


# Facing Democratic Challenges: The Role of Civil Society Organizations in the Governance of Genomic Technologies

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The discovery of CRISPR has fuelled the debate surrounding new genomic techniques (NGTs). This is of paramount importance given their potential impact on societies and ecosystems. Despite early enthusiasm about the potential of NGTs to “democratize” genome editing, it is increasingly evident that their introduction poses substantial challenges from a democratic point of view. Although greater engagement with the public sphere is urgently needed, it is something that is currently not widely studied from a political science standpoint. In this paper we offer an overview of the actors who have mobilized in relation to NGTs, with a particular focus on unduly neglected actors, such as civil society organizations. We also consider the views of those who have made proposals regarding the governance of NGTs more generally. The perspectives of these actors are not easy to reconcile with those of stakeholders, and we reflect on the democratic implications of this aspect.

The ground-breaking discovery of clustered regularly interspaced short palindromic repeats (CRISPR) has triggered debates about new genomic techniques (NGTs). In the decade since the development of the CRISPR/Cas9 gene-editing tool (Jinek et al. 2012; Cong et al. 2013), techniques that can alter the genetic material of organisms have found a wide variety of applications that had been previously inconceivable (Broothaerts et al. 2021). Genomic editing in microorganisms, plants, animals, and humans has enormous scientific potential to revolutionize entire fields and industries (e.g., Gao 2021; Schermer and Benzing 2019; Ledford 2015).

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Given the promised impact on societies and ecosystems, the importance of debates about NGTs cannot be emphasized enough. One of the main ongoing discussions concerns their governance. Indeed, extant arrangements regarding NGTs appear to be unable to address the political, economic, and ethical questions that the development of these technologies implies (e.g., Poort et al. 2022). The development of NGTs currently hinges on a complex interplay between transnational networks of authorities, entrepreneurs, and experts; however, it lacks a specific form of governance, let alone a democratic one, which is a cause for concern (see Schwindenhammer 2020).

The lofty idea that greater availability and applicability would herald an era of more democratic NGTs (Jackson et al. 2019) has subsided, and the aim now is to try and obtain a better understanding of what is in fact a very complex situation (Beumer 2021). Thus far, there has been a limited ability to govern ongoing developments and to do so in a democratic way (Montenegro de Wit 2020). As a result, many scholars have called for the governance of NGTs to be democratized at a national and transnational level.

Although the governance of genomic interventions in the human germline seems particularly urgent, subsequent calls for the democratization of governance have been made in relation to the use of NGTs more generally (Scheufele et al. 2021; Iltis, Hoover, and Matthews

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2021; Almeida and Ranisch 2022). Suggestions have pointed in the direction of more public engagement on the topic, including the establishment of an international observatory on genome editing (GE)<sup>1</sup> (Jasanoff and Hurlbut 2018), as well as calls for a global citizens' assembly on the issue (Dryzek et al. 2020).

Our aim here is to contribute to the debate on the democratization of NGT governance by shedding light on the overlooked role of civil society organizations, which are generally deemed fundamental to processes of democratization (della Porta 2013) and in articulating demands for justice (Cordelli 2016). In particular, we are interested in learning more about these actors and how they deal with the issue of the governance of NGTs, in order to understand whether it is possible to discern a more democratic governance model for NGTs. Given the importance of civil society in NGT governance, it is necessary to answer the two main questions that we pose in this paper. First, *what* are the civil society organizations that are mobilizing around the NGT debates? Second, *how* do they frame the governance of NGTs? In order to address the first question, we rely on a content analysis of the websites of the 77 organizations that have been mapped by our research. To answer the second question we engage in a frame analysis of the relevant documents that these organizations have produced on this topic. Our systematic review of civil society organizations and preliminary content analysis suggests that several of them are discussing a range of issues related to NGTs, often from a critical perspective. Although these issues include governance, it receives limited attention. The organizations investigated do not seem to advance workable proposals in relation to the governance of NGTs. Nevertheless, our investigation into the characteristics of these actors and their claims suggests a number of approaches that could be employed to engage them more effectively in decision making processes.

Notwithstanding the large number of calls to democratize the governance of genome editing, empirical research remains scant, particularly when it comes to the publics that are mobilized on these issues. Our paper intends to break new ground in this respect and to encourage a much-needed debate on NGTs in political science. Surprisingly, limited attention has been paid to NGTs within the discipline (see Meyer and Vergnaud 2021) and the main discussions on the topic in political science have come as spinoffs of the broader debate on bioethics. These discussions have focused on the challenges posed by genetic engineering from a normative political theory standpoint (Gregg 2022; Farrelly 2023) and contrasting perspectives on public engagement efforts specifically (Conley et al. 2023; Nicol et al. 2023). In the following section, we will outline the relevant

developments in the literature and propose one way forward in the investigation of this problem that is grounded in the study of civil society at large.

### **The Promotion of Democratic Governance of NGTs and the Role of Civil Society**

The discovery of CRISPR represents a scientific breakthrough (Science 2015) with far-reaching effects on biotechnology research, and a wide variety of commercial and clinical applications. The use of NGTs, including the application of CRISPR, not only differs based on the field in which they are applied (for instance, human, non-human) but also across jurisdictions (in this regard, we recommend consulting the Genetic Literacy Project<sup>2</sup>). Aside from the complex technical nature of the subject, this diversity in domains of application and in legislations makes the issue of governance and rules regarding the use of NGTs even more challenging. However, this has not inhibited the debate on this topic (Asquer and Morrison 2022; Sprink, Wilhelm and Hartung 2022). Human GE provides a useful illustration of this as it is possibly the most debated issue, albeit by no means the only important one. Between 2015 and 2018, Brokowski (2018) developed a (non-exhaustive) list of more than 60 statements released by the international community on the controversy surrounding the use of CRISPR in the human germline alone. In addition, there have been three international summits (in 2015, 2018 and 2023) on the topic and numerous conferences organized by transnational and national institutions (e.g., the Organization for Economic Cooperation and Development, the National Academies of Sciences and Medicine, the Royal Society, and the Chinese Academy of Sciences), as well as an expert panel on the governance of human GE appointed by the World Health Organization (WHO) in 2018 (see Meyer and Vergnaud 2021).

Extant governance arrangements in relation to decisions about NGTs tend to attract criticism. Among others, Yu et al. (2021, 2) argue that they fall short of “a robust, credible, and lasting regulatory regime.” In particular, the working of international summits on GE is often associated with that of the 1975 Asilomar Conference on Recombinant DNA, at which, not without shortcomings, scientists envisaged regulations for recombinant DNA technologies (see, e.g., Jasanoff, Hurlbut, and Saha 2015; Parthasarathy 2015).

However, the effectiveness of this model of governance by the few is at odds with the context in which the development of NGTs is taking place. Nowadays, the research community is much larger and diverse, both geographically and culturally speaking (Meyer and Vergnaud 2021). In addition, in contrast to the past, the

stakeholder community now includes many people who work in the private sector, giving rise to conflicts of interest. Moreover, the issue has grown in complexity and scope, and the public and their views on the topic have evolved (e.g., Kato-Nitta et al. 2019). Therefore, the need for a robust governance (Baylis 2019) and for broad societal consensus (Greely 2022) is evident, particularly in the wake of the advent of CRISPR and the possibilities it has opened up.

The most important clusters and leading organizations currently operating in the field of NGTs include the following: a small number of public and private universities; several research and medical centres in the United States, the UK, France, and China; several major pharmaceutical, medical, biotechnology, and agricultural companies, as well as some specializing in GE; the U.S. Department of Health and Human Services and the U.S. Department of Agriculture. There is a notable level of porosity between the academic and business communities, with therapeutics and medical solutions being the most relevant fields for genome-editing applications, followed by agricultural biotechnology (see Laibach and Bröring 2022). In the U.S. case at least, research has shown that public funding seems to drive innovation by enabling basic scientific progress. The participation of private for-profit actors and philanthropic organizations, tends to happen in the later stages of the process, potentially furthering the socialization of risk and leading to the privatization of rewards to the benefit of specific sectors of society and their interests (Fajardo-Ortiz et al. 2022; see also Mazzucato 2011). Furthermore, regulatory uncertainty strengthens the ability of commercial actors to influence policymaking, with pro-industry interests prevailing during important junctures in biotechnology legislation (Sheingate 2006). In the context of these powerful networks, civil society actors are conspicuous by their absence, and it is generally quite difficult to apply the lens of solidarity to human genetics, as noted by Mulvihill et al. (2017).

Against this backdrop, the research community and to a lesser extent—policymakers are aware of the need for more public dialogue (Nuffield Council on Bioethics 2016). As claimed by the National Academies of Sciences, Engineering and Medicine (2017) and the World Health Organization (2021), among others, engagement is a vital part of research on NGTs and their development (see also Cohen, Sherkow and Adashi 2022). However, this is not without its challenges. As Davies et al. (2022) argue, the public has a wide variety of values and interests when it comes to NGTs and there is no single role that the public plays in debates surrounding their development. Overall, there is a plurality of publics all voicing their views about GE that cannot easily be aggregated into one cohesive opinion.

In debates surrounding NGTs, as in other cases, the participation of publics cannot be taken for granted; they are often weak or absent and it has been argued that they are “called into being and always encountered in mediated forms.” In particular, publics are involved in dialogues in different ways as “stakeholders,” “populations,” and “participants,” and the different methods used to engage them determine the way in which their views on issues develop (Davies et al. 2022, 89). Davies et al. highlight the Royal Society’s participation initiatives to show that key players “[recognize] the public stakes in genome editing, the importance of having debates in public, and the legitimacy conferred by measuring public opinion.” Historically, however, “members of animal rights and welfare groups” as well as “those with a professional stake” have been screened out of polls about research on animals. This has created statistically unbiased but largely uninformed versions of the public viewpoint. Leaving out those who could meaningfully engage in debates about a particular issue hampers successful public participation (Wehling 2012) and leads to the view that the public is misguided (Wynne and Irwin 2003). Furthermore, with the exception of certain forms of patient and public involvement that are becoming increasingly important in genomics research and give greater scope for influencing priorities (Davies et al. 2022), the role of publics tends to be framed in terms of mere “acceptance” or “rejection” of given developments or “support” for them (e.g., Busch et al. 2022).

Although a shift is currently taking place from a knowledge-deficit approach to one of co-development (Hartley et al. 2019), the problem at hand is customarily understood in terms of the “cognitive distance” between scientists, policymakers, regulators, and the rest of the population (Cisnetto and Barlow 2020; Festinger 1962). Meyer and Vergnaud (2021, 11) show that it is not uncommon for the public to be referred to as “recalcitrant” and that the perceived challenge is to “educate, inform and convince the public of the positive features of gene editing”. Against this background, space for criticism, dissent, and disagreement is generally limited. As Wise and Borry (2022, 376) acknowledge, this is more problematic in so far as “genetic modifications generally have encountered much resistance from communities.” Resnik (2018), among others, insists on the importance of effective community engagement that is not limited to the issue of acceptance. Indeed, even in the absence of open resistance, the use of NGTs can change the legal and environmental context in which individuals operate. For example, the analysis carried out by Reeves and Phillipson on the potential impact of the mass release of genetically modified insects on organic

farms (2017) demonstrates that this is exactly what happens in many communities.

In recent years, the deliberative approach to democracy has emerged as an important locus of attention for the debate on the governance of NGTs, as part of the pursuit of an in-depth, high-quality and inclusive engagement with societies. In particular, scholars have argued about “the public engagement imperative” (Adashi et al. 2020), its potential (Park, Bagg, and Lewis 2023), its various forms (Neblo and White 2023), its strengths (Sheinerman 2022), and its limitations (Rzepiński 2023). While this debate is largely theoretical and mainly focused on bioethics and deliberative forums, it has nevertheless underlined the need to understand and empirically investigate the possibility of democratization beyond invited deliberative spaces (Gunn and Jongsma 2023). Here we build on this insight and, following the argument put forward by Christina Lafont (2019) against democratic shortcuts, we agree that having a lively and active civil society remains crucial to democratization. More precisely, we approach the problem of the democratization of ongoing developments in NGTs through a deliberative participatory approach, which gives primacy to the role of civil society actors and stresses the need to study these actors empirically. Naturally, the development of NGTs is not exempt from scientific or political contestation. Involving civil society actors within frameworks set up by powerful organizations without their having the means of questioning the marked structural inequalities involved in NGTs or subsequently being able to object to their use is problematic. Surveying the opinion of the general population regarding NGTs can offer useful heuristics to empowered actors (e.g., Scheufele et al. 2017). However, this does not solve the democratic shortcomings of extant governance if, for example, critical voices are then silenced or bypassed.

Unlike elite actors or other powerful stakeholders, whose views are embedded in relevant documents and calls for democratization, the position of civil society remains somewhat of a black box. Here, we take a step back to explore civil society actors and their perspectives as they are conceived at this point in time. We do this without, on the one hand, calling them into being by means of engagement in governance arrangements, or, on the other, collapsing them into broad and unsophisticated sentiment analyses of public opinion.

Our hope is to encourage further investigation from a political science perspective, both empirical and theoretical, around the governance of NGTs and the possibilities of democratizing the field. Indeed, political scientists can help to increase the understanding of ongoing developments in NGTs and contribute to a lively debate that is already occurring in other fields, including not only ethics (e.g., Caplan et al. 2015), but

also, for instance, political communication (e.g., Wirz, Scheufele, and Brossard 2020), and legal studies (e.g., Townsend and Shozi 2021).

## The Standpoints of Civil Society Organizations

When discussing civil society organizations, we refer to those groups, both formal and informal, that “provide services, advocate for social and political change, protect rights, lobby for and against various causes, monitor public activities, transmit art and culture, build knowledge, and educate” (Boris and Mosher-Williams 1998, 490). We refer to interest groups, which represent specific economic interests of a category (for instance, a professional category), mainly engage in lobbying political institutions, and offer services to their members (that belong to the category represented; Dalziel 2010); advocacy groups, engaged in lobby activities as well, but representing interests not strictly linked to its members and their activities, that do not concern exclusively the members of the group, and that are not exclusively economic interests; research/scientific networks of specialists, researching specific issue and engaged in science communication; community-based groups, both formal and informal, rooted within a specific social sector (for instance, local committees, youth organizations, cultural associations) with the aim to represent the (not economic) interests linked to such social sectors (Wilson, Lavis, and Guta 2012); social movement organizations that use protest actions, organize their activities at a distance from institutions, and that follow and engage with the aim of a broader social movement (della Porta and Diani 2015); local as well as international non-governmental organizations (NGOs), formal organizations that provide services to the public (such as channel funds, promoting specific projects) and can be engaged also in advocacy activity to follow what can be understood a “general” good (Lewis 2010), for instance, the reduction of inequalities, empowerment for local communities<sup>3</sup>. Such groups are autonomous (della Porta 2020) but contribute to the social fabric and are positioned between state action and the action of the individual (Walzer 1998).

In order to address the lack of investigation to date we began by collecting empirical data on how organized civil society engages with the governance of NGTs. Through a non-random “snowball” approach (Noy 2008),<sup>4</sup> we mapped a number of civil society organizations active in relation to the issues surrounding NGTs. Following this, we analyzed the content on the websites of these organizations and gathered data on the crucial characteristics of each group, on the basis of a semi-structured codebook.<sup>5</sup> In particular, we relied on the information shared in the various sections on each website that stated the key actors, activities, values, and documents of each organization to identify the different types of organizations, where they are

based, the activities they are involved in and the main issues they deal with.

In total, 77 actors interested in NGTs were identified, located throughout the world (for a full list of the actors, refer to [online appendix A](#)). We found a high proportion of actors in Europe (57.1%) and North America (20.8%), and a lower proportion in Oceania (6.5%), South America (2.6%) and Africa (2.6%). Most of the actors have a national scope (57.5%) since they primarily address national issues and have national goals. Many also have international/transnational interests (36.2%): they address transnational issues, try to build networks, connect with actors from other countries, and have goals that go beyond national borders and involve groups of states (e.g., African sub-continental areas). Regarding the rest of the actors, they were either found to work on a regional scale, or it was not possible to establish their scale with any certainty based on the information provided on their websites.

Most of the mapped actors are advocacy groups/networks (28.6%). There is quite an even split between community groups/networks (20.8%), interest groups (20.8%) and scientific/research groups (20.8%). Social movement organizations (6.5%) and NGOs (2.9%) are marginal in terms of their representation. Most of these actors (89.6%) have a formal constitution with a statute, prescribed roles, and internal rules. Importantly, the application of NGTs that they are most concerned with is in relation to plants (85%), which is where democratic participation is at its weakest (Montenegro de Wit 2020), with a much smaller focus on issues relating to animals and humans. What emerges from the content analysis of the documents where the issue of NGTs is addressed is that 95% of the mapped organizations oppose the use of NGTs or are strongly critical towards the use of such techniques (refer to [online appendix B](#) for a list of documents).

Most of the mapped actors are engaged in information (and counter-information) sharing activities (89.6%). Here, we refer to the dissemination of information on GE; the risks of NGTs; their potential and the latest developments in the field through the production of leaflets, brochures, and reports; as well as the convening of conferences with the subsequent publication of their outputs. We found advocacy activities to be among the most used forms of action (54.5%). These can be public/open letters, but also public claims and campaigns targeting private companies, political institutions, or the general public, aimed at encouraging public debate, but also at attempting to change policies and political decisions. There is also a significant number of protest actions (26%). These include protest actions of any kind, particularly petitions and boycotts, but also demonstrations, and networking activities (22.1%), namely activities aimed at engaging with other groups and building ties with them. To a lesser extent, other forms of action are also employed. Some actors are engaged in the provision of services for

their members (18.2%), such as training courses, legal actions, and research activities (14.3%), whereas others offer training courses that are open to the public (10.4%).

## Zooming In on the Governance of NGTs

As part of the overall mapping, we considered all those actors who expressed opinions on NGTs in a general sense (i.e. not focusing on a specific field of use) and who made claims regarding governance. In doing so we identified twelve organizations: five advocacy groups; four scientific groups; and three community groups. Among these, just two are in favour of NGTs or do not oppose their use, whereas the other ten are all opposed to them. With the exception of two actors (one based in Oceania and one based in North America), the rest are all based in Europe. Moreover, seven of them operate on an international or transnational scale, whereas the other five operate on a national scale.

All these groups are engaged in information and counter-information activities, and their websites contain news on NGTs and offer insights into their application. Furthermore, these actors may also be involved in organizing or participating in conferences and dissemination events. While four of these organizations engage in information activities exclusively, the other eight also employ other kinds of actions, such as advocacy campaigns, protest actions, and research activities.

Given that all these actors are engaged in information and counter-information activities, it was decided to analyse how they framed the governance of NGTs by analysing a total of twenty-five documents in which governance issues were addressed. The websites of the organizations were used as the source of data employed in the analysis, with information selected from the press releases, articles, and reports on NGTs, especially those in which the issue of governance is mentioned.

Our analysis was based on the frame-analysis approach, referring to the use of framing made within the study of social movements that conceive the frame as a strategic choice made by collective actors (Snow, Vliementhurl, and Ketelaars 2018; Caiani 2023). First proposed by Goffman (1974, 21), it refers to “interpretative schemes” that make it possible to “perceive, identify, and label” events that happen in everyday life. As social movement scholars Snow and Benford (1992) explain, frames not only allow significance to be attached to events and phenomena, they also drive individual and collective action. Frames have three core components: a diagnostic component, namely what is perceived to be a problem and who (or what) is responsible for it; a prognostic component, i.e., the possible solution to the problem; and finally a motivational element, that is, the motivational reason that pushes people to act (Snow et al. 1986). Here, we propose a frame analysis of the collective actors selected, with specific reference to the issue of the governance of NGTs.

Therefore, we explore why there is perceived to be a problem in relation to the governance of NGTs, and who is thought to be driving it. We will also explore possible solutions to problems raised by the actors.

### NGT Governance: A Global Issue

Our sample reveals some recurrent considerations relating to the global governance of NGTs. First, it emphasizes the fact that the regulations governing NGTs are not globally homogeneous (see excerpts P4, P15, P20, P21, P24 and P65). On one hand, the use of NGTs is understandably regulated in different ways depending on the field of reference. In some countries, they are permitted for use in relation to plants, especially those in the food supply chain, while their application to animals is tolerated solely if this concerns the extirpation of dangerous and harmful insects.<sup>6</sup> However, their application to the human field tends to be highly regulated in most countries (with substantial distinctions between germline and *somatic* human genome editing). On the other hand, the regulations controlling the use of NGTs also vary depending on the country—or region—in which they are used. This variety in regulation, especially from country to country, is perceived as being particularly problematic. It can lead to geographical areas where more research into NGTs is allowed and their use is permitted; this generates inequality and encourages an uneven application of the precautionary principle at the global level.

In the face of this uneven regulation, there is a call to ensure the consistent regulation of NGTs at a global level. One report on gene drives, produced in conjunction by three independent European scientific groups that are concerned about NGTs<sup>7</sup> and oppose their use, very clearly sets out that coherent regulations are necessary due to the nature of the techniques under discussion. The report addresses ethical concerns, the limits of such techniques and the possibility of adopting global rules for gene drives. It argues that

While not all gene drives are global in nature, the advent of CRISPR-based gene drives, which have the potential to spread ‘globally’ and also to be invasive in certain contexts, certainly makes this a realistic concern . . . Governance and regulation of gene drives and GDOs must furthermore be international in nature because of the potential for transboundary spread of GDOs. This is because even a small number of GDOs introduced in one country is very likely to have ramifications well beyond its borders. [P4]

The use of NGTs is generally regulated by the rules that control the production and diffusion of genetically modified organisms (GMOs). In turn, these rules are based on global directives on the use of biotechnology, which call for the extensive use of the precautionary principle. References to the already existing normative context are similar across our sample, in which the organizations often

cite European Commission directive 2001/18 (*Deliberate Release into the Environment of Genetically Modified Organisms*) on the use of GMOs in the European Union (EU), the Convention on Biological Diversity, and the more recent recommendation by the WHO on the use of (and research into) NGTs. The most commonly cited document is the Cartagena Protocol on Biosafety, which is considered a valid starting point for the development of new global rules for NGTs.

Despite the legal framework that is already in place, there is an obvious need for more precise rules on the use of NGTs. As these rules represent just one aspect of opposition to such forms of new biotechnologies, they should not only be specific but also restrictive. Once again, the previously cited report on gene drives exposes the need for this, linking it to the nature of the new techniques that have been discovered:

GDOs (Gene Drive Organisms) are covered by existing international biosafety regulation for research, development and use of genetically modified organisms (GMOs), also termed living modified organisms (LMOs). However, there is still an urgent need for specific strict regulation of GDOs that goes beyond existing biosafety regulation and that takes into account their unique features and effects. With GDOs, spread and persistence are their *raison d’être*, posing different legal and regulatory challenges, because of their high potential to spread beyond national borders, particularly in the case of “global” gene drives . . . The complexity of the systems that could be affected and the impacts that could be realised increases scientific uncertainty manifold, requiring more precautionary approaches to regulation than already required with GMOs. [P4]

It is also broadly accepted that regulations should not only control the use of NGTs outside of laboratories but that they should also be applied to research activities. Thus, there emerges a need to restrict actual research on NGTs or stop it altogether; it would be far better to wait for a clearer and more specific framework of rules within which to operate before proceeding. Save Our Seeds, a Europe-based advocacy group that mainly promotes organic agriculture and opposes NGTs, clarifies this point, and proposes a register of all the research on gene drives that is currently being undertaken:

Because even individual, unintentionally released GDOs could spread uncontrollably, both temporally and territorially, high safety standards for handling GDOs adapted to the respective organisms are of global importance and urgency, also in the laboratory. An essential prerequisite for adequate safety measures, but also for further discussion, is a central registry of all gene drive research and related field trials, which should include a precise description of the organisms, the gene drive constructs, and the goals pursued with them. [P21]

The issue of global governance is often concerned with the need to identify those actors who are actually responsible for the situation, with the claim that as many actors as possible should then be involved in establishing a new set of rules.

## Who Decides ... and Who Should Decide?

Civil society actors are not only asking for global rules to be implemented, but they are also calling for a global political actor with the power to propose binding rules for NGTs. There is no doubt that this equates to advocating for an unlikely and, at any rate, unparalleled development in global governance. Where they do exist, sporadic international treaties (e.g., International Treaty on Plant Genetic Resources for Food and Agriculture—ITPGRFA) or voluntary collaborative frameworks of regulation (e.g., International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use—ICH) tend to deal with similar problems, as opposed to global governance mechanisms, let alone representing a single political actor with binding powers. Nevertheless, Save Our Seeds asserts that the lack of a “global decision-making power” is a major problem when talking about the need for global rules for gene drive organisms (GDOs) and NGTs:

If gene drive organisms can and should spread worldwide, the question must be clarified as to who can ultimately decide on the release of gene drive organisms and who should be involved at what level. The establishment of such a body and decision-making mechanism at a global level is necessary and requires a broad social debate. [P20]

Organizations also point out that the global rules for NGTs should be discussed and validated by a broad group of actors. Indeed, the development of NGTs not only involves technical issues but also many ethical concerns. Due to the complexity of the issues raised by the use of NGTs, several actors should be involved in the decision-making process. Once again, we quote from the report mentioned earlier on gene drives, which considers the ethical concerns relating to NGTs. The report argues that rules need to be broadly validated, following a general discussion that involves many stakeholders from beyond the restricted field of technical experts:

If the debate about gene drives is confined to a narrow technical assessment of risks, thus privileging scientific and technical experts, it significantly limits who can legitimately participate in decision-making processes. It is clear that democratic and justice demands will often require the involvement of a wider range of actors. [P3]

Thus, a decision-making process is only fair and democratic if a “wider range of actors” are involved. Save Our Seeds also emphasizes this point, adding that the involvement should be “equal” and, thus, include all actors affected by NGTs. It also provides some indication as to “who else” should be involved, suggesting engagement with both local and indigenous communities:

Due to the international nature of the potential consequences of the release of GDOs, international standards and procedures for decision-making are also required for their approval. Crucial to this is the inclusion and equal participation of all potentially

affected parties. This refers first to states, but also specifically to indigenous peoples and local communities . . . . The basis of such decisions must be, at a minimum, the principles of free prior informed consent. [P21]

Civil society actors acknowledge that the absence of a global decision-making body does not mean there are no actors already involved in the governance of NGTs. On the contrary, they highlight that political, economic, and research interests are currently shaping the field of NGTs. Indeed, the challenge of regulating NGTs is in part linked to the fact that such different interests are at play.

When addressing the political field, both national and supranational political bodies need to be considered. These include national governments, but also supranational political bodies, such as the European Parliament, the European Commission, the African Union, the Centers for Disease Control and Prevention and, of course, the WHO. It is recognized that such organizations are trying to regulate the use of NGTs (in a way that is considered positive or negative, yet generally insufficient). InfoGM is a source of counter-information on GMOs and GDOs that mainly considers European countries, although it often also addresses cases outside of Europe. It is against the use of NGTs and focuses its attention on the economic interests linked to NGTs, looking at who files the patents on specific techniques. One example of this is their investigation into the public and private bodies that own the patents for the use of the CRISPR technique. Both public and private universities (primarily European and especially U.S. universities) have contributed to the development of the technique. They have secured licences to conduct research on CRISPR, without taking into account the commercial implications for the food and agriculture sectors. In addition, a number of private actors outside of the educational sector can also be linked to the public sector, usually via public universities:

To commercially exploit these patents, the aforementioned public structures have created intermediary companies (or surrogate companies). These grant rights around the world to companies that market applications of the Crispr/Cas9 system and pay royalties in return. They can grant different types of licenses (exclusive, semi-exclusive or non-exclusive), by technical field (human, plant, non-human animal, etc.), by territory (United States, Europe, China, etc.), by use (clinical, research, etc.) . . . . Thus, among the few companies holding exclusive licensing rights, we find Corteva Agrisciences and Bayer-Monsanto. [P15]

The research field is not immune to conflicts of interest. Informationsdienst Gentechnik is a German organization engaged in intensive information gathering activity in relation to biotechnologies, particularly genetic engineering, and is opposed to the use of NGTs. Although its main interests are based in Germany, it often reports on worldwide developments, especially those taking place in other EU countries. As far as the multiple interests surrounding NGTs are concerned, Informationsdienst Gentechnik

points to a study undertaken by the Greens in the European Parliament<sup>8</sup> that focused on the possible personal and economic interests of a number of researchers who were calling for the use of NGTs in Europe to be less strictly regulated:

As seemingly independent scientists, numerous genetic engineering researchers are campaigning for the relaxation of EU genetic engineering legislation in favour of new genetic engineering processes. A study by the Greens in the European Parliament shows that many of them could also represent their own economic interests—for example because they hold patents or patent applications for genetic engineering products. The Greens call for such conflicts of interest to be clearly declared. [P50]

Although most of the sample emphasizes how the scientific field, both public and private, has its reasons for avoiding restrictions on the use of NGTs (and may even benefit from the lack of a single set of rules), the Association for Responsible Research and Innovation in Genome Editing (ARRIGE) has a different opinion regarding the role that scientists may play in relation to NGTs and their regulation. ARRIGE is an independent group of European researchers that deals with GE issues. Although it supports the use of NGTs, it still agrees with other organizations that they should be subject to a single set of global rules. This framework would need to be compiled through an inclusive and transparent decision-making process in which it is envisioned that all interested stakeholders would participate, including scientists, who can inform stakeholders properly about the risks and benefits of NGTs, and advise the governments that intend to use and regulate them:

As scientists, our role is to inform and discuss with regulatory agencies and stakeholders the benefits and the risks of the technology, to help develop ethical guidelines and regulations for its implementation and to coordinate a safe risk management of the gene drive approach that is consistent with the Cartagena Protocol on Biosafety ... Governments in many countries may need further assistance from stakeholders, to allow the implementation of a gene drive in their communities, considering the global environmental impact and consequences on individuals. [P65]

The participation of all these actors in compiling a new set of rules for NGTs begs another question: How should such rules be chosen?

### How to Decide

Given the mix of actors and interests concerned in relation to NGTs, the actors involved in the decision-making process should be free of any conflicts of interests. For instance, the *Alliance Suisse pour une Agriculture sans Génie Génétique*, a national advocacy group that is not in favour of NGTs, calls for a “participatory process for assessing technological innovations,” which “especially needs to involve citizen stakeholders” [P24]. It proposes “responsible

governance,” which should go beyond the simple calculation of risks and benefits made by technicians and be open to a discussion about the profound values on which the different positions held by various actors in relation to NGTs are based:

Treating governance as more than simply controlling immediate, physical risk broadens the discussion and directs attention towards wide-ranging concerns associated with the intentional use of gene drives, rather than only with the unintended risks that may result. Such an opening up enables more transparent decision-making and more effective dialogue between innovators, risk assessors, risk managers, policymakers, and affected publics. If dialogue between different actors with different agendas is going to be fruitful, it is vital that any divergence in underlying values and assumptions is made clear, and is also permitted to be a legitimate part of the conversation. Otherwise, there will always be a danger that underlying value differences are never directly acknowledged or addressed; they therefore become hidden or masked within a debate that is ostensibly about risk but is actually about a clash in value systems. Indeed, in this sense, recognizing underlying values and assumptions and commitment to openness are complementary and mutually reinforcing features of good governance and ethical innovation. [P3]

Calling for this transparent and participatory process, the above-mentioned report on gene drives aspires to a new way of conceiving governance in this field, namely by moving from “risk governance” to “innovation governance”:

A more transparent and inclusive conversation that pays serious attention to the values and worldviews of different stakeholders is, however, more likely to uncover and explore alternative understandings of the problem and the available solutions at hand. Thinking more broadly in terms of “innovation governance” (i.e., how to govern and guide the innovation process as a whole) rather than “risk governance” (i.e., how to govern the potential physical impacts of any given technology) will also place technical solutions in their proper context as only one of many different ways to conceptualise and address a particular problem. [P3]

Interestingly, the organizations under examination do not propose following a specific method or procedure to create such an open, transparent and responsible decision-making process. For instance, the report on gene drives, which is the most comprehensive document on this topic to date, limits itself to providing a number of indications, calling for general forms of deliberative decision-making processes and citizen engagement:

Opening up the governance of gene drives to include a wide range of knowledge sources and perspectives, through the now well-established practices of public participation, citizen engagement and deliberative decision-making, will be the best approach to ensuring that the full range of relevant considerations are incorporated and addressed. [P3]

### Civil Society Organizations and the Governance of NGTs: Some Key Points

The development of the CRISPR technique breathed new life into the debate surrounding the use of NGTs, and



their ethical, economic, and social implications. The issue has substantial political relevance, and there is now a more critical understanding of the risks of using CRISPR tools despite the fact that there are no inclusive debates or shared norms. Any efforts aimed at democratizing the governance of GE should prioritise paying greater attention to the views of civil society actors. As highlighted by critical scholars of democracy, this is particularly important in situations in which movements are critical of established forms of engagement (see Young 2000; Lafont 2019; Montenegro de Wit 2020).

The research carried out as part of this study has made it possible to answer the question posed earlier about the nature of civil society organizations mobilized around NGTs, which is still overlooked in the literature. Among the actors mobilized in relation to NGTs that were captured in our investigation, the following were noted: 1) the majority are national in scope; 2) they are mostly solely focused on the repercussions of the use of NGTs in relation to plant life; 3) the majority of them are opposed to the introduction of NGTs; and 4), only a few consider the issue of their overall governance. One reason why civil society focuses by and large on non-human applications of genome editing might be related to the longstanding tradition of mobilization on GMOs and alternative agriculture (Motta 2014; Friedrich et al. 2019). Many of the organizations already active around GMOs are now mobilizing around the use of genome editing on plants (labelled “new GMOs”). It remains to be understood, however, what leads the bulk of public engagement to focus on human application of genome editing. That is important, as this tendency contributes to leaving the use of a wide set of NGTs beyond the reach of public scrutiny. This is a challenging situation due to a number of particular factors: 1) the issue is global in scale; 2) many governance efforts are transnational; 3) governance efforts tend to focus on the human genome; and 4), organizations affecting policy making, though more open to recognize potential benefits of public engagement, are still hesitant to hear civil society critiques of NGTs.

This leads us to the second question that we posed about the views of civil society actors on governance. Only a small minority of the groups examined express ideas about the governance of GE in general, let alone the issue of governance from a global standpoint. Those actors who expressed such views had some common features in their framing of the governance of GE, despite the fact that their views on the use of NGTs differed (they were mostly not in favour). Civil society organizations are calling for a set of specific global rules on the use of NGTs. Even if such organizations recognize the fact that NGTs are currently covered by the rules regulating GMOs and new genetic engineering techniques, it is considered that legal restraints do not go far enough. NGTs, and CRISPR in particular, have completely revolutionized the way in which genes are

modified or may be altered in the future. The greater power and pervasiveness of these new techniques not only calls for more research but also new rules to control new complexities more effectively. The lack of a political body that has the power to make binding rules on a global scale is perceived as a problem, although calls to create such an institution seem unrealistic and devoid of a real path towards implementation. Furthermore, it is acknowledged that political actors are already making decisions about NGTs, albeit usually not in the way that organizations had hoped for. Indeed, the issue of how to regulate the use of NGTs is influenced by many (mostly economic) factors, in which both public and private actors have vested interests. Thus, rather than simply asking for a new set of rules, actors are also calling for the creation of a decision-making process that will allow all stakeholders to participate. Indeed, the common diagnostic frame is characterized by the need to have a democratic space where all the parts can meet and discuss forming a common base upon which to make new and broadly accepted rules. No specific solutions or procedures are proposed, but actors consistently call for more participatory decision-making processes, free of conflicts of interest. Subsequently, they ask for “more democracy,” to be coupled with transparent processes. As has been outlined earlier, a number of critical scholars and some stakeholders in the field of NGTs have argued that democratization must occur through the inclusion of civil society actors. If this is the case, it is important to recognize that at least part of the research community and civil society organizations have a number of points in common as we discuss in the final section.

## Concluding Remarks

Our work intends to shed much-needed light on the governance of NGTs. Democratizing this issue remains a paramount challenge and political science can offer a unique contribution to understanding whether this might occur and how it may come about. The traditional model of the Asilomar Conference, namely a governing body led by experts, general non-binding rules and freedom for each country to implement its own proper set of rules seem problematic from a democratic standpoint and detached from the realities in which NGTs are developing. The emerging deliberative approaches represent an important development. However, as has been seen here, these are not without their limitations. There is a rather widely acknowledged need for more inclusion beyond technicians and policymakers to as many stakeholders as possible, including civil society. Looking deeper into the views of civil society on NGTs and their governance has shown, however, that the inclusion of civil society cannot happen according to the terms set by those actors already involved in the governance of NGTs, even those invoking greater civil society engagement. Impactful as they are, the development of NGTs seems bound to drive political

contestation and this dimension is often voiced by civil society. Against this backdrop, traditional approaches that seek public “acceptance” or gauge “support” foreclose the possibility of constructive engagement on knotty problems. At best it could be said that they leave disagreements untouched, while they also risk exacerbating them by fuelling mistrust and polarization. The same applies to more recent deliberative approaches if they cherry-pick civil society organizations based on their stance or exclude them altogether. The democratic shortcomings that greatly constrain democratization are not solved by establishing a model of involvement that occurs within the frameworks set up by powerful organizations that do not allow civil society to have the means to question the marked structural inequalities involved in NGTs or to subsequently object to their use.

Although this paper cannot address this problem in all its complexity, our research does make it possible to suggest some steps in this direction.

The first point relates to precisely which topics are problematized and who gets to make decisions on them. The raft of existing policy statements supporting public engagement tends to define the priorities of public engagement in a top-down fashion. However, it is advisable to engage publics not just on the topics that are identified as important by influential stakeholders or experts but also to bring engagement (as well as criticism) where publics exist. As seen earlier, the bulk of public engagement that occurs today, including the most advanced experiments, focuses on issues relating to human genome editing in general, and human germline engineering in particular. Comparable efforts are urgently needed in other areas (Montenegro de Wit 2020), such as on plants, where the bulk of civil society engaged in the topic of NGTs is both highly active and critical.

The second point relates to the substance of the NGT debates. The fact that almost every civil society organization investigated engages in activities of information or counter-information sharing, implies that these actors are already making claims, even if they are excluded from the decision-making processes. Excluding them means, at best, wasting potentially valuable insights and, at worst, allowing dubious claims to spread unchecked in public debates. It would appear to be more constructive and democratic to subject their arguments as much as possible to open and transparent processes of public deliberation that are capable of ascertaining their quality. Indeed, civil society organizations have often proved capable of engaging with thorny issues, contributing to policy decisions by democratizing decision-making processes and public debates. An inspirational example here is that of the AIDS/HIV epidemic, as famously argued by Epstein (1996). As he demonstrated, civil society contributed to the rise of a class of lay experts whose “credibility struggles” disrupted and reconstructed the way the problem was addressed in the 1970s.

The third point relates to the view of civil society organizations on governance. Only a limited number of them consider this point and, even if it is clear why they are demanding a global body that is able to govern the use of such new technologies, this proposal seems rather inconsequential. Nevertheless, their criticisms regarding the existing conflicts of interests when it comes to policy-making about NGTs and their call for greater transparency should be taken seriously. If heightened transparency is introduced as part of the structuring of a new decision-making process or new sets of rules, it may help to counter, or at the very least to not exacerbate, the climate of distrust that such technologies have the potential to generate.

The recognition that civil society can strengthen democracy and the recommendation that civil society perspectives be included in the ruling process must be accompanied by the awareness that civil society organizations should not always be considered to be the expression of a common, public interest. While some civil society organizations may be the expression of a progressive political orientation, others may be regressive. Some try to enlarge the system of rights to incorporate all those segments of society that are on the margins, while others conceive of rights as a finite resource that should be distributed in a restrictive way, based, for instance, on gender, nationality, and class. Some are transformative and prefigurative actors, while others reproduce within and outside systems of dominance and inequality. This is a complexity that cannot be eluded and makes the expansion of the decision-making processes a difficult yet indispensable challenge for democratization.

While future studies will undoubtedly improve on our analysis, our research shows that civil society groups can contribute to governing the development of NGTs. Although this aspect has been neglected in political science to date, we believe that it is no longer possible to evade the issue, especially in light of the changes that have been made to laws (e.g., the will of European Union to allow the trade of GMOs crops), the efforts made by some to implement more inclusive democratic processes, and the complexities we envisage will be brought about by future developments in NGTs. It is up to political science to contribute to enriching this ongoing debate, also by paying more attention to the views and interests of the broadest range of actors. Future research could provide a more nuanced understanding of the views of these actors and their relationship with other relevant stakeholders, such as in different national or regional contexts. Furthermore, there is a need to empirically understand the dynamics of inclusion (or exclusion) in the decision-making processes. Finally, it must be said that given the level of complexity involved in NGTs we hope that future research will begin to examine the domains in which they are applied in a more in-depth and comparative fashion (e.g., plants, human, and non-human animals).

## Supplementary material

To view supplementary material for this article, please visit <https://doi.org/10.1017/S1537592724001075>.

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## List of Documents

- P3:** “Chapter 4: Ethics and Governance” by Christopher Preston and Fern Wickson. In *Gene Drives: A Report on Their Science, Applications, Social Aspects, Ethics and Regulations*, May 2019, 215-253. Retrieved October 14, 2022 (<https://genedrives.ch/wp-content/uploads/2019/10/Gene-Drive-Kapitel-4-WEB.pdf>).
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**P65:** “Gene Drive Technology: State of the Question on Science and Ethics.” Association for Responsible Research and Innovation in Genome Editing, October 2020. Retrieved October 14, 2022 ([https://arrige.org/wp-content/uploads/2021/07/Statement\\_genedrives\\_ARRIGE.pdf](https://arrige.org/wp-content/uploads/2021/07/Statement_genedrives_ARRIGE.pdf)).

## Notes

- 1 The Global Observatory on Genome Editing established in September 2020.
- 2 <https://crispr-gene-editing-regs-tracker.geneticliteracyproject.org/>.
- 3 More information on the coding process is explained in the codebook and is available upon request from the authors.
- 4 This is a random sampling method commonly used when a representative sample of the population of interest is unattainable (Johnson 2005; Cohen and Arieli 2011). Despite some strengths (Audemard 2020), it is structurally biased because of its overall representativeness (Van Meter 1990; Berg 2006). Thus, we used diverse actors with which to begin the sample (Snijders 1992; Morgan 2008; Kircherr and Charles 2018), considering diverse types of actors (social movement organizations, research groups, advocacy groups) based in different geographical areas (South America, Europe, Africa, India and Oceania) and with different opinions on NGTs (some of them favourable, others not). Data was collected from April 2022 to July 2022.
- 5 The codebook is available upon request from the authors.
- 6 Projects on gene-edited mosquitos have involved California, Brazil, and some African countries (Burkina Faso, Mali, Ghana, and Uganda). Recently, in New Zealand, the possibility of using NGTs to eradicate rats has been discussed.
- 7 Critical Scientists Switzerland, European Network of Scientists for Social and Environmental Responsibility, and Vereinigung Deutscher Wissenschaftler.
- 8 The study entitled *Behind the Smokescreen* was published in September 2022 (<https://www.greens-efa.eu/en/article/study/behind-the-smokescreen>).

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