

Gene editing decisions and democratic participation: A privileged area for the application of the principles of deliberative democracy?

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ABSTRACT: The frontiers reached by gene editing and their applications for animals, plants and humans raise numerous tricky issues, posing new and renewed challenges for constitutional law scholars. This paper focuses on the role that the public can play in decision-making processes aimed at regulating gene-editing technologies. Thus, it reflects on the opportunity to develop and enhance deliberative arenas, which guarantee a fuller participation of citizens in legislative choices that touch upon controversial scientific issues of general interest, in compliance with the principles of deliberative democracy.

KEYWORDS: deliberative democracy; participatory democracy; deliberative arenas; gene editing; public participation

SUMMARY: 1. Introduction – 2. Deliberativism and participatory democracy: A theoretical framework and models to look at – 3. Genetic manipulation as a privileged field for public participation – 4. The case of the Global Citizens' Assembly on Genome Editing – 5. Conclusions.

1. Introduction

In 2020, the Centre for Deliberative Democracy and Global Governance at the University of Canberra (Australia) and an international network of researchers announced the convening of the first Global Citizens' Assembly on Genome Editing.¹ The initiative consists of creating a forum where citizens from all over the world can discuss, exchange opinions, and receive information on the developments and implications of the most advanced genetic engineering techniques, which now make it possible to alter the genetic sequence of any organism (plant, animal or human) "to

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¹ See N. CURATO, S. NIEMEYER, *Why we need a global citizens' assembly on gene editing*, in *TheConversation.com*, 17 settembre 2020; J.S. DRYZEK et al., *Global citizen deliberation on genome editing*, in *American Association for the Advancement of Science*, 369, 6510, 18 September 2020, 1435-1437; J.S. DRYZEK, A. BÄCHTIGER, K. MILEWICZ, *Toward a Deliberative Global Citizens' Assembly*, in *Global Policy*, 1, 2011, 33-42; J. CHADWICK, *Plumbers and teachers are invited to share their views on designer babies and genetically enhanced potatoes as part of a citizens' assembly on 're-engineering' the human species*, in *Daily Mail Online*, 18 September 2020. The official website of the "Global Citizens' Assembly on Genome Editing. Connecting citizens, science and global governance" project is: <https://www.globalca.org/>.

produce favourable characteristics or remove unwanted ones”.² At the end of the deliberative phase, the assembly is asked to produce recommendations (“moral and political regulation”³) that can be taken into account by those who are responsible for regulating these technologies at all levels.

For decades, the legal debate on genetic manipulation has focused mainly on the production of GMO foods – that is, agricultural products for human and animal consumption, the genetic material of which is modified in a way that differs from what occurs in nature. However, the DNA alteration techniques that have been developed over the years not only concern the gene modification of seeds and plant varieties, but also involve all life forms on the planet, including humans.⁴

One of the most promising and versatile technologies in this field is the CRISPR-Cas,⁵ which makes it possible to cut and replace genome sequences in a relatively simple way, applying a system that is naturally present in bacteria and other single-celled organisms. Genetic ‘correction’ can take place either in the germ line of an organism (i.e. before cell differentiation occurs) or later in its development, in the somatic line. When applied to germ cells, the modification not only affects the organism in which it is carried out – it will be passed on to all organisms that later receive its genetic heritage. Thus, manipulation of the germline entails the possibility that unforeseeable side-effects of the alteration will turn into permanent genetic mutations.⁶

Despite these shadows, there is no doubt that the potentials of CRISPR are vast and promising. They range from the improvement of food, to medical applications of enormous scope (e.g. the possibility of stopping the spread of diseases, such as malaria, by intervening in the DNA of insects that carry it,⁷ helping in the fight against cancer, and curing rare genetic diseases), and even to altering human embryos produced in vitro to remove from the genetic make-up of unborn children any genes considered to be decisive in the development of diseases or undesirable characteristics. In 2018, CRISPR was used to give birth to the first two genetically modified human beings in a controversial and opaque experiment carried out by the Chinese researcher Jiankui He. According to the scientist, the clinical trial he conducted involved couples of would-be parents made up of HIV-positive fathers and led to the production of embryos resistant to the virus in question by deactivating the gene that usu-

² N. CURATO, S. NIEMEYER, *op. cit.*, 1.

³ J.S. DRYZEK et al., *Global citizen deliberation on genome editing, cit.*, 1435.

⁴ The first famous attempt to genetically modify human embryos dates back to 2015, which was followed by the convening of an international summit of scholars (the International Summit on Human Gene Editing) in Washington, conceived as “an initial attempt to keep the discussion about human genome editing thematically broad and open to input from a variety of stakeholders” (A. BLASIMME, *Why Include the Public in Genome Editing Governance Deliberation?*, in *AMA Journal of Ethics*, 21, 12, 2019, 1067).

⁵ Acronym for *Clustered Regularly Interspaced Short Palindromic Repeats-Cas*. On this technique see <https://bit.ly/3gBT8b7>.

⁶ Therefore, as recalled in S. BONOMELLI, *Gene editing embrionale: il vaso di pandora è stato scoperchiato? Riflessioni a margine del caso di Jiankui He*, in *BioLaw Journal*, 3, 2019, 72, both the Oviedo Convention and the Universal Declaration on the Human Genome and Human Rights UNESCO absolutely prohibit genetic interventions on the germ-line.

⁷ See M. ANNONI, T. PIEVANI, *What is wrong in extinguishing a species? Charting the Ethical Challenges of using Gene-Drive Technologies to eradicate A. gambiae vector populations* in this Special Issue.

ally allows contagion in humans.⁸ The genetic editing operation was therefore intended to prevent the children born from the experiment from contracting HIV in the future.⁹

It is quite clear that the advances made in gene editing and the horizons towards which such technologies are moving raise numerous delicate questions, not only on the ethical and scientific levels, but also on the legal one, posing new and renewed challenges for constitutional law scholars.¹⁰ In this paper, we have chosen to reflect, in particular, on the role that the general public can play in decision-making processes aimed at regulating these technologies. In this way, we intend to contribute to the debate on the opportunity to develop and enhance deliberative arenas¹¹ that, like the one convened by the scholars of the University of Canberra, guarantee a fuller participation of the public in regulatory choices that involve controversial scientific issues of general interest,¹² in accordance with the principles of so-called deliberative democracy.¹³

To this end, we will first define deliberativism and attempt to identify the models of participatory democracy that appear to be the most suitable to be taken into consideration for science- and technology-based decisions. It will be made clear, however, that “the models adopted are very varied, so that it is not possible to refer to a standardised model, but rather to certain guiding principles”.¹⁴

Second, an examination will be made of the characteristics that make the chosen field, namely gene editing, a particularly interesting test bed for the application of deliberativist theories.

Finally, before turning to conclusions, the merits and limitations of the Global Citizens’ Assembly on Gene Editing will be highlighted, with particular emphasis on the choice of conducting a global experiment.

⁸ On this experiment see S. BONOMELLI, *op. cit.*, 67 ss.

⁹ However, the experiment seems to have largely failed. See D. PERRIN – G. BURGIO, *China’s failed gene-edited baby experiment proves we’re not ready for human embryo modification*, in *TheConversation.com*, 9 December 2019.

¹⁰ On the “interactions between the two ‘codes’ (genetics and law) that make up the ‘palimpsest of life’ in the process of ‘bioconstitutional’ reconfiguration of rights” (M. TALLACCHINI, *Scienza e diritto. Prospettive di produzione*, in *Rivista di filosofia del diritto*, 2, 2012, 317) see S. JASANOFF (ed.), *Reframing Rights. Bioconstitutionalism in the Genetic Age*, Cambridge, 2011.

¹¹ See L. BOBBIO, *Le arene deliberative*, in *Rivista Italiana di Politiche Pubbliche*, 3, 2002, 5 ss. and more recently V. MOLASCHI, *Le arene deliberative. Contributo allo studio delle nuove forme di partecipazione nei processi di decisione pubblica*, Napoli, 2018 and *Id.*, *La democratizzazione delle decisioni science and technology based. Riflessioni sul dibattito pubblico*, in *Nuove Autonomie*, 3, 2017, 464. Here, deliberative arenas are referred to as “instruments, inspired by the principles of deliberative democracy, which are increasingly being used in the case of public decisions concerning scientifically and technically complex issues, typically in the fields of health and biomedical research, biotechnology and the environment”.

¹² For the definition of a “controversial scientific issue”, refer to L. VIOLINI, *Le questioni scientifiche controverse nel procedimento amministrativo*, 1986, Pavia.

¹³ On this subject, in the Italian literature, see *inter alia*, U. ALLEGRETTI, *Basi giuridiche della democrazia partecipativa in Italia: alcuni orientamenti*, in *Democrazia e diritto*, 3, 2006, 151 ss. e *Id.*, *Democrazia partecipativa*, in *Enciclopedia del Diritto – Annali IV*, Milano, 2011, 295 ss.; R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa. Relazione al Convegno “La democrazia partecipativa in Italia e in Europa: esperienze e prospettive”* - Firenze, 2-3 aprile 2009, in *Rivista Astrid* e *Id.*, *Democrazia deliberativa e principio di realtà*, in *Federalismi.it*, numero speciale 1, 2017, 1 ss.; A. FLORIDIA, *La democrazia deliberativa. Teorie, processi e sistemi*, Carocci, Roma, 2013 e *Id.* *Democrazia partecipativa e democrazia deliberativa: una risposta plausibile alla “crisi della democrazia”?*, in www.fondazionefeltrinelli.it, 29 marzo 2019.

¹⁴ U. ALLEGRETTI, *Basi giuridiche della democrazia partecipativa in Italia: alcuni orientamenti*, *cit.*, 152.

2. Deliberativism and participatory democracy: A theoretical framework and models to look at

Usually, when describing the institutions and mechanisms that characterise our contemporary democracies, recourse is made to the concepts of “representative democracy” and “direct democracy”. If we take the Italian Constitution as an example, it outlines a democratic state that entrusts the main decision-making functions to state bodies that *represent* the people and are linked to them through direct or indirect elective mechanisms; at the same time, there are also institutions of so-called direct democracy, such as referendums, popular legislative initiatives and petitions, which allow the electoral body to make decisions that affect the system *without the mediation* of representatives.

The creation of institutions of direct democracy within representative systems responds to the need “to ensure popular participation in decisions that affect the entire community and to bridge the gap between the people and the state apparatus”.¹⁵ The institutions or procedures that the doctrine frames as examples of “participatory democracy” and that have their roots in the various theories of “deliberative democracy”¹⁶ tend towards a similar objective, albeit in different ways.¹⁷ It is not by chance that the diffusion of instruments typical of these meanings of democracy is considered, *inter alia*, a consequence of the crisis of representative democracy.¹⁸

Two clarifications are necessary before proceeding to a definition. First of all, we agree with the view that “Participatory Democracy and Deliberative Democracy are not alternative forms to representative democracy; rather, they are models or ideas that can indicate certain characteristics and mark the greater or lesser quality of representative democracy itself”.¹⁹ The institutions and forms that are generally brought under the umbrella of these concepts can therefore be seen as complementary to the institutions of representative democracy and direct democracy.²⁰

¹⁵ R. BIN, G. PITRUZZELLA, *Diritto costituzionale*, XXI ed., Torino, 2020, 75.

¹⁶ On the possibility that the implementation of forms of participatory democracy offers a credible response to the need for citizens to participate in the life of society and institutions, see U. ALLEGRETTI, *Basi giuridiche della democrazia partecipativa in Italia: alcuni orientamenti*, *cit.*, 151.

¹⁷ L. BOBBIO, G. POMATTO, *Il coinvolgimento dei cittadini nelle scelte pubbliche*, in *Meridiana: rivista di storia e scienze sociali*, 58, 2007, 46. *Contra see* G. SCOFFONY, *La démocratie participative dans les États fédérés américains*, in F. ROBBE (ed.), *La démocratie participative*, Paris, 2007, 98, according to which the institutions of direct democracy are also forms of participatory democracy.

¹⁸ See V. MOLASCHI, *Le arene deliberative*, *cit.*, 18-19; G. PEPE, *Il modello della democrazia partecipativa tra aspetti teorici e profili applicativi un'analisi comparata*, Padova, 2020, 13 ff. and A. FLORIDIA, *Democrazia partecipativa e democrazia deliberativa: una risposta plausibile alla “crisi della democrazia”?*, *cit.*, *passim*.

¹⁹ A. FLORIDIA, *Democrazia partecipativa e democrazia deliberativa: una risposta plausibile alla “crisi della democrazia”?*, *cit.*, 2.

²⁰ Cfr. U. ALLEGRETTI, *Basi giuridiche della democrazia partecipativa in Italia: alcuni orientamenti*, *cit.*, 153; M. SETÄLÄ, *Connecting deliberative mini-publics to representative decision making*, in *European Journal of Political Research*, 56, 2017, 846 ff. An interesting – albeit not without criticism – combination of instruments of direct democracy and participatory democracy has been realised on several occasions in Ireland, where important referendums on ethically sensitive issues have been anticipated by deliberative assemblies: see E. CAROLAN, *Ireland's Citizens' Assembly on Abortion as a Model for Democratic Change? Reflections on Hope, Hype and the Practical Challenges of Sortition*, in *IACL-AIDC Blog*, 28 November 2018; C. O' CINNEIDE, *The Citizens' Assembly Viewed in External Perspective: Useful, but not a Deliberative Deus Ex Machina*, in *IACL-AIDC Blog*, 12 December 2018.

The second clarification concerns the relationship between deliberative and participatory democracy: although there are divergent reconstructions, here we adhere to the approach according to which the deliberativist doctrines²¹ constitute the theoretical basis on which the practices attributable to participatory democracy are founded.²²

It is not easy to offer a single definition of deliberativism. It constitutes a highly varied theoretical background.²³ However, it is possible to trace two characteristics that serve as the lowest common denominator among its various theorisations:²⁴ first, it is a concept of democracy in which public decision-making processes must include a phase of exchange of opinions and information that is as complete and impartial as possible; second, the discussion (or deliberation) must be inclusive, ideally involving all the subjects concerned by the final decision, or at least a representative sample.

With regard to the forms that participatory democracy can take, many practices have been tried out all over the world, both at national and local levels:²⁵ suffice it to say that more than a hundred different types of participatory mechanisms have been counted in the literature.²⁶ Among the best known and most widespread models are citizens' juries, deliberative polls, town meetings, *Planungszellen*, participatory budgets and consensus conferences.²⁷ The latter, in particular, are relevant to the theme of this paper, since they constitute "a typical example of a participatory process aimed at the democratisation of public decisions, so-called science and technology based".²⁸ In fact, they put experts on a given scientific-technical issue in dialogue with a sample of the citizenry potentially affected by a certain change and, at the end of the exchange between citizens and scientists, allow the identification of shared positions on the use of the technology or discovery under discussion. However, there are also cases in which the outcome of the work is not linked to the achievement of a consensus; therefore, these conferences should not be considered consensus conferences but rather "citizen conferences" or "citizen assemblies".²⁹ Such is the case of the Global Citizens' Assembly convened by the Australian network.

²¹ The first theorisation of the concept of deliberative democracy can be found in J.M. BESSETTE, *Deliberative Democracy: The Majority Principle in Republican Government*, in R. GOLDWIN, W.A. SCHAMBRA (a cura di), *How Democratic is the Constitution?*, Washington, 1980, 102 ss.

²² R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa*, cit., 2 ss.

²³ *Idem*, 3.

²⁴ Cfr. V. MOLASCHI, *Le arene deliberative*, cit., 34 ss. According to Pellizzoni, who speaks of deliberative democracy as the "most significant innovation in democratic debate and practice in recent decades" (L. PELLIZZONI, *Comunità, partecipazione e democrazia deliberativa: un'esperienza italiana*, in *Quaderni di sociologia*, 68, 2015, 149), the key option of the deliberative ideal is the establishment of organised discussion.

²⁵ For an interesting example of a deliberative arena organised at municipal level see G. BALDUZZI, D. SERVETTI (eds.), *Discutere e agire. Una sperimentazione di democrazia deliberativa a Novara*, Novara, 2014.

²⁶ See V. MOLASCHI, *Le arene deliberative*, cit., 60-61.

²⁷ For a description of the individual models listed, *ibidem*, 62-85. See also D. GIANNETTI, *Modelli e pratiche della democrazia deliberativa*, in G. PASQUINO (a cura di), *Strumenti della democrazia*, Bologna, 2007, 139 ss. e U. ALLEGRETTI (a cura di), *Democrazia partecipativa. Esperienze e prospettive in Italia e in Europa*, Firenze, 2010.

²⁸ See V. MOLASCHI, *Le arene deliberative*, cit., 64. The same opinion is shared by L. BOBBIO, G. POMATTO, *op. cit.*, 49.

²⁹ This demonstrates that the ideal models proposed are often not applied blindly but adapted to circumstances and objectives (L. PELLIZZONI, *op. cit.*, 150).

The work of these conferences is highly structured and usually consists of three stages: in the first stage, the citizens involved receive the information needed to frame the terms of the issue; this is followed by the actual discussion between laypeople and experts, who must be exponents of different theses and positions; finally, the assembly produces recommendations that are submitted to policy makers and made available to the public.

This type of deliberative arena has already been used several times to discuss issues related to genetics: GMOs, gene therapies, genetic testing, human genome mapping and so on.³⁰ However, unlike the global assembly convened last year, these have always been national or sub-state initiatives.

One of the first Italian consensus conference experiments on genetic modification took place at the regional level, in Lombardy, in 2004. On this occasion, two randomly selected panels of Lombardy citizens were asked to discuss the issue of open-field experimentation with GMOs with various experts. The conference, organised by the Bassetti Foundation and the Research Institute of the Lombardy Region, resulted in the citizens drawing up a series of recommendations to be forwarded to the regional government. However, as this was an experimental procedure, the results obtained did not really affect regional decisions on the release of genetically modified products into the environment.³¹

One of the most interesting systems to look at is undoubtedly that of France, where participatory procedures are used in relation to scientifically debated or technically complex questions: this is the case of the so-called *débat public* and the *États généraux de la Bioéthique* have been tried out. The former is a procedure to which decisions on the launch of certain categories of major works are subject, which includes an important phase of public information and then a four-month period of debate open to the entire population. At the end of the procedure, a report is drawn up for consideration by the body responsible for carrying out the project.³² The *débat public* model inspired the Italian legislature to draft Article 22 of the Public Contracts Code for large-scale infrastructure projects,³³ according to which large-scale projects “with an impact on the environment, on towns and cities and on regional planning” are subject to the public debate procedure.³⁴

The *États généraux*, on the other hand, consist of a series of consultations and public debates with broad participation, divided into various panels organised at the regional level, which precede the revision of the law on bioethics.³⁵ At the end of the work, the *Comité Consultatif National d’Éthique* has the task of drawing up a report summarising the results, which is sent to parliament for discus-

³⁰ See the report by the Loka Institute for Science & Technology of, by & for the people: <http://loka.org/TrackingConsensus.html>.

³¹ The Policy paper *Democrazia partecipativa e legislazione regionale* by Eupolis Lombardia, published in June 2014 and available on the portal: www.polis.lombardia.it.

³² See V. MOLASCHI, *La democratizzazione delle decisioni science and technology based*, cit., 478 ss. See also G. PEPE, *Il modello della democrazia partecipativa tra aspetti teorici e profili applicativi un’analisi comparata*, cit., 74 ff. and S. CASSESE, *La partecipazione dei privati alle decisioni pubbliche. Saggio di diritto comparato*, in *Rivista trimestrale di diritto pubblico*, 1, 2007, 19 ff.

³³ See the legislative decree no. 50, 18 April 2016, as amended by the legislative decree no. 56, 19 April 2017.

³⁴ On this issue, V. MOLASCHI, *Le arene deliberative*, cit., 258 ss.

³⁵ On the *États généraux* held in 2018, see L. GAFFURI, E. PULICE, Francia - Stati Generali di Bioetica: pubblicato il rapporto di sintesi del Comité consultatif national d’éthique, in www.biodiritto.org, 5 June 2018.

sion in the legislature.³⁶ This second paradigm appears to be particularly interesting *ratione materiae*: in fact, genetic screening and genomic medicine are among the bioethical issues that defined the scope of the 2018 *États généraux* debate.³⁷

Within the heterogeneous practices mentioned above, some cross-cutting features can be identified that are particularly suited to deliberation on gene editing: first, these are places and procedures that allow for informing, as well as consulting and acquiring the opinion of, the majority of the individuals who are the recipients of a given decision or of as representative a sample of them as possible; second, “the effect of participation is not to transfer the final decision-making power to the participants”,³⁸ nor to directly bind the legislature, but to open a public debate and allow the exchange of arguments that find their synthesis in a final product (be it a report, a budget or recommendations). On the one hand, the fact that the outcome of the deliberation is not binding but at most carries out a “moral suasion capable of actually conditioning the formulation of public choices”³⁹ can be seen as an element of weakness of the participatory arenas. On the other hand, this characteristic helps to mitigate the objection that it would be inappropriate to entrust ordinary people (i.e. non-scientists) with decisions based on complex findings and knowledge.⁴⁰ Moreover, unlike a more incisive instrument, such as the popular referendum,⁴¹ a possible rejection by the public of a certain technology does not close the matter in the long term. On the contrary, given the argumentative nature of deliberation, it helps to highlight the conditions under which it is possible to continue.

3. Genetic manipulation as a privileged field for public participation

In order to understand whether, and to what extent, public involvement can and should play an important role in decisions on gene editing regulation, it is necessary to take into account a number of factors that are peculiar to the technologies in question: the connection with environmental issues, the spatial and temporal extent of the effects that may arise from their application and, of course, the ethical sensitivity of the issues raised.⁴²

This latter aspect, together with the divisiveness of the subject and the variety and relevance of the interests involved, has made the question of genetically modified organisms “the quintessential type of decision that the public has an explicitly stated desire to participate in”.⁴³ This is a desire that is already understandable in relation to the genetic alteration of agricultural products – which has an im-

³⁶ Cfr. A. BLASIMME, *op. cit.*, 1067-1068.

³⁷ L. GAFFURI, E. PULICE, *op. cit.*

³⁸ R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa, cit.*, 4.

³⁹ G. PEPE, *La democrazia partecipativa ambientale tra ordinamenti sovranazionali ed ordinamento italiano*, in *Federalismi.it*, 2, 2020, 183.

⁴⁰ “Should leaders listen [...] to the public, some of whom may be convinced their last Whopper contained a Frankenfood patty because an Instagram influencer told them so?” (N. CURATO, S. NIEMEYER, *op. cit.*, 2).

⁴¹ One example is the 1987 referendum that effectively brought an end to the use of nuclear energy in Italy. A second referendum in 2011 ruled out the possibility of a new nuclear programme on our planet.

⁴² This is especially true of their application to humans: suffice it to say that the Universal Declaration on the Human Genome and Human Rights, adopted on 11 November 1997 by the 29th session of the UNESCO General Conference, speaks of the human genome as the “heritage of humanity”. (art. 1).

⁴³ T. ETTY, *Biotechnology*, in *The Yearbook of European Environmental Law*, 5, 2005, 314.

pact on food, the environment and the economy – and is destined to grow in relation to the use of techniques that allow intervention in animal and human DNA, given the greater impact they can have on people’s lives and futures.

According to some, this demand for involvement should be protected as a real right under international law⁴⁴ – “the human right to science”.⁴⁵ It should be understood not only as the right to benefit from scientific progress, but also as the right to “real participation in scientific life, which could also be understood as the right to be involved in the definition of research activities”.⁴⁶

Moving from the dimension of individual interest in participation to the broader horizon of benefit for the common good, we need to remember and treasure the lesson of Asilomar. As is well known, in the mid-1970s, Asilomar State Beach hosted a very important conference on the risks of recombinant DNA, which involved biologists, doctors and lawyers and led to the drafting of a series of guidelines on the “safe” use of genetic modification techniques and the production of GMOs. Although the initiative had the merit of demonstrating the sense of responsibility of the scientists involved, who participated with the aim of identifying the limits to which they voluntarily submitted when carrying out their activities, it has been severely criticised for excluding “laypeople” from the debate.⁴⁷ This prevented ethical and value-based arguments, which are necessary to establish “what forms of progress are culturally and morally acceptable”,⁴⁸ from finding their rightful place alongside the assessment of scientifically measurable risks. Furthermore, it is legitimate to ask whether the deep divisions and contestations that still characterise the debate on GMOs could have been mitigated if the public had been properly informed and consulted from the outset.⁴⁹ It is precisely the lesson of Asilomar that has led authoritative doctrine to hope that future deliberations on gene editing (and CRISPR in particular) will be based on a rethinking of the relationship between science and democracy.⁵⁰ The same technological development could benefit from such a rethink if it resulted in less aversion on the part of the public, which – when not adequately informed – tends to view progress with fear.

A second element that makes gene technology an area of interest for deliberativism is its contact with the environment. The debate on environmental democracy⁵¹ and participation in decision-

⁴⁴ See in particular Art. 27(1) of the Universal Declaration of 1948 (“Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits”), as well as Art. 15(1) of the International Covenant on Economic, Social and Cultural Rights of 1966 (“The States Parties to the present Covenant recognize the right of everyone: (a) To take part in cultural life; (b) To enjoy the benefits of scientific progress and its applications; (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author”).

⁴⁵ M. MANCISIDOR, *Is there such a Thing as a human right to science in international law?*, in *ESIL Reflections*, 4, 2015.

⁴⁶ C. FLAMIGNI, *Sul consenso sociale informato*, in *BiLaw Journal*, 2, 2017, 202.

⁴⁷ S. JASANOFF, J.B. HURLBUT, K. SAHA, *CRISPR democracy: gene editing and the need for inclusive deliberation*, in *Issues in Science and Technology*, 32, 1, 2015.

⁴⁸ *Ibidem*, 3.

⁴⁹ Similarly, *ibidem*, 5.

⁵⁰ *Ibidem*, 3.

⁵¹ See *ex multis* M. MASON, *Environmental Democracy: A Contextual Approach*, Londra, 1999; C. PITEA, *Diritto internazionale e democrazia ambientale*, Napoli, 2013; G. PAROLA, *Environmental Democracy at the Global Level*:

making processes concerning the environment has been ongoing for a long time and has led to important results, particularly at the level of international law:⁵² we need look no further than the approval of the Aarhus Convention on access to information, citizen participation and access to justice in environmental matters,⁵³ implemented at the European level by EC Regulation 1367/2006. The forms taken by democratic participation in environmental decision-making do not always follow the patterns of participatory democracy but, thanks also to the Aarhus Convention,⁵⁴ the environment is undoubtedly considered “a context suited to welcoming the new frontiers of participation that deliberative democracy expresses”.⁵⁵ In fact, this sector, “revealing impatience with traditional procedural participation, has, over the years, demanded forms of broader dialogue between institutions and members of the public with a view to acquiring and balancing the multitude of interests involved”⁵⁶ and, as we have seen, the deliberative arenas described in the previous paragraph are precisely in the direction of this dialogue.

The fact that the cultivation of GMOs falls within this context is beyond dispute, and in recent years, the European Union’s Court of First Instance⁵⁷ has ruled that decisions relating to their commercialisation can also be considered matters of environmental law.⁵⁸ It follows that, within the EU, the so-called participation rights recognised by the Aarhus Convention and the Regulation also come into play in the process of authorising the marketing of GMOs. It is to be expected that the scope of these rights will be further extended in the future as gene technology progresses. To some extent, this has already happened, again through the courts, when in 2018 the Court of Justice of the European Union ruled that, as far as EU law is concerned, both products obtained by transgenesis (i.e. by inserting foreign DNA into the organism) and those obtained by mutagenesis are subject to the rules governing GMOs.⁵⁹ The Court also made it clear that the obligations relating to GMOs also apply to organ-

Rights and Duties for a new Citizenship, Londra, 2013; G. PEPE, *La democrazia partecipativa ambientale tra ordinamenti sovranazionali ed ordinamento italiano*, cit., 179 ss.

⁵² International law has also had the merit of emphasising the importance of public participation in the promotion of Sustainable Development (cf. para. 43 of UN Resolution A/RES/66/288 “The Future We Want”). This is also evident in the 2030 Agenda for Sustainable Development and, in particular, in Goal 16. See G. RAGONE, *The GMO Authorization Procedure in EU: Inclusivity, Access to Justice and Participation in Decision-Making*, in *Diritto Pubblico Europeo Rassegna online*, 2, 2019, 206 ss.

⁵³ See S.T. MCALLISTER, *The Convention on Access to Information, Public Participation in Decision-Making, and Access to Justice in Environmental Matters*, in *Colorado Journal of International Environmental Law and Policy*, 1999, 187 ss.; M. LEE, C. ABBOT, *The usual suspects? Public participation under the Aarhus Convention*, in *Modern Law Review*, 66, 2003, 80 ss.; M. PALLEMAERTS (a cura di), *The Aarhus Convention at Ten: interactions and tensions between conventional international law and EU environmental law*, in *Europa law publishing*, 2011.

⁵⁴ And in particular to its Second Pillar.

⁵⁵ V. MOLASCHI, *La democratizzazione delle decisioni science and technology based. Riflessioni sul dibattito pubblico*, cit., 464.

⁵⁶ G. PEPE, *La democrazia partecipativa ambientale tra ordinamenti sovranazionali ed ordinamento italiano*, cit., 183.

⁵⁷ *TestBiotech et al. v. Commission* (T-177/13), 15 December 2016.

⁵⁸ see G. RAGONE, *Il delicato ruolo del giudice tra valutazioni scientifiche controverse e scelte politico-discrezionali in materia di OGM*, in *DPCE online*, 4, 2016, 252.

⁵⁹ *Confédération paysanne et al.* (C-528/16), 25 July 2018. See M.C. ERRIGO, *Diritto e OGM. Una storia complicata*, in *BioLaw Journal*, 1, 2020, 304.

isms obtained by means of mutagenesis techniques that emerged after the adoption of the reference legislation, as in the case of CRISPR.

If the environment is fertile ground for deliberativism, it is also because, in this context more than in others, it is necessary to “realise that [law] is no longer only the product of institutionalised popular sovereignty but is also the result of an increasingly non-institutionalised popular sovereignty”.⁶⁰ In fact, while traditional representative institutions are responsible for decisions that affect the territories from which they derive legitimacy, choices concerning the environment generally have a broader scope, transcending territorial boundaries and affecting a population that does not necessarily belong to the same legal system.

The links between deliberativism and globalisation have been highlighted by various scholars. Some point out how the processes of globalisation, by contributing to the crisis of traditional representative institutions,⁶¹ have the consequential effect of favouring the spread of deliberativist theories. Others, observing the shift from government to governance fostered by globalisation, suggest that – in the absence of representative institutions of global dimensions – deliberative arenas are the ideal place to discuss decisions that may have global reach.⁶² This is the case in the regulation of impactful technologies, such as gene editing, including those applications that cannot be traced back to environmental matters and particularly those related to the human genome: “the human genome is not the property of any particular culture, nation or region; [...] It belongs equally to every member of our species”.⁶³ This awareness, together with the imponderability of the magnitude of the effects of interventions on human DNA over time (especially when conducted in the germ line), has led to the assertion that “decisions about how far we should go in tinkering with it have to be accountable to humanity as a whole”.⁶⁴

But how can we consult citizens from all over the world and have a dialogue with them on the limits to which such complex technologies can be pushed? The Global Citizens’ Assembly in Canberra is a first attempt to meet this challenge.

4. The case of the Global Citizens’ Assembly on Genome Editing

The convening of a global citizens’ assembly on genomic manipulation requires addressing problematic issues and implementation limitations that are not easy to overcome.⁶⁵ In particular, how should

⁶⁰ R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa*, cit., 9.

⁶¹ See for instance G. PEPE, *Il modello della democrazia partecipativa tra aspetti teorici e profili applicativi un’analisi comparata*, cit., 13 ss.

⁶² J.S. DRYZEK, A. BÄCHTIGER, K. MILEWICZ, *Toward a Deliberative Global Citizens’ Assembly*, cit., 33 ss.; J.S. DRYZEK et al., *Global citizen deliberation on genome editing*, cit., 1435 ss.

⁶³ S. JASANOFF, J.B. HURLBUT, K. SAHA, *op. cit.*, 2.

⁶⁴ *Ibidem*, 2.

⁶⁵ More generally, on the critical aspects of deliberative assemblies, see E. CAROLAN, *op. cit.*, passim. The Author, referring to the actual deliberation phase, emphasises the non-neutral nature of choices regarding “how to frame an issue; in what order it should be approached; from what disciplinary perspectives; using what kinds of ‘evidence’ and ‘experts’; and subject to what limitations; shape how the process develops”. All of these elements “inevitably privilege particular kinds of input and require difficult trade-offs between abstract delibera-

participants be selected? How should the work be organised and by whom should it be directed? What impact can be expected from such an experiment?

In general, the aspect of audience selection is one of the thorniest issues⁶⁶ since, in addition to having a significant impact on the success of the initiative, it represents a clear paradox: with participatory democracy, “one aspires to include everyone, but – in fact – one manages to actually involve only a few”.⁶⁷

The methods usually employed in deliberative arenas can be grouped into three archetypes, which can be applied in a mixed way: the open-door method, the microcosm and the mini-public.⁶⁸

The open-door mechanism consists of self-selection: any citizen who so wishes and is informed of the existence of a particular arena can take part until a sufficient number of participants has been reached. The second method, the microcosm, presupposes that an organiser from outside the forum selects the participants, trying to create as faithful a representation as possible of all those who have a specific interest in the deliberation. In this case, the participants end up being the bearers of a pre-established vision and give rise to a ‘hot’ discussion.⁶⁹ This is an advantage from the point of view of the citizens’ knowledge of the subject, but is detrimental to the possibility of the argumentative exchange being genuine and fruitful. Lastly, the archetype of the mini-public⁷⁰ involves the random selection of a sample of the population, possibly stratified in socio-demographic quotas (by gender, age, origin, etc.): “the bet is that any citizen, put in a position to talk to others and to acquire the necessary information, will be able to express precise positions on any public problem and build, together with others, intelligent solutions”.⁷¹ This type of selection leads to a debate that tends to be free of partisan interests⁷² and is the most common in consensus conferences and citizens’ assemblies. The Australian Global Citizens’ Assembly is no exception.

In this case, the draw aims to select between 24 and 100 participants (depending on the scale of funding available), with people from all continents of the world, reflecting the global community as accurately as possible in terms of age, gender, education level, ethnicity and residence. If funding allows, the global assembly will be preceded by national forums, in which case some of the participants may be drawn from those taking part in the preparatory arenas. Once the panel of participants has been constituted, the work will be organised and led by the University of Canberra’s Deliberative Democracy and Global Governance Centre, although the venue will not necessarily be in Australia. It is quite usual for this kind of conference to be followed step by step by deliberation professionals who can ensure that all stages of the work are carried out correctly.

tive goods like expertise, independence, experience, impartiality, participation, openness and evidential scrutiny”.

⁶⁶ See also L. PELLIZZONI, *op. cit.*, 150

⁶⁷ L. BOBBIO, G. POMATTO, *op. cit.*, 52.

⁶⁸ See R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa*, *cit.*, 5; L. BOBBIO, G. POMATTO, *op. cit.*, 52-53.

⁶⁹ *Ibidem*, 58.

⁷⁰ Term first used in A. FUNG, *Recipes for public spheres: Eight institutional design choices and their consequences*, in *Journal of Political Philosophy*, 3, 2003, 338 ss.

⁷¹ L. BOBBIO, G. POMATTO, *op. cit.*, 56-57.

⁷² On the advantages and disadvantages of “cold” deliberations, see L. BOBBIO, G. POMATTO, *op. cit.*, 58.

In the given case, the programme foresees five working days. The first day will be devoted to the presentation of the rules of operation of the conference and to getting to know the participants. The next three days will be devoted to discussing the genetic modification of plants, animals and humans, respectively. The discussion will be conducted in groups in the presence of ethicists, legal experts and scientists, who will be asked to share their knowledge. On the fifth and final day, participants will be asked to draw up a document containing practical recommendations for decision makers, as well as for the scientific community, identifying the ethical issues they consider most problematic and the regulatory principles they consider most appropriate. The resulting synthesis document will be presented not only to national authorities and legislators but also to global players (such as the secretary-general of the United Nations and the directors-general of the WHO and FAO).

Although the final report has no legal force and will be amended at a later date to bring the debate up to date with the progress of genetic research,⁷³ it will provide decision-makers with a point of view that would be difficult to obtain in any other way: that of the citizens – the global community – who will be affected by the decisions.

5. Conclusions

The innovative reach of genetic engineering technologies, which can be applied to all forms of life on the planet (including humans), makes it necessary to reflect on which decision-making processes are best suited to influence what has been defined as “our genomic future”.⁷⁴ Here, we have chosen to consider the opportunity to involve the public through participatory tools based on the principles of deliberative democracy, focusing in particular on the model offered by so-called consensus conferences. As we have seen, unlike the institutions of direct democracy, “these spaces of participation and deliberation [...] do not have, and cannot claim, any direct decision-making power, but this does not make them irrelevant”.⁷⁵

Among the merits that have been recognised in these kinds of democratic experiences is that they open up a dialogue between institutions and civil society.⁷⁶ This can “play a decisive role in legitimising (or critically, de-legitimising) the decisions taken by the institutions”,⁷⁷ enriching the democratic nature of our legal systems.⁷⁸ Dialogue with the public in the phase preceding the actual decision-making moment can also contribute to the undertaking of better choices: decision-makers can, in fact, base their decisions on considerations other than those offered to them by experts in the field.

⁷³ J.S. DRYZEK et al., *Global citizen deliberation on genome editing*, cit., 1437.

⁷⁴ A. GREENFIELD, *Our genomic future*, in *News Scientist*, 241, 2019, 24-25.

⁷⁵ A. FLORIDIA, *Democrazia partecipativa e democrazia deliberativa: una risposta plausibile alla “crisi della democrazia”?*, cit., 3.

⁷⁶ J.S. DRYZEK et al., *Global citizen deliberation on genome editing*, cit., 1436.

⁷⁷ *Ibidem*, 3.

⁷⁸ R. BIFULCO, *Democrazia deliberativa e democrazia partecipativa*, cit., 7.

In short, if the decisions concerning these technologies were anticipated by a public discussion, they would enjoy greater legitimacy,⁷⁹ and there would be a way to bring out – and, in time, correct – the criticalities perceived by the public. Of course, as has already been pointed out, the outcome of the deliberation will not necessarily correspond to an improved impact on the final decision; this is due both to the possible inexperience of the participants and to the non-binding nature of their recommendations. In a certain sense, the relationship between the citizens participating in the deliberation and the final decision makers is comparable to that between the *amicus curiae* and the courts: their opinion may be ignored but, at the same time, their point of view enters the cognitive horizon of the subject who has the right to the last word.

A further beneficial effect of the establishment of deliberative arenas for emerging scientific and technical issues is the reduction of anti-scientific populism by increasing public confidence in how policy-makers use expert advice.⁸⁰ As seen in the management of the global emergency following the COVID-19 pandemic, on the one hand, the role of experts (and committees with the appropriate scientific and technical expertise) is crucial to support decision-making in certain areas; on the other hand, the internal divisions within the scientific community, the opacity of the criteria for relying on a certain vision, and the instability of scientific findings, which are subject to continuous revision and re-evaluation over time, may cause scepticism among the public about the validity of the decisions made.

Allowing a section of the population affected by a given innovation to ask questions and talk to scientists and experts, besides being an interesting example of co-production between science and society,⁸¹ helps to create an “informed social consensus”.⁸² This principle, which has been “knocking at the door of bioethics for some time”⁸³ and which expresses an ideal relationship between citizens and scientific research, “can play a role in guaranteeing and promoting science at a time when its daily progress is giving rise to growing hopes and concerns”.⁸⁴

In conclusion, it seems possible to say that the potential of the creation of places of public participation in science and technology-based decisions, such as the Global Citizens’ Assembly announced by the Centre for Deliberative Democracy and Global Governance, is to take steps towards “overcoming the crisis of legitimacy from which scientific and political institutions suffer”.⁸⁵ This suggests the need to continue the debate on deliberativism and its concrete ways of implementation in order to contribute to overcoming its limitations, which we have tried to highlight over the course of the discussion.

⁷⁹ The stronger legitimacy of decisions preceded by public consultation makes it necessary to reflect, secondly, on the modalities and the degree of pervasiveness that judicial review can adopt on them. Regarding the models of control by the courts on participation procedures, see S. CASSESE, *op. cit.*, 18 ss.

⁸⁰ See V. MOLASCHI, *La democratizzazione delle decisioni science and technology based. Riflessioni sul dibattito pubblico*, cit., 469 and A. BLASIMME, *op. cit.*, 1068.

⁸¹ Cfr. M. TALLACCHINI, *op. cit.*, passim.

⁸² On this notion, see C. FLAMIGNI, *op. cit.*, passim.

⁸³ *Ibidem*, 202.

⁸⁴ *Ibidem*, 201.

⁸⁵ V. MOLASCHI, *La democratizzazione delle decisioni science and technology based. Riflessioni sul dibattito pubblico*, cit., 470.