features of the online system that was designed and devised for this project lies in the technical possibility to have all information materials available in some editable format. We chose wikis as the most commonly used collaboratively editable format and tried to make it explicit to users that comments and modifications were not only welcome, but also encouraged. We assumed this feature to work as a pre-emptive objection to the usual charge that information materials in deliberative and consultative contexts can and do result in some degree of influence on the outcome.

Having those materials open to comments and edits can be regarded as a form of warrant against this unwanted sort of influence. Despite our best efforts, however, data concerning the actual use of this feature are somewhat discouraging and must be taken seriously into consideration for further implementational attempts.

The website had two couples of wikis, i.e. one about the science of DTC GTs and one about the ethics of DTC GTs, each available to groups (c) and (d) separately. Members of the respective groups were allowed to interact with each other, commenting on the same wiki and contributing to its shaping. In the two paragraphs that follow I summarize the way these two wikis were used—or not used—by participants in the consultation.

The science of DTC GTs

Only one member of group (c) (the group theoretically tasked with discussing with no explicit goal), commented on the wiki concerning science suggesting two changes without contributing directly to its writing. The changes were: (i) a suggestion to list explicitly nutrigenetics tests along the other kinds of tests and (ii) the request to rewrite a passage about the limitations of DTC GTs making it explicit that issues of clinical validity of tests for genetic susceptibility do not affect tests depending on the way they are commercialized (DTC or mediated by professionals) but rather by the analytical tools deployed. Both comments were received and their integration, given that the participant appeared unwilling to formulate the new version of the document himself, was therefore negotiated in the comments section of the wiki with a member of our scientific panel and subsequently integrated in the text.

Group (d) did not comment this wiki and none of its members contributed to it.

The ethics of DTC GTs

No member of group (c) contributed or commented on this wiki.

The wiki available to group (d), instead, though it received no comments, had one member adding one sentence to a paragraph tackling reasons why DTC GTs could be presented as autonomy-enhancing (see Direct-to-consumer genetic tests). The participant précised that purchasers of these tests could still refer back to their trusted healthcare professional if they deemed it necessary.

According to respondents to our post-test survey belonging to groups (c) and (d) and to the subset of those who claimed they had participated (N=41), only three people said they perceived wikis to be unbalanced and or partial. None of these dissatisfied participants however commented or contributed to the wikis, even though they all claimed they knew they could. One gave no reason for not commenting, another one said he/she had no time to contribute and the last claimed he/she did not know how to formulate his/her comment/contribution. Only 4 people did not know they could actually contribute to the wikis or comment on them, suggesting that this feature was stated clearly in the presentation of the process. Half of these said if they knew they could comment and/or contribute they would have done so. Among those who knew they could contribute/comment, approximately the 30% (N=11) of participants said they did so, which oddly is incompatible with the actual number of comments and contributions reported above. For the 70% of respondents who said they did not comment/contribute to the wikis, there were no shared reasons. Participants could flag up to three reasons why they did not comment/contribute and very few people claimed they did not know how to technically do so. Answers are then equally distributed to the other suggested reasons, which were that the participant did not know how to formulate their thoughts, that they did not have time to contribute and that they were not interested in contributing.

It is worth noticing in passing that the scarce use participants in these two groups made of their possibility to contribute to the documents somewhat resonated the partial lack of interest members of group (b) showed when presented with this same possibility in their post-test survey. Even though more than the 85% of respondents in group (b) reported being very satisfied (4 or 5 on a 5-point Likert scale) with the balance of materials, it is still striking that no one completely agreed with the statement reporting their wish to comment/contribute to the documents and that roughly the 64% of respondents felt less than neutral about that possibility.

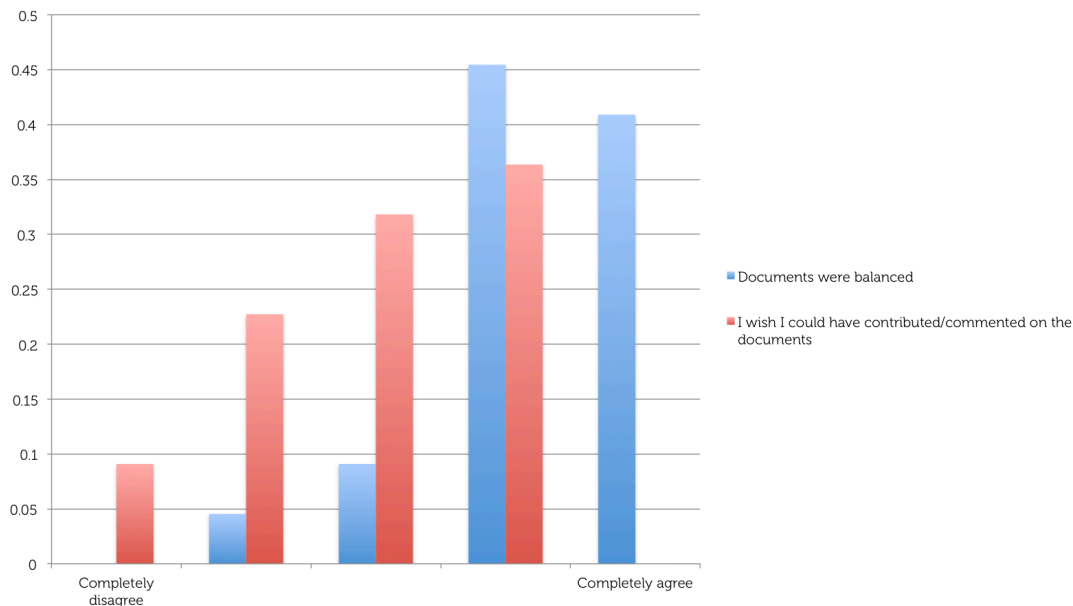


Figure 62 Members of group (b)'s satisfaction with information materials and willingness to contribute and comment on those.

This is very relevant information for future attempts at developing e-democratic tools for bioethics and I will delve more in depth into the bearings this finding might have on a revision of our institutional hypothesis.

Who made it through?

In Fabio Chiusi's recent *Critica della democrazia digitale* (Chiusi 2014) the author makes reference to an unwritten rule in the world of online political/civic engagement initiatives, which he calls the *1/100/1000 rule*. According to this rule, every thousand invitations, a hundred actually responds and only one effectively participates. If we take this estimate to be approximately correct, our own initiative managed to recruit a very active population. The approximate ratio of invitations to responses is roughly of one order of magnitude¹⁴⁶. However, of those who responded to the invitation almost the 50% took action and provided some (fairly time-consuming) input into the consultation¹⁴⁷. I will describe the kind of inputs that were measured to give an overview of the participation that the website made possible.

A total of 432 users did, or at least tried to, create their account in Moodle. 24 did not manage to get those accounts confirmed, highlighting some issues with the reception of emails sent out via our server.

¹⁴⁶ Notice that it is hard to estimate even approximately the actual outreach of the advertisement summarized above.

¹⁴⁷ Compare this datum with the 34% of people willing to participate actually showing up for Neblo et al. Deliberative synchronous forum, which they dub "reasonably high" (Neblo et al. 2010, 10).

	Control	Information	Non-goal oriented discussion	Goal oriented discussion
At recruitment	77	78	77	78
First vote	39	39	35	38
Scientific competence	-	33	24	33
Ethical competence	-	22	13	21
At least one view			10	24
At least 1 post	-	-	3	11
Second vote	25 (32.5%)	26 (33.3%)	15 (19.5%)	21 (26.9%)

Table 6 Comparison of drop-outs between different groups.

It is difficult to recognize a clear-cut trend in **Table 6**: as the burden of participation increases (from control to discussion), the likelihood that people stop engaging seems to progressively increase, even though not so decisively for group (d). A similar trend would be unsurprising and consistent with what we know about online political/civic engagement initiatives (Smith, John, and Sturgis 2013).

We further analyzed the data looking for effects individual traits and belonging to groups might have on compliance to treatment. As highlighted by Smith and colleagues (2013), compliance in online deliberative forums can be particularly tricky to define: specifically, on the one hand, reducing compliance to the mere outspoken (in our case written) expression of one's ideas can underplay the value of 'lurking', i.e. the practice of logging in the forum and simply following the discussion unfold, which can have some effect on preferences (just as listening to a discussion can result in changes in attitudes). On the other hand, defining compliance with treatment as the mere logging in the forum, can obfuscate relevant information as to the differences that there might exist between those who actually participate and those who do not. Keeping this in mind, compliance to treatment was defined in our case as completion of the ethical reasoning task for group (b), and viewing *or* posting on the forum for groups (c) and (d). The difference between treatments groups (c) and (d) were subjected to is in-built in the kind of interaction hosted by the forum which was meant to be goal-oriented for group (d) and non-goal-oriented for group (c).

We obtained a dichotomous vector compliant/non-compliant and we logistically regressed the dichotomous variable to quantitative and qualitative variables.

Groups and gender were coded as dummies. So were education and income, regardless of their being ordinal, in that coding them as dummies better accounted for the chance that the ordinal effect was not linear in our sample, meaning that the distance between clusters might have been varying. Age is instead treated as a continuous variable. All observations were used in the analysis, with only one exception, for which no age was available.

	Estimate	Std. Error	z value	p value
(Intercept)	17.37795	1290.71271	0.013	0.989
AGE	0.01344	0.01076	1.249	0.212
EDUCATION 3	-16.62596	1290.71295	-0.013	0.990
EDUCATION 4	-17.63454	1290.71259	-0.014	0.989
EDUCATION 5	-16.88715	1290.71258	-0.013	0.990
EDUCATION 6	-17.00477	1290.71258	-0.013	0.989
GROUP B	-2.20811	0.39329	-5.614	1.97e-08 ^{***}
GROUP C	-3.06627	0.45019	-6.811	9.69e-12 ^{***}
GROUP D	-1.91055	0.37796	-5.055	4.31e-07 ^{***}
MAN	15.61762	1685.29114	0.009	0.993
WOMAN	-0.18952	0.28839	-0.657	0.511
INCOME 2	0.72235	0.66675	1.083	0.279
INCOME 3	0.81780	0.59410	1.377	0.169
INCOME 4	0.28798	0.58298	0.494	0.621
INCOME 5	-0.22462	0.59377	-0.378	0.705

Table 7 Testing effects of individual traits and belonging to one group on compliance to treatment, defined according to the group. Results marked with *** are significant at the 0.001 level.

The table above summarizes the results of our logistic regression, which was computed using the following formula:

logit(COMPLIANCE)

$$= a + b * AGE + c_1 * EDUCATION3 + c_2 * EDUCATION4 + c_3 * EDUCATION5 + c_4 * EDUCATION6 + d_1 * GROUP B + d_2 * GROUP C + d_3 * GROUP D + e_1 * MAN + e_2 * WOMAN + f_1 * INCOME2 + f_2 * INCOME3 + f_3 * INCOME4 + f_4 * INCOME5$$

Contrary to what Smith, John and Sturgis (2013) have shown, we found no significant effect of traits such as age, gender, family income, and education on the likelihood that participants engaged through the entire consultation, sticking to the treatment that they were randomized to, suggesting that, either within such a highly self-selected sample, or concerning such highly technical issues, no individual trait is specifically predictive of that individual's input to the consultation. Similarly to their findings, though, effects of belonging to the three treatment groups were detected at a 0.001 significance level.

Participation and compliance in our specific experiment are partly intertwined, given that some steps in the workflow were inaccessible to those who did not comply. Therefore this finding essentially confirmed what was intuitively visible in **Table 6**, meaning the level of participation decreased, as the requirement for engagement increased. However it also shows something less well-known: participants tasked with some specific goal seem to be more prone to sticking to their treatment than both participants simply supposed to discuss and participants simply supposed to get information and prove they understood it. It must also be pointed out that the peculiar nature of our information group, whose members were required to engage in demanding activities such as counterarguing their own position and prove their competence, might have little to no advantage over requiring people to engage with the same activities, but add the possibility to discuss in a forum on top of that.

The transformative potential of deliberation

Why is it that when preferences change, we are better off, democratically and deliberatively speaking, than we were before deliberation? Can't it be that preferences change in the wrong direction? And which one is the wrong direction? After all it is intuitive that after discussing thoroughly some issue, some people will change their minds. But will they do so according to democratically and deliberatively desirable criteria?

To properly address this worry it is essential to trace some link between the apparent triviality of opinion changing as a result of some social encounter and the desirable effects of deliberation. However, even though a number of studies have engaged with the question whether opinions change (Luskin, Fishkin, and Hahn 2007; Fishkin 2009; Farrar et al. 2009; Setälä, Grönlund, and Herne 2010), few undertook the project of evaluating how and why they do so. As a result, "it remains unclear *why* these opinion changes occur" (Himmelroos and Christensen 2014, 2).

Michael Neblo, in “Change for the Better? Linking the Mechanisms of Deliberative Opinion Change to Normative Theory”, a manuscript, which still appears under review on his personal webpage¹⁴⁸, addresses head on the issue of why exactly preference changes would be so important to deliberative democratic practice. Essentially, he says, normative theories of deliberative democracy postulate that preferences and attitudes change “*via mechanisms specified in the normative theories*” (Neblo 2014, 1) themselves. But if that is not the case, deliberative democratic enthusiasts simply cannot go on to claim that preferences change, so to say, for the better. The case for more deliberative institutions would be a lot weaker if it turned out that sources of opinion change are group conformity or social power, for instance. Therefore Neblo goes on to test which mechanisms (derived from a number of hypotheses drawn from the received view of normative deliberative democracy) play some part in changing people’s preferences in a field experiment. I take this to be a sensible move and, although I will not tackle the issue of the mechanisms of preference change with the same level of detail and statistical sophistication Neblo employs, I will present both the mere dynamics of changes in preferences at the aggregate and individual level, and a rough assessment of the quality of the argumentation in groups (b), (c) and (d) and of the deliberation that took place in groups (c) and (d). This latter assessment was performed using the aforementioned DQI.

Changes in preferences

I will present the distribution of preferences in the four groups at the beginning of the consultation, when users were polled. For all four groups I will then compare the initial preferences and the final preferences of only those who expressed their preferences twice. In doing so I will report the pre-participation and post-participation means for each group. Finally, I will show, via a multiple linear regression, that compliance to each treatment has some non-zero effect on individual preferences, namely moving them towards the left end of the spectrum (i.e. disagreement concerning the practice of DTC wholesale of genetic tests).

Of the 310 participants who were successfully profiled before the consultation and then randomized to the four groups, 39 expressed their initial preferences in the control group, 39 expressed their preferences in group (b), 35 in group (c) and 38 in group (d). Preferences were distributed as shown in

¹⁴⁸ The manuscript is available for consultation here: <https://polisci.osu.edu/sites/polisci.osu.edu/files/NebloChange4B063014.pdf> (last access August 4th 2014).

Figure 63. Very few people completely agreed to the practice of DTC GTs (around the 13%), with approximately the 60% of participants feeling they did not agree, either partially or completely, with having genetic tests sold directly to consumers without any professional mediation.

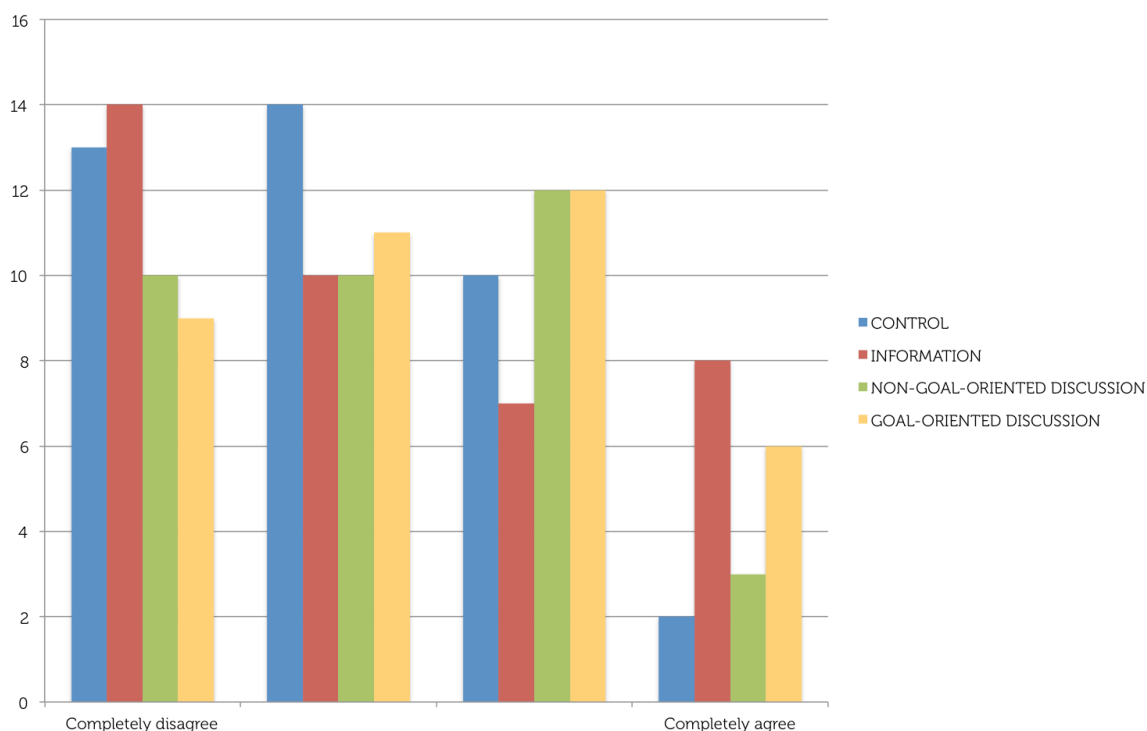


Figure 63 Preferences of all groups before the consultation.

The most intuitive aggregate measure of attitude for groups is the mean of their preferences whereas the standard deviation of the distribution of preferences suggests the degree of variance of opinions within the groups. The control group had an overall mean of 0.33 with a standard deviation of 0.33 points around the mean, group (b) had an overall mean of 0.40, with a 0.40 standard deviation, group (c) had an overall mean of 0.41 with a standard deviation of 0.35, and group (d) had a mean of 0.47, with a standard deviation of 0.37. The variance of opinion is therefore comparable across the four groups and their mean value does not differ substantially. Not everyone who expressed his or her preference at this stage, however, then went on to participate in the consultation. Actually, participants' preferences were measured twice for 25 members of the control group, 26 of group (b), only 15 in group (c) and 21 in group (d). Hence, the effect of participation on participants' attitudes is only measurable on this non-random subset of the sample.

The participating subset of the control group had a mean attitude of 0.34 after the consultation, which grew from 0.31 before the consultation, with a net change of only 0.03 points. A fair amount of people

(10) changed their opinions in this group over the month in which the consultation took place. These changes essentially flat out when aggregated, probably due to the random nature of their sources. The slight change anyway happens towards the left end of the spectrum.

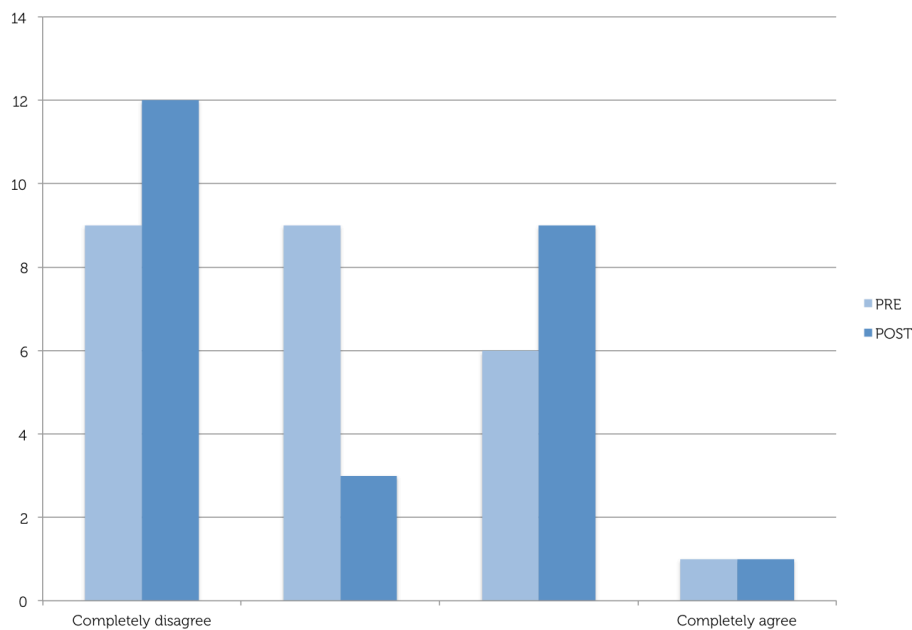


Figure 64 Preferences at the beginning and at the end of the consultation in the control group.

The 26 members of group (b) who expressed their preferences both times, had a mean attitude of 0.43 before going through the information process and then ended up with a 0.39 mean, changing the average attitude of the group by -0.038 . The negative value means the attitude of the group shifted towards the left end of the spectrum, agreeing less to the practice.

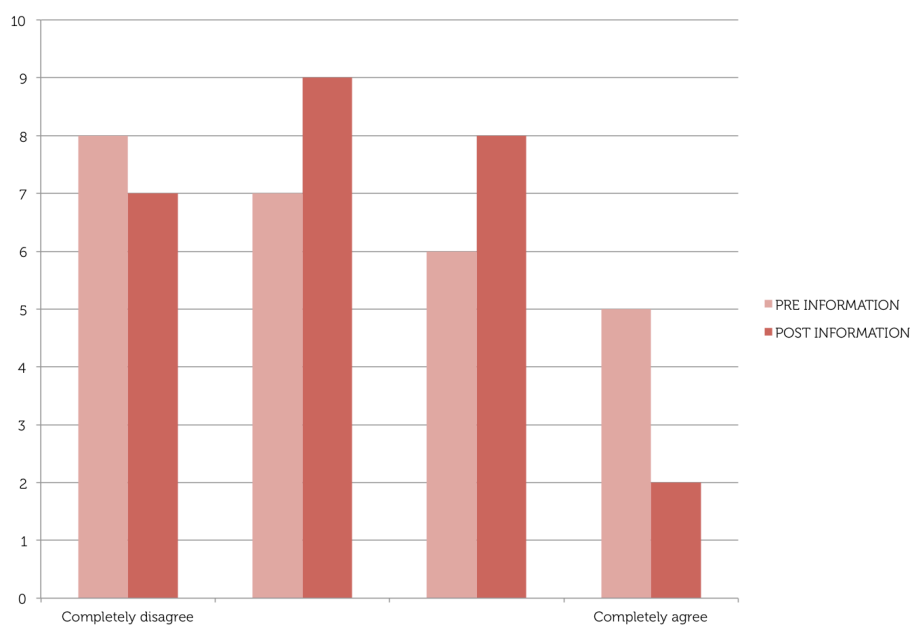


Figure 65 Preference before and after information in group (b).

The very few people in group (c) reaching the stage when they were asked to express their view again, had a pre-test mean of 0.22, which grew slightly up to 0.23 (changing of a mere 0.01).

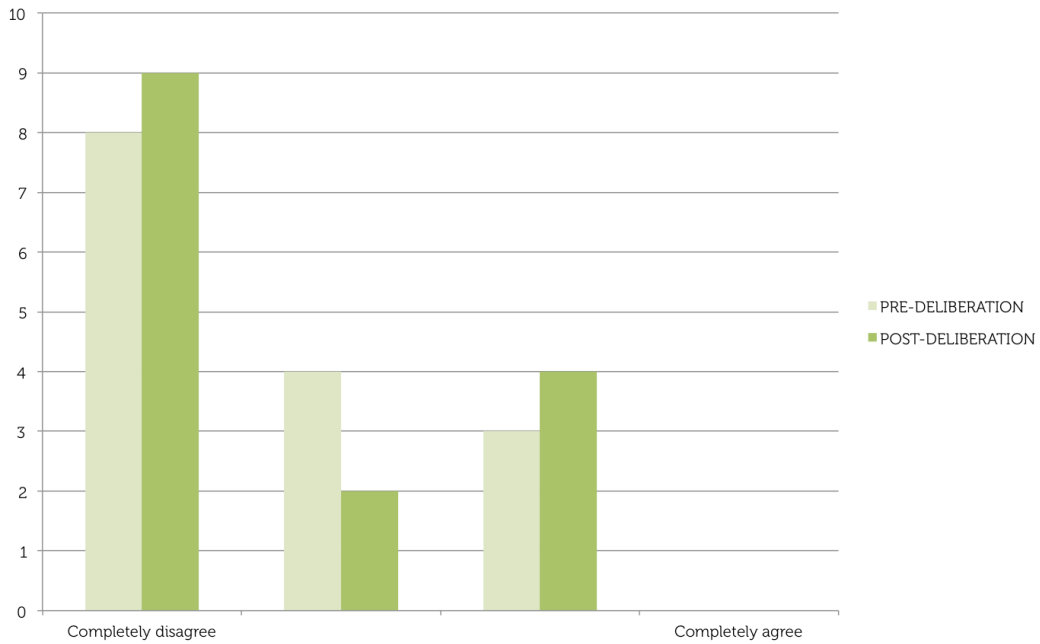


Figure 66 Preferences before and after deliberation in group (c).

Finally, **Figure 67** shows the shift in preferences of members of group (d) voting both times. The mean attitude of this group before deliberation was 0.37, which then grew to 0.46 moving towards agreeing slightly more to the practice of DTC GTs.

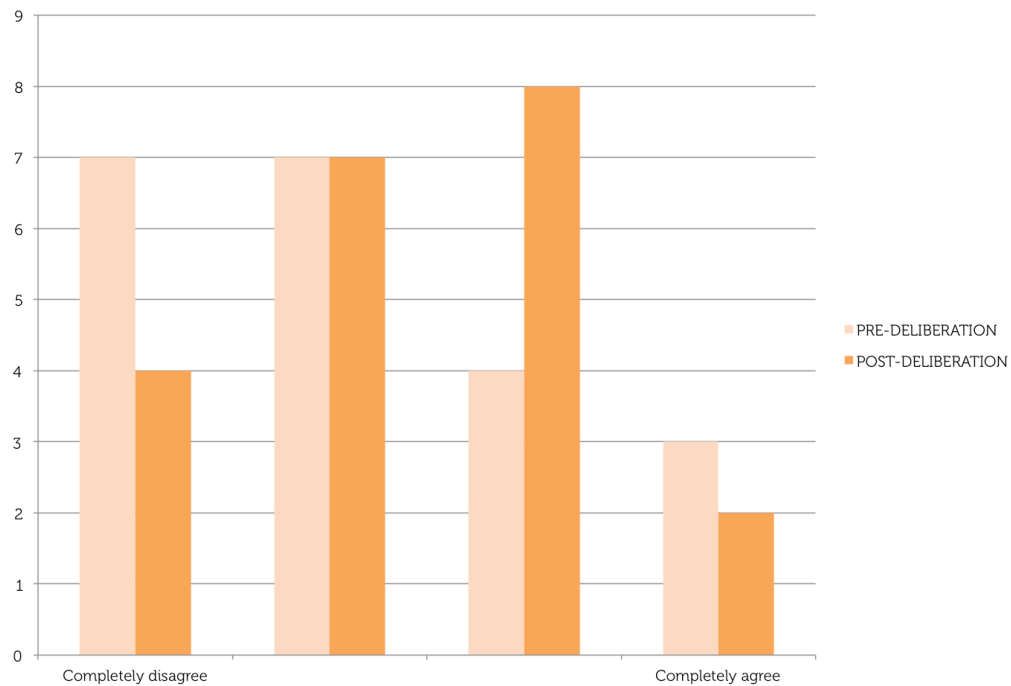


Figure 67 Preferences before and after deliberation in group (d).

In order to explain how preferences changed at the individual, rather than at the aggregate level—which is crucial in that it allows a higher resolution on the actual mechanism of preference change taking into account the effect of compliance/non-compliance with treatments, instead of the mere randomization to a group—we developed a simple linear multiple regression model to test whether individual traits (education, age, gender and income), randomization to groups, and compliance to the respective treatments were predictive of the likelihood that participants changed their minds in some recognizable direction.

The table below summarizes our findings.

	Estimate	Std. Error	t value	p value
(Intercept)	0.515682	0.185106	2.786	0.006887 **
EDUCATION4	-0.226628	0.156824	-1.445	0.152954
EDUCATION5	-0.250557	0.155578	-1.610	0.111857
EDUCATION6	-0.262746	0.156822	-1.675	0.098374 .
AGE	-0.006935	0.001752	-3.957	0.000181 ***
GROUP B	-0.106067	0.089545	-1.185	0.240277
GROUP C	0.018879	0.085687	0.220	0.826266
GROUP D	0.109155	0.124359	0.878	0.383130
WOMAN	0.041495	0.049153	0.844	0.401472
INCOME2	-0.124510	0.116812	-1.066	0.290185
INCOME3	0.032311	0.101294	0.319	0.750704
INCOME 4	-0.014375	0.095688	-0.150	0.881023
INCOME5	-0.056708	0.094824	-0.598	0.551774
COMPLIANCE	0.381826	0.113270	3.371	0.001230 **
GROUP B:COMP	-0.225827	0.145031	-1.557	0.124024
GROUP C:COMP	-0.335867	0.147297	-2.280	0.025690 *
GROUP D:COMP	-0.289755	0.168930	-1.715	0.090789

Table 8 A summary of the results our regression investigating the effect of a number of factors on preference changes as compared to control. No participant belonging in the cluster “EDUCATION 3” cast both votes; therefore we could not test the effect of that variable on changes in preferences.

We found that age had a significant effect on preference change across groups. This means that as age grows, preferences tend to change more towards disagreeing with the practice (due to the negative

coefficient). The coefficient we found is however relatively small, suggesting that the variation, though non-zero, is in fact not massive.

More interestingly, instead, compliance to the treatment has a clearly significant effect on the change in preferences, modifying compliers' attitudes towards DTC GTs making them see the practice as more 'agreeable', in a sense, after having undergone treatment. This is especially important given that there is no independent effect of participation to the specific groups and that, when we tested for the interaction of compliance and randomization to a group, the effect can still be regarded as significant¹⁴⁹.

This last finding highlights the existence of some mechanism modifying preferences that is linked to the compliance of users to the three different treatments we devised. In the next paragraph I will tackle the issue of what mechanism exactly played this important role, providing some quantitative and qualitative analysis of the argumentative activity of participants both in the ethical reasoning task (for group (b)) and in the discussion forum (for groups (c) and (d)).

Quantity and quality of argumentation and deliberation

Group (b), as specified above (and just like groups (c) and (d)), was asked to engage both with some scientific primer to DTC GTs and with a short argumentative exercise. In order to complete this task, participants were invited to take into consideration one of the arguments in support of their intuitive thesis (say they disagreed with DTC GTs, we prompted them with the argument from undesirable psychological effects that tests may have). They were subsequently asked come up with some argument to object to this specific argument, in order to show that they could conceive of acceptable reasons not to agree with their own position. A first assessment of the mechanism by means of which compliance impacts attitudes comes from the number of words participants produced when engaged in this task. Even though it might at first seem counterintuitive to analyze speech acts that essentially happen in isolation as pieces of a discourse, I take this ethical reasoning exercise as a special sort of discourse happening within subjects' inner forum. This discourse, given the nature of the task, demands speech acts that are essentially other-regarding, which can therefore be sensibly and fruitfully analyzed as parts of a discourse.

¹⁴⁹ The only partly significant interaction is between GROUP C and COMPLIANCE. But this is probably due to the very low number of participants who cast both votes in the non-goal-oriented discussion group.

Members of group (b) generally produced fairly long and argumentatively structured replies to the task. On average their posts were 162 words long. This can be contrasted with the 66.4 words for group (c) and 85 words for group (d). A cursory look at the boxplot below reveals that this difference in mean is clearly due to some very long counterarguments submitted by two members of group (b). The differences between groups are otherwise contained.

Only four members of group (b) handed in their counterarguments while appearing not to have understood the purpose of the task: they simply provided their reasons for their own view. This is probably due to the weird logic of the request, whose articulation was criticized by some interviewed users as to its clarity, but it can also alert us to the difficulty implicit in putting oneself in other people's 'moral' shoes.

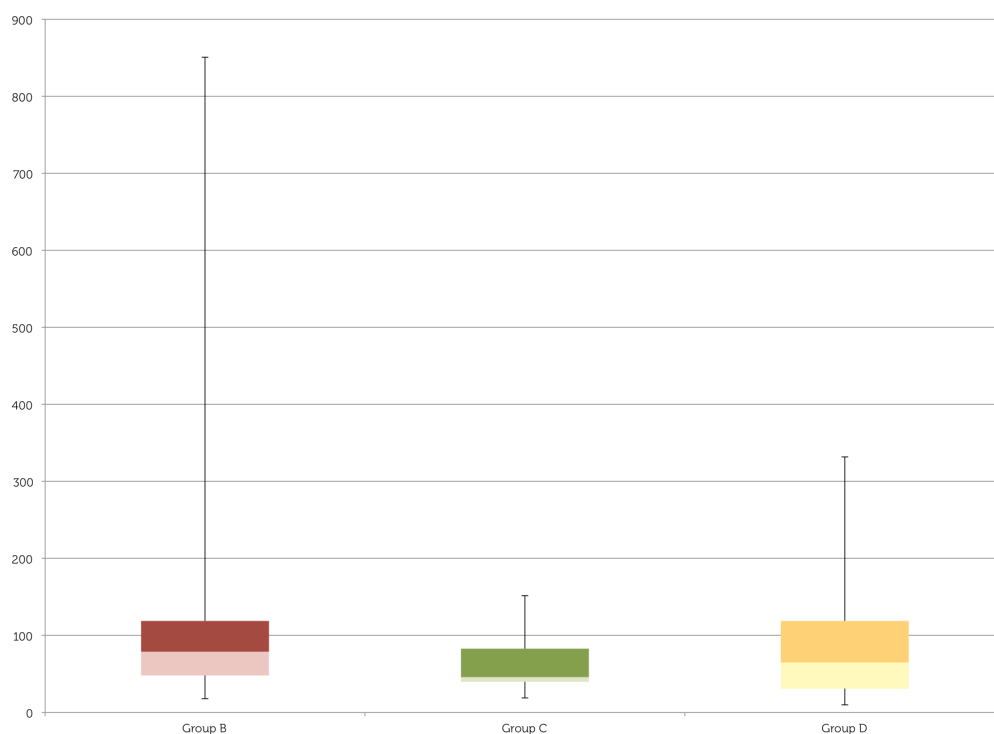


Figure 68 Boxplot of the number of words produced by each participant in groups (b), (c) and (d). Comparing averages is misleading due to a small number of very long contributions in group (b).

As I did for the other two groups, I proceeded in this case to analyze participants' contributions using the DQI presented above.

Using the DQI requires identifying parts of one's speech putting forward a clear "*demand*, that is, a proposal on what decision should or should not be made" (Steenbergen et al. 2003, 27). This is more or less explicit in all written speech-acts produced for this task, in that participants were required to

hypothetically subscribe to the demand that DTC GTs be regulated somewhat contrary to what they believed to be 'right'. Once identified the relevant speech-acts, in this case all 22 arguments uploaded, a team ought to code each speech-act along five measures, with a total of seven components. One of these measures (and its one component) clearly does not apply to our context and I believe does not apply to the context of online asynchronous interaction altogether: *participation* in the DQI is assessed as the 'freedom' with which a speaker (in our case a writer) can proceed to voice his/her position. Sensibly, the proxy used to gauge the freedom of participation is whether a speaker is interrupted or not. However, there is no way in which a writer on an online forum can possibly be interrupted, therefore I did not code speech-acts along this measure. The index is devised so as to behave properly even in cases in which some components do not apply, thus excluding the measure of participation does not raise significant issues. The other measures, some of which, as will be noted, are again irrelevant to this specific context (but will be relevant in the analysis of the discussion forums), are:

- The *level of justification*, whose codes range from 0 to 3. 0 applies to speech-acts that offer no justification for the demand, 1 to those that propose a reason but fail to link it to the demand, 2 to those that qualify their demand making at least one complete inference (even implicitly so) and 3 to those that articulate two or more complete inferences in support of their demand.
- The *content of justifications*, accounting for mentions of group interests, the common good, or both. Code 0 applies to explicit references to group interests, code 1 applies when no mention of either group interests or the common good are made, code 2a is used to single out speech-acts that use utilitarian justifications, i.e. what is best for the highest number, and code 2b applies to references to some version of the Rawlsian difference principle, i.e. what is best for the worst off. The authors note that 0s, 2as and 2bs are not mutually exclusive, thus suggesting coders to pay attention to the balance between the underlying mentions.
- *Respect* is coded along three component dimensions: respect for the groups whose needs the policy at issue addresses (from 0 to 2, corresponding to disrespect for the groups, implicit respect and explicit respect), respect towards the demand (which only applies to discourses in which more than one demand is being discussed, and will therefore not be applied in our issue-specific case), and respect towards counterarguments, going from 0 to 3, with 0 coding for acts that ignore counterarguments, 1 for acts that acknowledge the argument but makes a

negative statement about it, 2 for acts that acknowledge the counterargument and do not make any value-judgment about it, and 3 for acts that explicitly value the counterargument.

- *Constructive politics*, which will only apply to the discussion forums, is meant to assess the way in which the speeches try and build consensus. In this case code 0 applies to acts that express no willingness to change one's position, code 1 to acts that suggest some mediating proposal concerning some other issue not relevant to the one on the agenda, and code 2 applies to acts that try and build a relevant mediating proposal. Group (b) and (c) were not tasked with finding any consensual solution and this dimension will hence not be coded for them.

Relevant components were then added up and straightforward descriptive statistics on the 4-components index are reported. Given that I was the only coder, no measure of coding consistency is presented.

Most members of group (b), as I said above, presented full-fledged arguments which effectively took up the suggestion that there might be at least one reason to disagree with their own initial view. This contributed to a fairly high 4-components DQI, with a mean of about 6 points and very few cases in which participants failed to consider the counterargument suggested. **Table 9** below summarizes descriptive statistics for the DQI analysis of the groups' posts.

One of the participants, initially contrary to DTC GTs, for instance, simply restated his own demand, without furnishing it with any reason whatsoever.

Participant X: “[...]It is plausible that a widespread system of healthcare professionals helping consumers in gaining knowledge about the topic, cannot but be beneficial to the informed choice of the consumer¹⁵⁰.”

In opposition to this contribution, which is an excerpt of an 87-words long comment, one member of the group, also initially contrary to DTC GTs, presented a 433-words long comment outlining in three numbered parts a summary of the argument (the argument from psychological harm) he would then proceed to object to, presenting two interdependent reasons why that objection stood (first distinguishing between concern and pathological psychological states such as distress and depression,

¹⁵⁰ The Italian text reads: “Verosimilmente la presenza di un sistema capillare di professionisti sanitari che aiutino il consumatore alla conoscenza del tema, non può che essere di beneficio alla scelta consapevole da parte del consumatore.”

and secondly making reference to the empirical evidence that no such pathological states are linked to DTC GTs). The participant, whose contribution scored 7 points on the DQI, then concluded integrating the objection in a restated version of his demand:

Participant Y: “[...W]e can say that, provided there is no evidence that these tests have such negative psychological effects, then, at least provisionally, the case for a need for psychological support during the process of administration of the test fails¹⁵¹”

	MEAN	MEDIAN	SD	MIN	MAX
4-components DQI	5.909090909	6	1.540225429	2	8

Table 9 4-components DQI for the ethical reasoning task performed by members of group (b).

As to the analysis of the discussions held on the forum, scores are not immediately comparable, given that one component is added to the index, namely constructive politics. In the discussion forum of group (c), only 2 speech-acts were identified. This is of course compatible with the very limited number of posts that members of this group produced. Given the number I will simply present the two speech-acts’ DQI in its components.

The first participant posting a contribution produced 19 words in which she presented her demand that experts assess the merit of having genetic tests administered to someone. She made no reference to interest groups, implicitly suggesting however respect for those who might be concerned by the policy, took into consideration no counterargument, and simply held tight to her own position. This speech-act’s DQI was 2.

The second participant, instead, presented two arguments, though in outline, supporting her own position, she made no mention of interests and implicitly respected groups touched by the policy. She took into consideration possible objections, but did so remarking they were not worth. Finally, she sat on her own position. This 100-words long speech-act’s DQI was 6.

Finally, discussion among members of group (d), which was slightly more lively, gave rise to 8 speech-acts expressing or underlying demands (some of these acts are replies to comments on previous

¹⁵¹ The Italian text reads: “[P]ossiamo affermare che se, per ora, non sono state trovate evidenze a supporto del fatto che i risultati di questi esami abbiano effettivamente conseguenze psicologiche negative, allora viene meno, per ora, anche la necessità di un supporto psicologico nel processo di somministrazione del test genetico.”

demands, others simply imply the demand). All of these scored fairly high in the 5-components DQI. The table below reports descriptive statistics about these speech-acts. In particular it is worth noticing three contributions trying to put forward an explicit mediating proposal. One in which a participant stated she had changed her mind.

Participant Z: “That’s true, you convinced me, then what is the MD for? Any blood tests’ results are given directly to the patient. There is no mediation, I think. You consult the MD later, to understand better. This is true also of genetic tests.”¹⁵²

This excerpt suggests the participant felt compelled by other participants’ arguments, to reconsider whether mediation was in fact required for DTC GTs and implicitly made a case for a milder regulatory framework than she had previously suggested.

	MEAN	MEDIAN	SD	MIN	MAX
5-components DQI	7.5	7.5	1.511857892	5	9

Table 10 5-components DQI for group (d)'s discussion forum.

In this case, as for both groups (b) and (c), the quality of the discussion can be said to be fairly high along all measures singled out by the DQI. This suggests that the instrument, as it is, though unable to recruit properly inclusive participation and foster collaborative drafting of information material and consensus proposals, behaves indeed well as a place for informed discussion. In the last part of this dissertation I will present a revised version of this instrument that takes into account all the information gathered thanks to this preliminary experimental deployment.

Post-test assessment and internally perceived legitimacy

The post-test survey submitted to all willing participants, parts of which have already been presented above, gave us also some clues as to participants’ perception of the value of the tool. The graph on the next page plots the results of users’ evaluation (N=81) of the platform along five measures, each of which was presented as a 5-point Likert scale going from “Completely disagree” to “Completely agree”. Users-friendliness of the website was ranked the lowest among these dimensions (54% of respondents

¹⁵² The Italian text reads: “E’ [sic] vero, mi avete convinto, allora a cosa serve il medico? Anche per qualunque esame del sangue il risultato viene consegnato nelle tue mani. Non c’è intermediazione, mi pare. Il medico lo consulti dopo, per capire meglio. Questo vale anche per i test genetici. [...]”

disagreed or felt neutral about the claim that it was easy to navigate the site and retrieve content; also some users pointed out difficulties navigating in their open answers), which, especially given the skilled sample we recruited, suggests more effort need to be made as to the accessibility and usability of the instrument.

Interestingly, even though no actual collaborative collective proposal came out of the consultation process, the 67% of respondents agreed or agreed completely that the instrument helps developing collective proposals. This suggests some disarray between the actual, limited, use participants made of the instrument and how they felt the instrument *could* work. However, given that very few participants tried to collaborate to achieve some collective proposal, I take very seriously the comment by one user who pointed out that the way to contribute to the collective report was unclear, and advised creating a more structured backbone for users' contributions¹⁵³. This suggestion will be elaborated further below.

Respondents also felt confident that this specific tool, and alternative implementations of participatory initiatives, were fruitful ways to tackle the issue of governance of science and technology. Roughly the 80% of them agreed or agreed completely that “bioeticadeliberativa” was a useful tool for the participatory governance of science and that, irrespective of the actual tool, consulting the population concerning ethical issues arising from science and technology is useful.

Finally, this subset of our sample perceived that this kind of initiative has a definite legitimacy-enhancing import on science and technology policy. As I anticipated, this is only partially interesting in that the consultation yielded no binding output and we could not therefore investigate properly its empirical legitimacy.

¹⁵³ This is the comment in Italian: “sinceramente era poco chiaro come contribuire al documento finale, forse sarebbe stato utile proporre delle sotto-tematiche su cui chiedere suggerimenti e idee”.

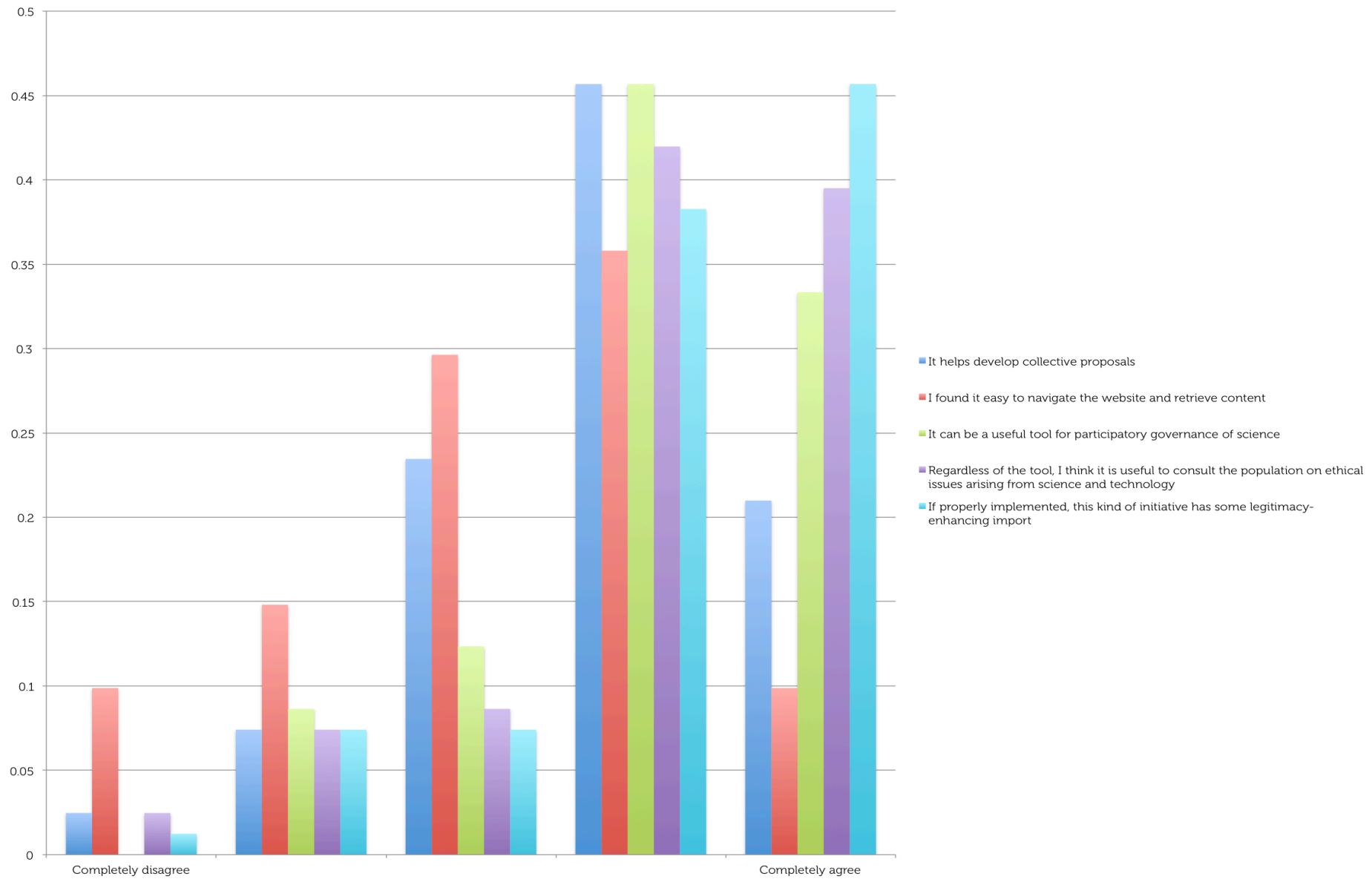


Figure 69 Assessment of the tool along five measures. The last one gauges the extent to which the procedure is taken to enhance the legitimacy of policies concerning ethically controversial science and technology

Participants' recall and satisfaction

In order to assess what participants perceived the purpose of the experiment was, we asked them (N=100) to report about their feeling in this respect. They were presented with five options among which they could choose only one. Interestingly, the 37% of them rightly believed the experiment to be just that: an experiment supposed to collect data about the tool. However, 35 respondents were instead of the opinion that the initiative was meant to work as an actual consultation of the population about DTC GTs. This is relevant in that, at least a part of the sample, participated throughout the project, submitting it that their opinion would count to some extent.

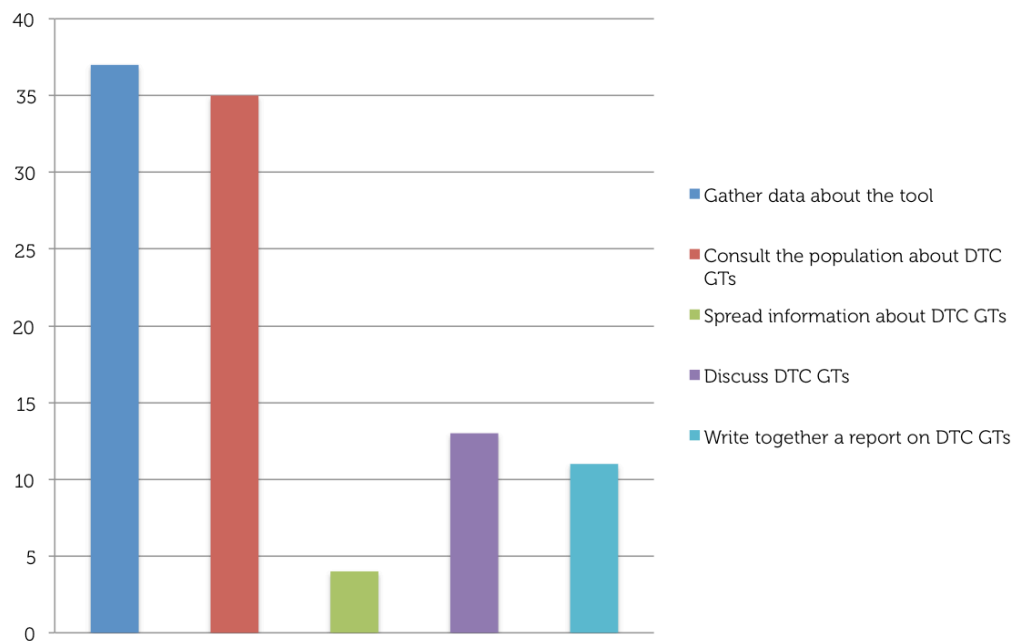


Figure 70 Users perception of the main purpose of the consultation. Columns show absolute numbers.

This finding is consistent with the more than half of respondents reporting they perceived the consultation to have “a clear impact in the real world”, regardless of whether it did in fact have any.

Another interesting fact emerges when we compare the reasons for self-reported non-participation in the consultation (non-participation was defined explicitly in the question as not having undertaken any of the activities after the initial socio-demographic survey), amidst which the lack of time stands out clearly, and the response the participating population gave concerning the degree to which they felt the consultation was demanding. More than the 41% of respondents disagreed (35%) or completely disagreed (6%) that the consultation was demanding. Nevertheless there was the clear perception that information materials were way more than enough: most of the respondents said they disagreed with the statement according to which “There was too little information material”.

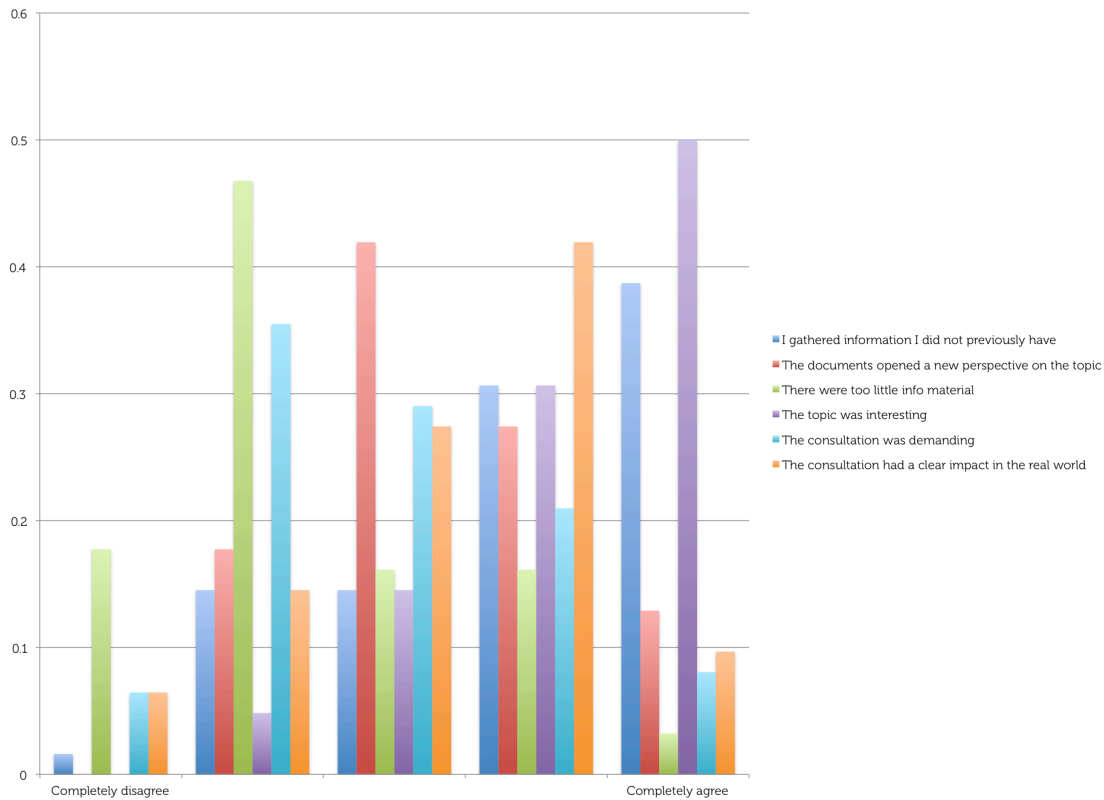


Figure 71 Perceived limitations/features of "bioeticadeliberativa". Columns show percentages.

It thus looks like the demand put on the sample was not perceived to be too high, even though specific parts of the participatory workflow, namely getting through information materials, might have been perceived as too burdensome.

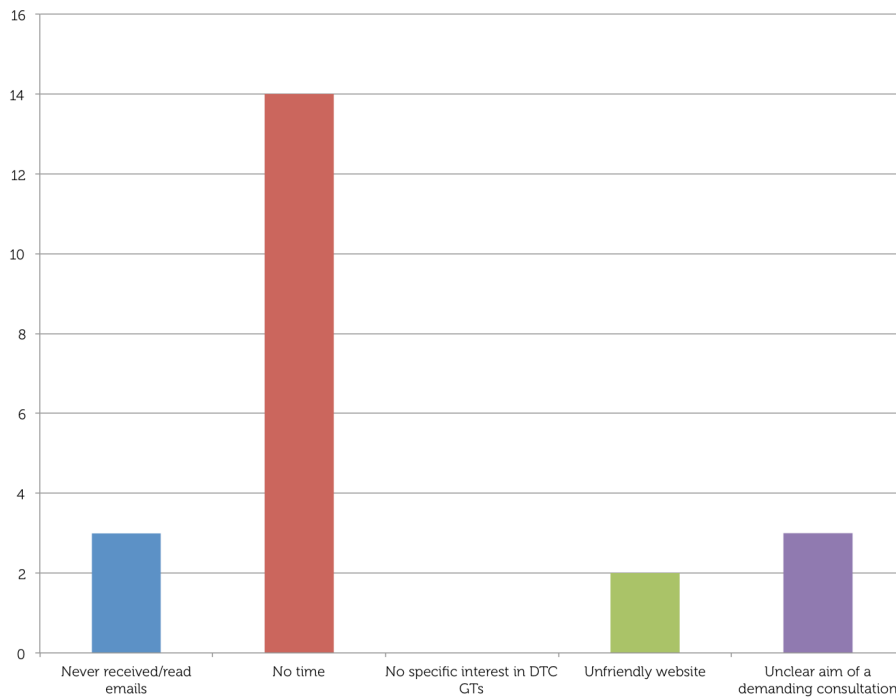


Figure 72 Reasons why self-reported non-participants did not participate. Columns show absolute numbers.

Anticipation of such a burden might have motivated the belief that one might not have had enough time to participate properly.

It is worth noting only in passing that more than the 80% of participating respondents felt the topic was interesting. Given that respondents were a highly self-selected subset of the initial sample, it is likely that those not interested in the topic simply did not bother to fill in any survey after the first one.

Import and usability of the forum

As remarked more than once already, not many members of groups (c) and (d) took advantage of the availability of the discussion forums. Respondents to the post-test survey who claimed they did not use the forum said they did so mostly (12 out of 27) because they lacked time to do so, which is compatible with what we have seen so far concerning the demand of participation. Interestingly, instead, 7 people said they did not use the forum because they did not feel they knew enough. As to those who used the forum, although there is a general positive evaluation of the instrument, surprisingly even as to its usability (even if within this limited subset of the sample, which is very likely to be a highly skilled proportion of a highly skilled sample), respondents show clearly that they did not change their minds as a result of their participation to the forum. This specific datum is discussed below.

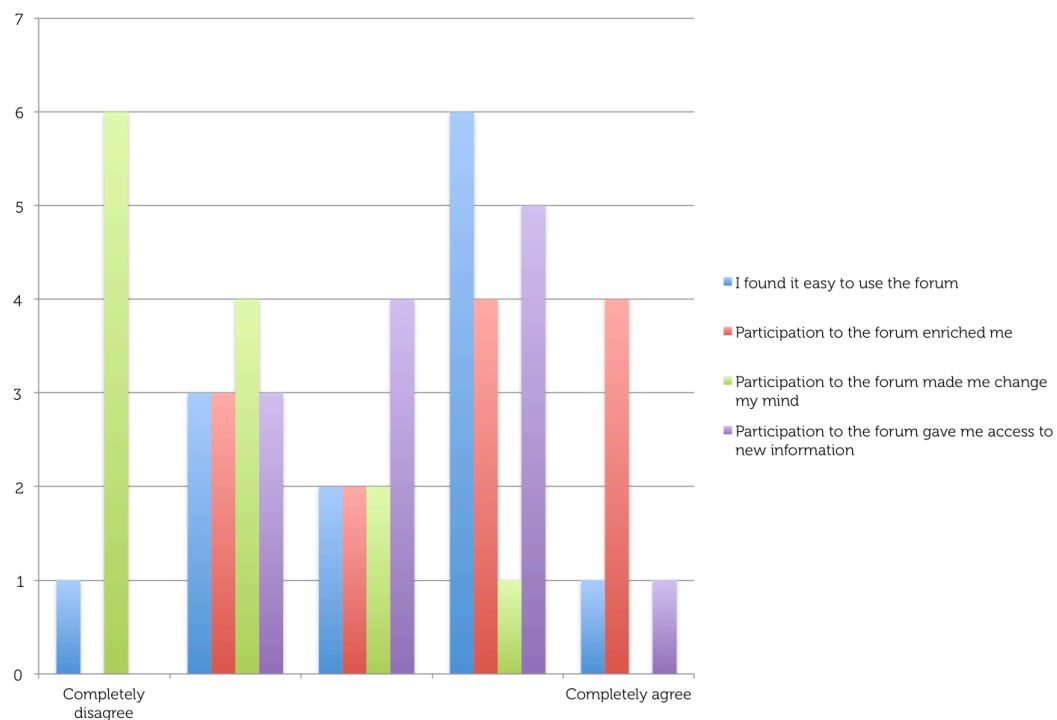


Figure 73 Respondents' opinion of the discussion forums. Columns show absolute numbers.

Preliminary discussion

The actual discussion of our results will take the form of a revision of the normative hypothesis laid out in Part II. It makes however sense to preliminarily single out some interesting bits that emerge from the sizeable amount of data that we collected.

I described in quite some detail all the ways in which our recruited sample differed from the Italian general population. Particularly striking was the educational attainments of the sample.

It was then highlighted how compliance to either one of the three treatments (which has been shown not to be influenced by any of the members' individual traits), information, non-goal-oriented discussion and goal-oriented discussion, made a statistical difference, i.e. it had a non-zero effect, on members' of the experimental groups' preferences. In particular, it apparently cause a shift towards agreeing more to the practice of DTC GTs.

I then proceeded to investigate what putative mechanisms for preference change might have been playing some role to this end. I found that the deliberative quality of the discussion held in the forum (and in the inner-forum for members of group (b)) was relatively high. However, our post-test survey revealed that most users of the forum felt compelled to report that participating in the forums did not make them change their minds. The forums in fact hosted fairly little discussion (though, as I said, of high deliberative quality) and this should alert us to a cautious interpretation of data that come from that part of the experiment. Nonetheless, the fact that information alone had a recognizable effect (in the same direction in which groups (c) and (d)'s treatments exerted an effect) on people's preferences might be telling about the best use to which online engagement initiatives might be put. If we combine this information to the self-reported lack of time non-participant respondents singled out as the main reason for not participating, we might draw the conclusion that the role discussion plays in this context could be somewhat reduced.

In the next section I explore the ways in which the information we gathered can be used to feed back into a new normative hypothesis as to the democratization of bioethics.

Revising the hypothesis

The experiment we performed made clear that, although participation in all three treatment groups was indeed deliberative, the institution we devised failed in terms of inclusiveness. This means that it failed by falling short of the very normative standards of legitimacy that has been articulated in Part II. We only gathered scant information as to the descriptive legitimacy that, once implemented, this institutional arrangement might be able to yield and therefore I will not go so far as to claim that the political theory itself—moderate epistocracy—needs be revised. Instead, in order to give a flavor of how the feedback loop between normative theorizing and empirical investigations that I described extensively in Part I ought to work, in what follows I propose a tentative revision of the institutional arrangement.

bioeticadeliberativa 1.0

Setting aside the widespread rhetoric of an alleged historical shift from deficit to dialogue “recognised and repeated by scientists, funders and policy-makers” (Stilgoe, Lock, and Wilsdon 2014, 5) that would have supposedly led to a genuinely publicly engaged, thus more democratically legitimate, science, one is left with a number of issues that affect the actual practice of public engagement with science. The most worrying, for the account developed in this work, is the one identified by Lovbrand and her colleagues (Lovbrand, Pielke, and Beck 2010). These authors have noted how engagement initiatives seem to be systematically affected by a problem of scale, the same problem of scale highlighted in John Parkinson’s *Deliberating in the Real World* (Parkinson 2006): only those who are involved in the initiative perceive it to cast legitimacy onto the decisions that follow. Unfortunately our small preliminary study confirmed, within the domain of bioethics, the evidence available concerning the link between social capital and participation in deliberative exercises (Price 2009): those effectively participating tend to be better educated, middle-aged and white. These are the people for whom it is likely that participation results in higher perceived legitimacy. In this context, arguments in favor of epistocracy notwithstanding, it seems reasonable to try and tweak the institutional setting so as to lower formal barriers to access in order to try and enhance inclusiveness.

In this paragraph I suggest some ways in which the hypothetical institutional arrangement presented in Part II should be revised in the light of the empirical data concerning the normative legitimacy that the arrangement preliminarily obtained. In particular, given that we witnessed a relatively high degree of

considered judgment, but the experiment failed to deliver on the good of inclusiveness, I will present ways to lower barriers to access, both formal and informal.

The experiment presented above can then be seen as a pre-release test, a so-called beta version, of the actual institution we were and still are planning to build. In what follows I envisage the ways in which the blueprint for our plan can and ought to be restructured. In this sense what follows is really an overview of a potential 1.0 version of the platform as we developed and tested it heretofore. This is however not to be seen simply as an instantiation of ‘pre-market’ testing good practices of some product. These efforts have rather been construed so far as an essential part of a process of continuous institutional experimentation and improvement that is inherent in the modest realist framework outlined in Part I. As I noted above, given the fairly preliminary nature of the results, these cannot possibly be telling about the political theory that informed our hypothesis, but still information concerning the normative legitimacy of the institution and the exploratory data concerning the descriptive legitimacy of the project can be fruitfully put to work in order to produce a redressed version of bioeticadeliberativa—bioeticadeliberativa 1.0.

A new GUI and UX

A clear limitation of the arrangement that its test unveiled was its inadequacy in prompting contributions on the part of the participants. Specifically, the task of coming up with the actual guidelines was essentially disregarded by participants who fancied instead discussing on the forum. This might be due to a number of reasons: most people claimed they had little time and commenting upon others’ ideas requires less engagement than contributing to a document; the document and the forum were on two different pages probably hampering the simultaneous browsing of both; the task was either not explicit enough or perceived as not having impact in the real world (though this seems to go counter what users reported); the long process of getting to the materials might have ‘tired’ users up, to the point that the resources they were planning to invest in the initiatives had been consumed before they actually got to contribute. Whatever the reason, though, it is crucial that participants be presented with the aim of drafting a document containing guidelines as soon as they land on the website. Furthermore, all interactions concerning the document ought to take place on the same webpage.

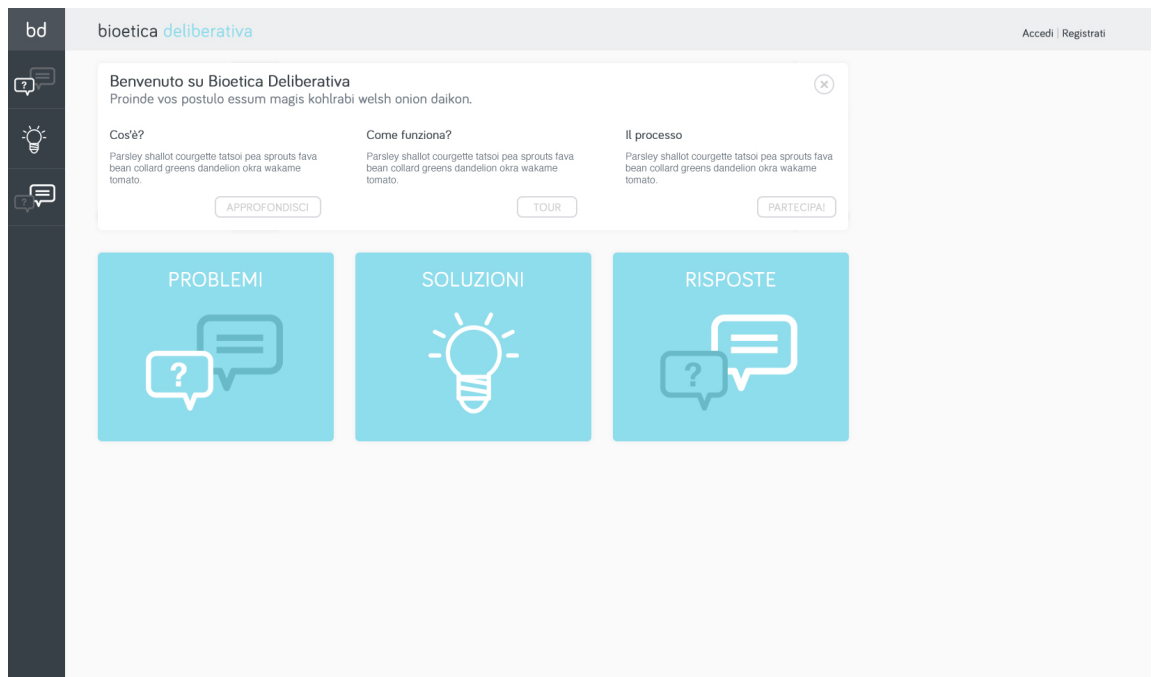


Figure 74 bioeticadeliberativa 1.0. Homepage.

As it has been noted “the design of the user interface has a significant impact on the platform’s effectiveness” (Nelimarkka et al. 2014, 2) and “to maximize rates of participation, forms of engagement should be lightweight, integrating well with everyday life and posing few barriers to access” (Graeff 2014, 7). Therefore, given the feedback on the usability of the tool we received, a radical restructuring of both the GUI and the UX of the platform is in order.

First, the new implementation will feature a renewed area for the selection of problems that users feel should be tackled. Each issue will have a timestamp attached that is equivalent to the day it is first posted. A timer will count down the days that remain for the issue to gain enough supporters (the number of participants needed being represented by a bar filling up). This visual representation uses signifiers familiar to more or less skilled users for they are widely resorted to in crowdfunding websites whose purpose is relatively similar to the one performed by this section of bioeticadeliberativa, i.e. backing (in this case only by publicly supporting) some project.

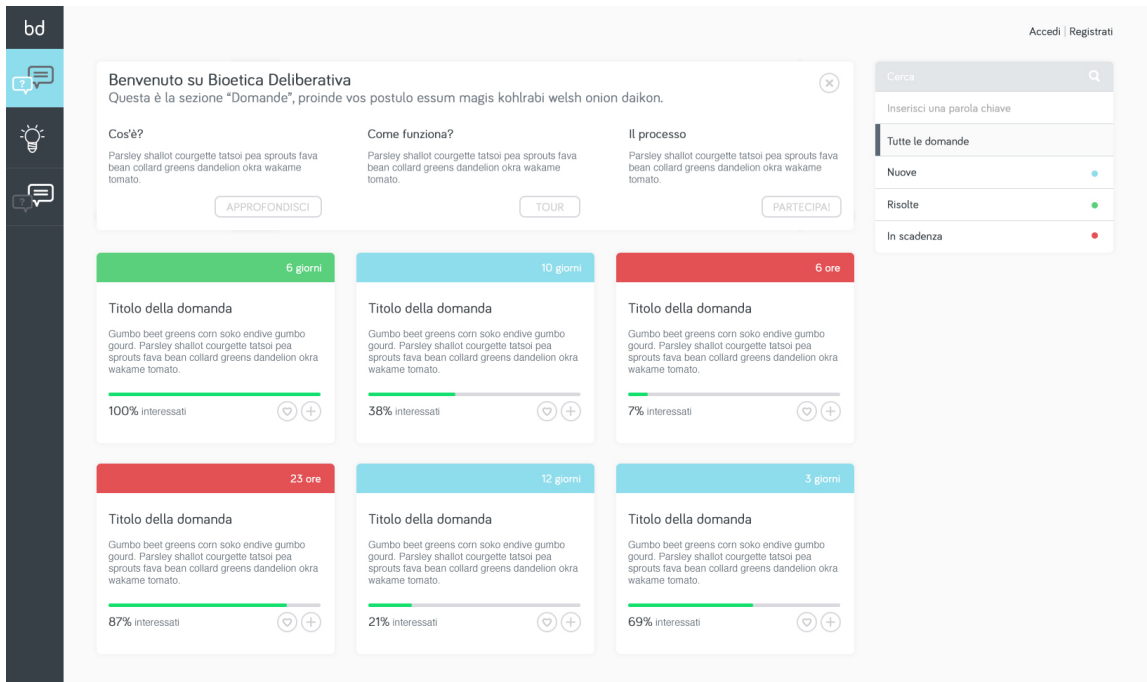


Figure 75 bioeticadeliberativa 1.0. Issues voted and their timing.

Issues selected are then addressed by a panel of appointed experts who is tasked with laying out the materials that will populate the page dedicated to the issue when it is first uploaded onto the platform.

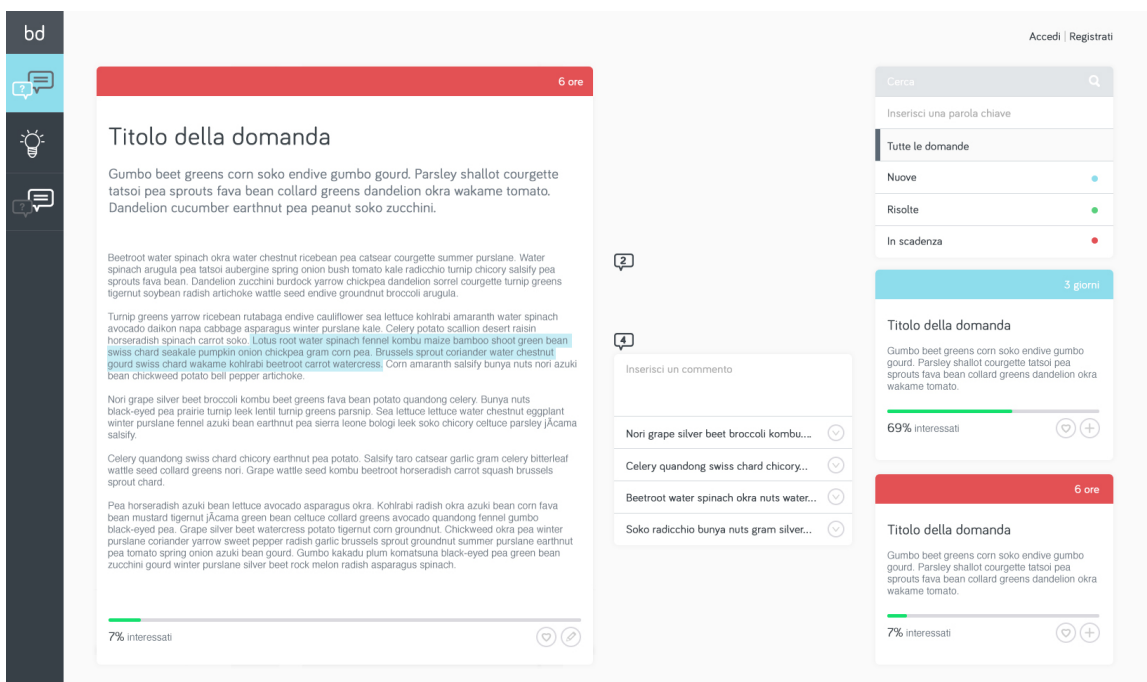


Figure 76 bioeticadeliberativa 1.0. Collaborative drafting environment.

Each of these pages is divided in paragraphs. Participants can highlight parts of the text, comment upon them and suggest reasons for revision. Comments and suggestions can be up or down-voted by other participants, but everything is displayed on one page.

Every user can draft alternative versions of specific paragraphs and each of those versions can be voted into the original document if the number of votes it receives crosses a given threshold. A final version of the document freezes once enough participants deem it ready (again aggregating votes).

Participation by sortition

The idea that equality might be promoted by resorting to lottery mechanisms in the appointment for specific deliberative bodies, though dating back at least to Aristotle (who claimed, in his *Politics*, that “it is held to be democratic for officials to be chosen by lot, and oligarchic by election” Aristotle 1998, 116–7) and part of the conception of democracy held by influential political theorists such as Rousseau’s (Rousseau 1998), has been recently gaining traction both in academia and in the real world¹⁵⁴ as a result of growing concerns for the ways in which current liberal democratic practices diverge from most (if not all) democratic ideals (Bartels 2008; Graeber 2013; Della Porta 2013). I cannot explore in depth here the intricacies underlying the use of lottery for committees that are tasked with coming up with norms and policies concerning specific morally problematic issues, but I believe that at least the problem of the scarce representativeness of the sample emerged in our experimentation can be successfully addressed with this participatory scheme.

Given that mustering large-scale participation has revealed difficult both online and offline (testimony to this difficulty is our experiment but also essentially all open recruitment participatory initiatives, even when promoted by institutions supposedly endowed with decisional powers¹⁵⁵), the unrealistic conception of normative legitimacy that submits it that “[o]utcomes are legitimate to the extent they receive reflective assent through participation in authentic deliberation by all those subject to the decision in question” (Dryzek 2001, 651) does not stand the slightest of chances of being workable both in theory¹⁵⁶ and in practice. Random selection by lottery, in this regard, can improve substantially upon open-recruitment for my institutional arrangement in that (i) it entails a closer compliance with what Pettit has called indicative representation, i.e. the representer standing for the representee “in the

¹⁵⁴ A collaborative blog has developed around the topic of sortition as an instrument for democratic development (<http://equalitybylot.wordpress.com/about/> last access September 6th 2014).

¹⁵⁵ As noted above, the PARTECIPA! Initiative, for instance, though presented as a success story, only managed to recruit, at the most, 200’000 people (more than 200’000 surveys were filled properly, but this number sums up participation to two surveys, one brief and one longer and more in-depth, some of which have been submitted by the same people), with prime-time TV advertisement and governmental support.

¹⁵⁶ The demand that participation be actual gives rise to a paradox well summarized by Philip Kitcher: “A group of one thousand citizens, confronting one hundred issues a year, could allow five minutes per person per issue—assuming complete dedication to the project and universal insomnia; if the number is increased to one million, each person’s allotment drops to 0.3 seconds” (Kitcher 2011, 79).

sense of typifying or epitomizing” him/her and acting how the representee *would act* (Pettit 2010, 65)¹⁵⁷ therefore enhancing the degree of inclusiveness that the institution might realize, (ii) it taps renown goods of sortition such as that “it gives everyone an equal chance of being chosen” and that it “also gives individuals an equal chance to develop their character and sense of self-worth through serving in office” (Carson and Martin 1999, 34), and (iii) it reduces perverse incentives towards undesirable influences exerted on elected representatives by entrenched ruling elites, making the selection of those who will hold offices unpredictable thus their influence or bribing impossible.

The practical unfeasibility of large-scale legitimation recalled above raises, as opposed to more ‘in principle’ objections to those conceptions of normative legitimacy, the further issue that some people do not seem to *want* to participate in the process of legitimation that some theorists envisage. This unwillingness to participate construes participation, at least *to someone*, as a form of evil. Hence a scenario in which those unwilling to participate are not conscribed to do so seems preferable to one in which that evil is imposed upon them. Therefore, the kind of random selection just outlined, can only be presented as furthering uncontroversial goods if participation itself is regarded as an uncontroversial good (which for someone apparently it is not). Hence, random selection ought to be used for the issue-specific crowdsourcing of policy with at least one proviso: that randomly selected participants belong to the pool of those who expressed their willingness to participate (in our case everyone who registered to cast a vote on what issues should be considered for deliberation). Such a selection by lot would prevent wronging those who do not want to participate, but it would also engender some damage to the indicative representativeness of those who will hold the office. This is because the self-selected participating sample will be likely to display the usual kind of skewedness. In this context then it makes sense to resort to stratified sampling, i.e. a random sampling respecting proportionality in characteristics that one deems important, such as gender, ethnicity, age and education, as a means to restore descriptive (or indicative) representation. Although, as Dowlen notes (Dowlen 2008), stratified sampling introduces reasons to modify the odds that some have a higher or lower chance of being appointed depending on the group/s they belong to¹⁵⁸—reasons which might be objectionable—this risk “should not be overstated” (Stone 2011, 134). In particular it should not be overstated in this case,

¹⁵⁷ The indicative conception of representation is opposed to the responsive conception according to which representatives act on behalf of and speak for their representee (either as delegates or as trustees).

¹⁵⁸ Essentially this reason in our case depends on the belief that democratic decisions ought to be taken as inclusively as possible and therefore participating samples ought to proportionally represent the overall population in some respects.

in which the only alternatives are both unattractive: in fact, one could either (a) recruit those for whom participation is an evil, sampling from the general population and, in order to prevent skewed attrition from recruitment to participation¹⁵⁹, compel everyone to participate, or (b) selecting purely randomly over an unrepresentative participating pool, which would instead damage inclusiveness unduly increasing the chances that those already overrepresented are appointed.

Revising the GUI and UX of the platform while resorting to stratified random selection among participants of course cannot do on their own and my corollary institution is still supposed to work as specified above, leaving the decision by a randomly selected committee up for grabs and allowing for the expression of explicit dissent by *anyone*, thus preventing illegitimate decisions from becoming binding on everyone.

Conclusion

If the arguments laid out in this dissertation are sound, then I have pointed to some interesting conclusions concerning the relationship between politics and bioethics:

- i. I showed that public bioethics is a political endeavor throughout and that, as such, it deserves to be governed according to *some* political theory;
- ii. In trying to adjudicate *which* political theory would suit the governance of bioethics, I investigated the dilemmatic nature of the problem of normativity in political theory arguing that any ultimate politico-theoretical adjudication is doomed unless we find a way out of the dichotomy between radically anti-foundational political realism and foundational political moralism;
- iii. I suggested that such a way out could be effectively grounded in a new reading of political realism as the application, in the domain of politics, of insights coming from scientific realism. Within this framework: (a) democratic experimentalism à la Dewey can fruitfully be construed as the scientific method for politics; (b) political theories postulate principles, ideals and values that, for our best political theories, exist independently of the theories themselves; (c) institutional arrangements hypothesized on the grounds of those principles, ideals and values,

¹⁵⁹ This is a well-known effect. Even when randomly sampled, participants who do show up and engage tend overwhelmingly to display traits usually already associated with political participation, such as older age, higher educational attainments, higher income and so forth (see, for instance, Smith, John, and Sturgis 2013; Neblo et al. 2010, 10–11).

can resort to mechanisms such as voting, deliberation, association, etc. without any need to mobilize full-fledged politico-theoretical models; (d) these arrangements are tested in practice and their performance measured along the axes of *normative* and *descriptive* legitimacy.

- iv. Tools to account for the descriptive legitimacy that institutions yield are essential to complement measures of the degree to which postulated notions of normative legitimacy are realized empirically, if we want politics to be a progressive endeavor;
- v. A moderate and participatory epistocracy, consistent with well-established principles, ideals and values articulated in deliberative democratic and republican scholarships, might fit the scope and aims of public bioethics. An online platform might support deliberation by participatory epistocratic issue-specific committees.

The preliminary empirical test of the institutional arrangement articulated in Part II, whose results have been presented in detail in Part III, unveiled some problematic shortcomings. In particular:

- vi. The framing and the recruitment strategy of the initiative seem to have seriously hampered the realization of the good of inclusiveness, thus damaging the normative legitimacy of its output. Furthermore, participants proved very prone to considered judgment, but failed to participate effectively and epistocratic constraints seem to have put too much of a burden on participants, most of whom felt they did not have enough time to contribute.
- vii. Therefore, proceeding from the data obtained thanks to our preliminary implementation, I proposed some tentative revisions of the institutional arrangement.

I conclude here open-endedly. This might give the feeling that something is missing. The point, though, is that something is indeed missing and would be missing even in case we were able to perform a field experiment with an institution reshaped as suggested in the last paragraph. Because the endeavour of a Deweyan democracy is just as endless as a fortunate image claimed the frontier of science to be (Bush 1945).

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