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RESEARCH ARTICLE

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Towards societal alignment in the governance of human germline genome editing in the Netherlands

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ABSTRACT

Although international consensus exists among scientists that *clinical application* of human germline genome editing (HGGE) should not occur in the near future, the Dutch parliament is considering significantly expanding HGGE *research* options. Because HGGE policy determines medical practice and potentially the lives of future generations, it is crucial that public values are safeguarded in pertinent decisions. This study applies the governance ecosystem model and anticipatory governance to provide (i) insight into the HGGE governance ecosystem in the Netherlands, and (ii) recommendations to improve societal alignment. We identify gaps in foresight and engagement activities, and a suboptimal integration of public values. We propose interdisciplinary co-creation of future scenarios, recurrent mixed-method studies, public engagement in funding requirements and transparent policy evaluation to improve societal alignment in HGGE governance. The paper demonstrates the synergy of the governance ecosystem model and anticipatory governance when developing recommendations for societal alignment.

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Human germline genome editing, governance ecosystem, anticipatory governance, responsible innovation, societal alignment

Introduction

Human Germline Genome Editing (HGGE) is a technology that includes modification of the genetic material of reproductive cells, or an egg cell just after it has been fertilized (early embryo). HGGE has been the subject of public imagination for decades – depicted in movies, books, and other cultural outings.[1] The discovery of the Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR)-Associated protein (Cas)-mechanism, most notably the CRISPR/Cas9 technique (Gupta and Musunuru 2014), catalysed visions of an era in which hereditary diseases can be eradicated but also in which the potential modification of 'undesirable' genetic features could lead to the re-enforcement of existing (or genesis of hitherto absent) inequalities (Doudna 2020).

The controversy around HGGE is reflected in the international consensus among scientists and international organizations, such as the WHO and UNESCO, that utilising CRISPR-Cas9 to modify the DNA of embryos to establish a pregnancy ('reproductive HGGE') is unacceptable for two reasons (see International Commission on the Clinical Use of Human Germline Genome Editing 2020; Technology Committee on Science, Policy and Global Affairs, and Engineering National Academies of Sciences 2016). First, CRISPR-Cas9 technology is currently not considered sufficiently safe and effective for reproductive HGGE. Second, the essential governance frameworks and ethical principles to guide the use of CRISPR-Cas9 for reproductive HGGE are not in place. Although medical and commercial applications of

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reproductive HGGE are still far from maturity, scientists across the globe are studying the safety and effectiveness of genome editing using CRISPR-Cas9 and related tools. These are activities that contribute to the development of technologies and methods to modify the DNA of reproductive cells or embryos. In this paper, we use the term 'HGGE research' to refer to these research activities.

The Dutch Embryo Act describes what scientists in the Netherlands can and cannot do with human embryos in a research context (Ministerie van Volksgezondheid, Welzijn en Sport 2021, art. 24). Currently, the Embryo Act does not permit the creation of human embryos for scientific research. However, when the Embryo Act came into effect in 2002, the ban was meant to be temporary and it can be lifted relatively easily when required by scientific or societal developments. To assess whether the Embryo Act is still in line with recent societal and scientific developments, it is regularly evaluated by a special multidisciplinary committee consisting of experts.[2] In the most recent evaluation (2021), the committee concluded that Dutch regulation of embryo research was too strict and the ban on creating embryos for research should be lifted. The committee also recommended that the Dutch government make explicit that preclinical research on the safety and effectiveness of HGGE is not prohibited by the current version of the Dutch Embryo Act.

In May 2023 the liberal political parties VVD and D66 tabled a private member's bill (a bill initiated by members of the parliament) with the intention to remove the ban on creating embryos for research and allow research into the safety and effectiveness of technologies that enable genome editing in human embryos, which might constitute the first step towards future medical applications of HGGE. Subsequently, the Dutch Council of State, the independent advisory committee for government and parliament, reviewed the private member's bill and analysed the argumentation in the 2021 evaluation of the Embryo Act. The Council criticized that public concerns regarding possible future developments, like HGGE, were not considered in the discussion of the explanatory memorandum of the member's bill surrounding research embryos (Raad van State 2024, sec. 5d). For instance, the public's concerns that were elicited in the 2019–2020 broad societal 'DNA Dialogue'[3] (Van Baalen et al. 2021) – for example, that clinical HGGE should only be used to prevent severe genetic conditions and not for human enhancement, or clarification of the meaning of terms like 'severe' and 'human enhancement' – are not discussed or reflected upon. Similarly, the Council of State wrote that the Embryo Act evaluation committee should take these public concerns seriously in the current assessment of the desirability of lifting the ban on research embryos (Raad van State 2024). It remains unclear if the private member's bill or a variant thereof will attract enough support in the Dutch parliament to pass into law. In recent legislative periods, the topics of research embryos and HGGE have not been a priority. These governments have consisted of coalitions of at least one progressive party and at least one conservative party with regards to medical ethics, resulting in little action with regards to the embryo law.

As changes to HGGE policy determine the potential utilisation of HGGE in medical practice and inevitably impact the lives of future generations, it is crucial that mechanisms to ensure that HGGE policy decisions are aligned with (current and evolving) public values are designed *a priori*. However, it remains unclear who is responsible for ensuring that public values are included in HGGE policy, by means of which mechanisms, and to which degree this, potentially, is already happening.

Societal alignment

In 2024, the Council of State indicated that public support is crucial for the legitimization and justification of the governance of HGGE research (Raad van State 2024). Ribeiro and colleagues (2018) argue that, to avoid entrenchment in society (so-called 'technological lock-in') of societally undesirable modes of utilising biotechnologies, public participation and inclusion of public values are crucial at an early stage of the development pathway. A core challenge is to achieve 'better alignment between the goals of science, technology and innovation and those of diverse publics' (Ribeiro et al. 2018, 318).

In our view, this alignment does not necessitate that the preferences of the majority of the public determine science, research and innovation policy directly. Rather, it means that the values expressed by the general public are taken seriously through a formal process of *mutual reflection and exchange* between the public, other stakeholders, scientists and policy-makers in HGGE governance (Geuverink et al. 2024). With public values, we mean the variety of values that exist in society related to HGGE, including values deemed important by marginalized and/or generally underrepresented groups in society. These are not just opinions about HGGE technology, but underlying principles that shape the way people think about

health, parenthood, technological developments, etc. In line with Ribeiro and colleagues (2018), these values can be described as principles on which the governance of HGGE should be based.[4]

In the context of societal alignment of HGGE research, Nelson, Selin, and Scott (2021) performed a systematic review of the scholarly literature on the governance of HGE (human genome editing) and concluded that the 'scholarly discourse around HGE governance, despite its great volume, has little engaged with the questions of systemic structure and institutional design which will shape HGE's societal outcomes' (Nelson, Selin, and Scott 2021, 405). Similarly, Novitzky et al. (2020) show that, in recent years, EU efforts towards the integration of societal alignment in research policy and governance have been lacking. This is the case despite significant financing and strongly expressed ambitions (grounded in the responsible research and innovation approach) for societal alignment in the Horizon2020 programme (Novitzky et al. 2020).

This might also be the case, as, according to Nelson, Selin, and Scott (2021), 'expert communities tend to decide, mostly based on their own judgment, the biological risk or benefit, individual patient situations, or vaguely defined conditions of societal acceptance, under which the development and application of various species of HGE may, or should, proceed' (Nelson, Selin, and Scott 2021, 405). They recommend improving societal alignment based on *anticipatory governance*. However, their recommendations on how to achieve this remain quite general. The aim of our contribution is to provide concrete recommendations for societal alignment of HGGE governance based on an analytical strategy that combines two approaches, namely (1) applying the governance ecosystem framework to define and structure the context of HGGE research in the Netherlands and (2) analysing the status quo through the lens of anticipatory governance.

Governance ecosystem for science and technology

The *governance ecosystem for science and technology* model by Kool et al. (2017) is designed to identify processes and/or actors by which/whom public values can be safeguarded or violated. The framework helps to establish how the governance processes work, including how different stakeholders influence them and which interests or values are articulated well (or less well). In addition, we use the framework to explore if, and if so to which degree, mechanisms for societal alignment are currently in place for HGGE research governance in the Netherlands.

Figure 1 (adapted from Kool et al. 2017, 95) shows the complex dynamics that happen in the governance of new technologies, between the different domains in which governance activities[5] take place. These are: (1) politics and governance, (2) laws and regulations, (3) science, and (4) society. In general terms, highly complex interactions take place between these domains. Multiple actors operate within these domains, such as policy-makers, scientists and citizens, all of whom have their own interests, needs, values and practices. The different processes in governance are interdependent and influenced by these different actors. The interfaces between the domains provide challenges and opportunities for effective governance.

Kool et al.'s framework describes three governance processes: (1) *agenda-setting*, (2) *policy-making* and (3) *policy-implementation* (Kool et al. 2017). For *agenda-setting*, ethical or societal questions are often raised by scientific advisory panels, citizens, interest groups and media. These questions need to be put forward by governance stakeholders. For *policy-making*, it is essential to determine who is responsible for decision-making, and what decisions should be made (Kool et al. 2017). For example, sometimes it is necessary for policy-makers to draft new laws and regulations. The adjustment of existing policies is also an option. *Policy-making* is a political process, in which different values play a role. The decisions are translated into practice during the *policy-implementation* stage (Kool et al. 2017). This process also involves various stakeholders, such as researchers, medical professionals, and ethics committees that control regulations.

Anticipatory governance

The framework of anticipatory governance is intended to proactively align scientific developments with public values and provides helpful tools to include such values in technological innovations at an early stage of their development. Guston (2014) describes anticipatory governance as 'a broad-based capacity extended through society that can act on a variety of inputs to manage emerging knowledge-based technologies while such management is still possible' (Guston 2014, 219). Anticipatory governance covers activities relating to three core capacities[6], i.e. *foresight*, *engagement* and *integration* (Guston 2014). *Foresight*

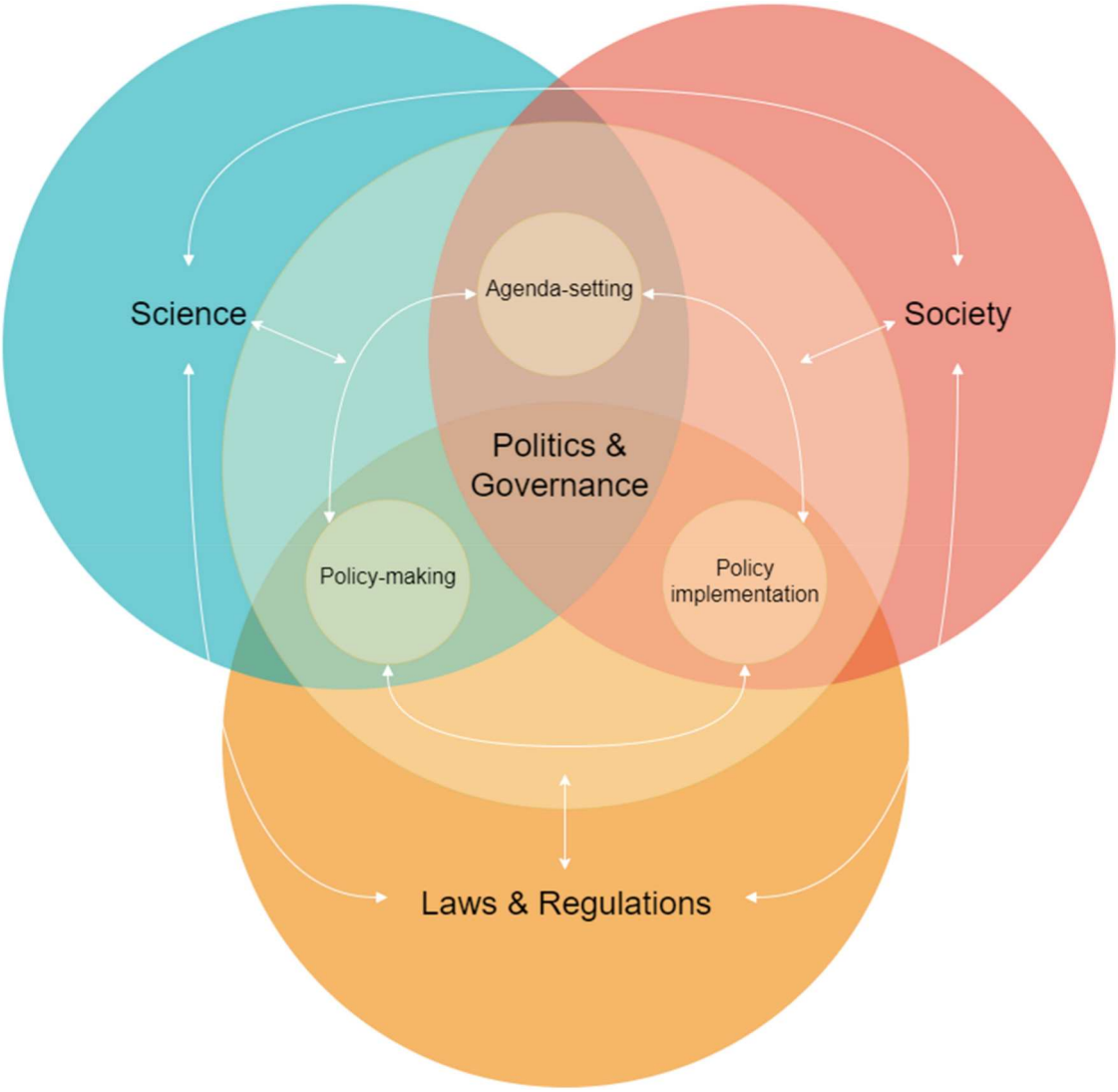

Figure 1. The governance ecosystem for science and technology (adjusted from Kool et al. 2017, 95), showing the different domains in which governance activities take place: (1) politics and governance, (2) laws and regulations, (3) science, and (4) society, as well as the governance processes: (1) agenda-setting, (2) policy-making and (3) policy-implementation. The arrows indicate the interactions between the domains and process in the governance ecosystem.

concerns the construction of plausible future scenarios. Based on current knowledge regarding a technology, and considering pertinent trends and developments in society, multiple scenarios of how the technology might develop are imagined. Policy-makers, scientists, other stakeholders and the public can use these scenarios to reflect on the possible impacts on society and the desirability thereof. Additionally, the scenarios can be used to consider and plan the requirements for steering the technology in a desired direction. *Engagement* refers to interaction between 'technoscientific decision-makers', like policy-makers, scientists and organizations that fund research, and the general public. It has multiple goals. On the one hand, it is aimed at enhancing the formation of informed public opinion and harnessing the capacity in civil society to address issues related to scientific or technological developments. On the other, the goal of engagement is to improve the identification of public values by technoscientific decision-makers. Identifying public values is crucial for the latter in order to consider relevant societal perspectives. Engagement can be facilitated by organizing an exchange of perspectives between the public and technoscientific decision-makers to facilitate a process of mutual learning regarding values that need to be safeguarded in (the governance of) science and technology. Finally, *integration* includes the development of methods and mechanisms to respond to (unmet) societal needs in the sociotechnical process of research and development. This can be operationalised in several ways, for instance, by improving the awareness among (biomedical) research practitioners to

develop reflective capacities or through democratizing institutionalized research funding processes by emphasizing in the latter the importance of public engagement methods.

Based on the governance ecosystem for science and technology and anticipatory governance, this study explores the current Dutch HGGE governance ecosystem. It specifically investigates the alignment of public values with the development of HGGE research and clinical applications. By applying anticipatory governance to our mapping of the Dutch HGGE governance ecosystem, we follow up on the recommendations provided by Nelson, Selin, and Scott (2021). By building on their insights and considering the specific context of the Netherlands, we are able to provide more specific recommendations to improve societal alignment, grounded in concrete policy mechanisms.

Methods

Study design

To map the governance ecosystem of HGGE research in the Netherlands, we performed a qualitative multi-methods study, including desk research, stakeholder analysis and semi-structured interviews. Our desk research and interview study were structured by the domains and governance processes taken from the *governance ecosystem of science and technology* model. Furthermore, the framework of *anticipatory governance* was used to analyse the results and to identify gaps regarding the capacities for anticipatory governance (i.e. foresight, engagement and integration) in the Dutch HGGE governance ecosystem.

Stakeholder analysis

The different domains of the *governance ecosystem for science and technology* provided a typology to perform stakeholder analysis, in order to identify which actors and organizations are involved in HGGE research governance in the Netherlands. This was done using the interest-power matrix (a framework that categorizes stakeholders based on their interest in the subject and their power to influence the outcome) and in consultation with co-workers from the DNA Dialogues consortium.[7]

Desk research

For the desk research we searched for legislative and policy documents relevant to HGGE research governance and clinical application, including Dutch national law, European law and international treaties and agreements, using a large online search engine (Google) and the document databases from the Dutch government (rijksoverheid.nl and tweedekamer.nl), the European Parliament (www.europarl.europa.eu), the Council of Europe (www.ceo.int), UNESCO (www.unesco.org) and the World Health Organisation (www.who.int). In addition, we have searched academic literature concerning the governance of human genome germline in Google Scholar and Scopus.

Interviews

We conducted twelve semi-structured interviews with thought leaders in the field to gain a better understanding of the dynamics and the organization of the governance ecosystem, the values and interests at play and to gather experiential knowledge about governance mechanisms that would otherwise not be identified by ecosystem mapping alone (Bednarek-Gilland 2016).

The inclusion criteria (Table 1) for participant selection were as follows: Participants had to be medical professionals working in the field of reproductive medicine and/or researchers working on either (1) fundamental research involving genetic modification techniques in the lab, and/or working with animal embryos or embryo-like structures, or (2) clinical research investigating the development of human embryos and/or working on the optimization of pregnancy or fertility procedures. To ensure sufficient experience in the relevant academic or clinical fields, participants had to possess a doctoral degree (PhD). In addition, participants had to have a good working knowledge of guidelines and procedures within their field, which is why they also had to be actively involved in their professional associations.

Table 1. Inclusion criteria

• Researchers/medical professionals in the field of reproductive medicine • Researchers performing HGGE research* • Bioethicists working on the ethical implications of HGGE research*		Sufficient experience in the relevant academic or clinical fields (PhD) Active involvement within professional and/or research association
• Health research funders		
* *HGGE Research*	*Fundamental*	*All research practices involving genetic modification techniques in the lab, and/or working with animal embryos or embryo-like structures (ELS)*
	Clinical	*All research practices investigating the development of human embryos and/or working on the optimization of pregnancy or fertility procedures*

All respondents were (potential) thought leaders, meaning that they participated in (governmental) advisory boards, round table conversations, or were outspoken on medical ethical developments in the media (e.g. website articles). To increase diversity in our sample, different professionals were approached, such as gynaecologists, clinical embryologists, clinical geneticists and fertility doctors. We also approached bioethicists that were researching the ethical implications in the aforementioned fields, as well as health research funders, to provide insight into the mechanisms by which funding decisions concerning emerging and possibly controversial biomedical research are made.

The interview guide (see Appendix A) covered the following topics: (1) governance structure of HGGE research, including influences from science, society, laws & regulations, and the values that interviewees considered important, and (2) mechanisms for safeguarding public values as a means to facilitate societal alignment in the governance of HGGE research (in the stages of agenda-setting, policy formation, and policy implementation). The interview guide was expert checked by two co-authors (SvB, JKT) and piloted. All interviews were transcribed *ad verbatim*. Thematic analysis was performed on the interview transcripts using a deductive codebook based on the *governance ecosystem for science and technology* and complemented by inductive coding following the approach as described by Braun & Clarke (2006). Themes were continuously evaluated within and across interviews, resulting in a final thematic code map (see Appendix B).

Ethical considerations

The document review component of this study neither involved human participants nor the collection of personal information and, therefore, did not require ethical approval. As indicated by the Vrije Universiteit Amsterdam (BETHCIE) self-check tool for assessment of the ethical review of research with human participants, the empirical component based on interviews also did not require review by a medical ethics committee, since we did not involve vulnerable groups or posed any risks to our participants. All participants signed informed consent forms prior to the interview.

Results

For each domain of the governance ecosystem, we have specified the important actors in HGGE research governance using the outcomes of our stakeholder analysis and desk research below (see Figure 2 for a visual mapping of the actors in the ecosystem).

Stakeholder analysis

Laws & regulations

In Table 2 we provide an overview of important national and international legal and policy documents. While guiding principles have been formulated by 'global' and European institutions, they are not immediately relevant for our specific study aim, which is why we only briefly summarise them here.

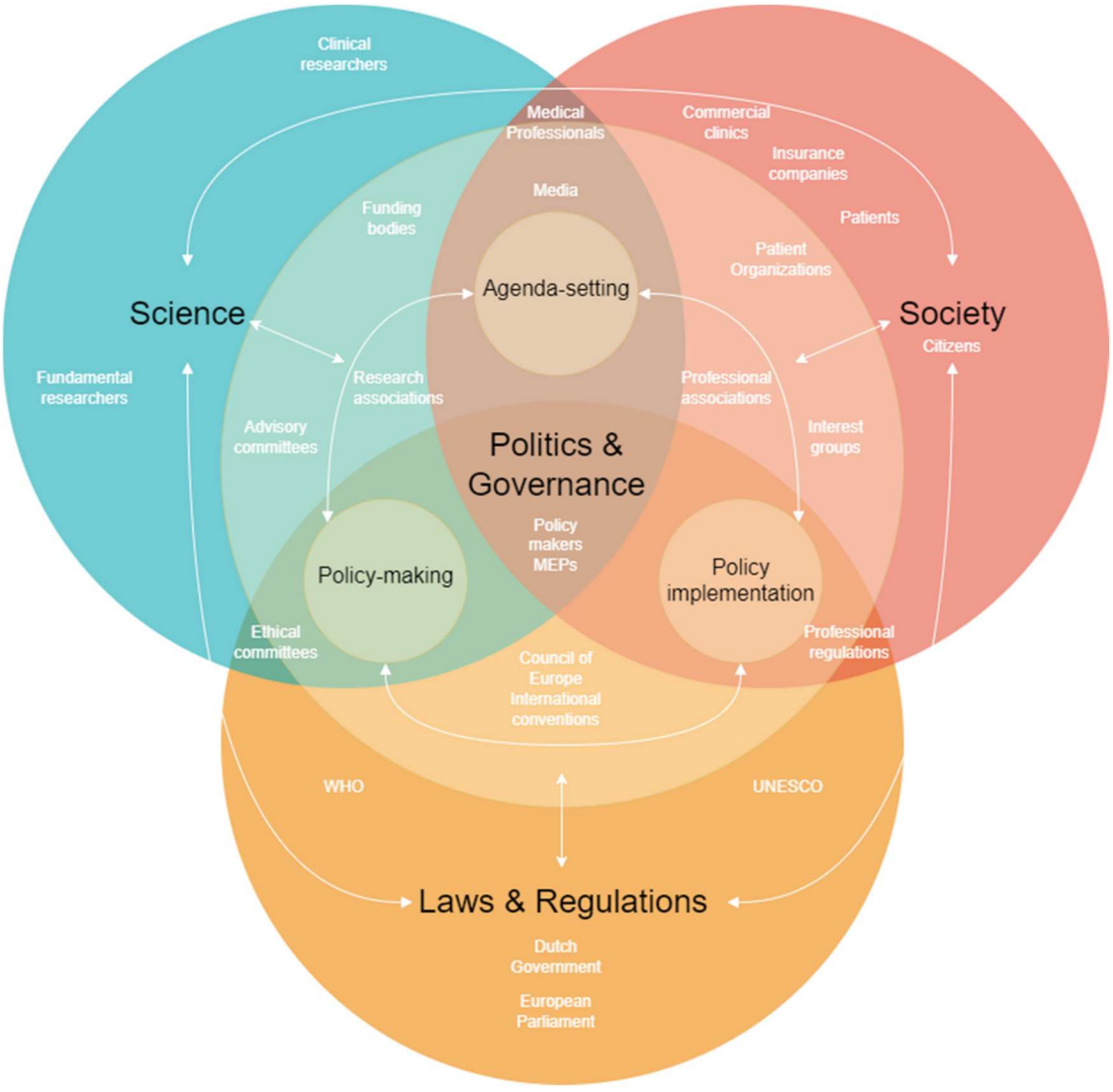

Figure 2. The mapping of the relevant stakeholders for the governance of HGGE research in the different domains of the governance ecosystem.

Global level. Three international bodies have formulated non-binding advice on HGGE which can shape the background against which European and Dutch laws and regulations are formulated. In brief, UNESCO states that dignity is inherent in the human genome and promotes caution for practices that could impact human dignity and the protection of future generations (IBC 2015). The WHO emphasizes that HGGE practices should be guided by specifically defined ethical values (WHO 2021). Finally, the international commission on the clinical use of HGGE, convened by the U.S. National Academy of Medicine, the U.S. National Academy of Sciences, and the U.K.'s Royal Society, states that application of HGGE for pregnancy should not happen until the effectiveness and safety of the technique is clearly established, a national societal dialogue should take place in advance of decision-making and an International Scientific Advisory Panel should monitor developments in the clinical and scientific field (International Commission on the Clinical Use of Human Germline Genome Editing 2020).

European level. The Council of Europe (CoE) formulated the Convention on Human Rights and Biomedicine (Council of Europe, 1997)[8] an international, legally binding instrument for the protection of human rights in the biomedical field. Article 13 prohibits the clinical application of HGGE (Baylis et al. 2020). The Netherlands has signed but not ratified the convention, i.e. the principles of the convention are not written into Dutch law. The European Clinical Trials Regulation (European Union) prohibits clinical trials

Table 2. Overview of important national and international legal an policy documents.

Organisation	Document name and publication date
International	
UNESCO	Universal declaration on the human genome and human rights (1997)
UNESCO	International declaration on human genetic data (2003)
UNESCO	Universal Declaration on Bioethics and Human Rights (2005)
WHO	Human genome editing: position paper (2021)
WHO	Human genome editing: recommendations (2021)
WHO	Human genome editing: a framework for governance (2021)
International Commission on the Clinical Use of Human Germline Genome Editing	Heritable Human Genome Editing (2020)
Europe	
Council of Europe	Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo Convention) (1997)
EU	Biotechnology Directive (1998)
EU	Charter of Fundamental Rights (2000/C 364/01)
EU	Clinical Trials Regulation (2014, replaced the 2001 Clinical Trials Directive)
The Netherlands	
Ministry of Health, Welfare and Sport	Embryo Act (2021)
Ministry of Health, Welfare and Sport	First evaluation Embryo Act (2006)
Ministry of Health, Welfare and Sport	Second evaluation Embryo Act (2012)
House of Representatives	Roundtable conversation on Embryo Act with scientists and ethicists (2018)
Ministry of Health, Welfare and Sport	Third evaluation Embryo Act (2021)
Parliament	Private member's bill Paternotte (MP for D66) & Hermans (MP for VVD) (2023)
Council of State	Advice on private member's bill Paternotte and Hermans (2023)

that result in the modification of the human germline (The European Parliament and the Council 2014). Article 6 of the European Biotechnology Directive (The European Parliament and the Council 1998) prohibits patenting of HGGE applications. Also, eugenics – to modify certain genetic traits based on considerations of desirability – is explicitly prohibited by Article 3 of the EU Charter of Fundamental Rights (The European Parliament, the Council and the Commission 2000).

National level (Netherlands). As alluded to above, in the Netherlands, HGGE for reproductive practices is banned by the Embryo Act. This prohibits alterations to genetic material in the nucleus of gametes or embryos for pregnancy (Ministerie van Volksgezondheid, Welzijn en Sport, 2021, Article 24). As discussed in the introduction, there is a temporary agreement (moratorium) which prohibits the production of embryos for the sole purpose of conducting research in the Netherlands. On average, the Embryo Act is evaluated every five years.

Because of the Embryo Act, research can only be performed on embryos that are surplus in in-vitro fertilization (IVF) procedures. These embryos are either not adequate to be placed into the womb, or not needed anymore for IVF treatment, and would otherwise be discarded. Another research method is to create embryo-like structures (ELS) from stem cells (Ministerie van Volksgezondheid, Welzijn en Sport, 2023). However, scientists in the Netherlands point out that these practices are inadequate because they want to study embryonic development in the early stage (<3 days), which is not possible with embryos from IVF or ELS. They point out that there exist more relaxed rules in Belgium, the United Kingdom and Sweden, which draws them to perform research abroad (Staten-Generaal 2018).

Science

Currently, HGGE is not directly studied in the Netherlands. Therefore, the stakeholder analysis is based on actors associated with technologies that are closely related to HGGE research, such as scientists involved in basic research on genetic modification or embryonic development, or clinical research regarding embryonic development or reproduction. As individual actors, these stakeholders can be influential (for example, when they act as advisors to policy-makers in evaluation committees or hearings). Moreover, they can be members of research associations/societies that develop and establish standards, guidelines, protocols and oversight mechanisms that impact how scientists perform research and are required to deal with ethical considerations.

Besides basic and clinical scientists, ethicists play an important role by addressing the ethical implications of gene editing research and the developments in reproductive medicine. For example, in 2020 there was a joint statement of multiple bioethics councils (the Nuffield Council on Bioethics, the German Ethics

Council and the French National Advisory Committee on Ethics in life sciences and health) advising the strict control of HGGE practices (STOA 2022). Ethicists are also active in medical research ethics committees (MRECs) that review research proposals according to legal and professional guidelines, and advisory committees for the evaluation of laws and regulations such as the Embryo Act.

Furthermore, medical professionals, such as fertility doctors, embryologists, gynaecologists, and clinical geneticists, work at the interface of science and society. Many medical professionals are also scientists, involved in clinical research aimed at improving clinical practice. Similarly, medical professionals are often organized in professional and/or research associations/societies.

Society

Societal actors. The potential application of HGGE primarily affects patients with, and carriers of, a severe hereditary disease, such as sickle cell disease or cystic fibrosis (Turocy, Adashi, and Egli 2021). In addition to impacting the life of patients, HGGE technology can also impact society as a whole. Societal concerns include the potential impacts on diversity, the acceptance of differences, non-discrimination, and (socio-economic) equality and solidarity – but the *de facto* consequences for future generations and thus society are currently unknown (Van Baalen et al. 2021). Some of these concerns are also expressed by societal interest groups or religious communities.

Commercial actors. Commercial parties can influence the governance of HGGE research, e.g. by advocating for changes to the rules, or the introduction of products and services. There is a big industry behind fertility research and a rise of commercial fertility clinics (Stelling 2018), that could have a business interest in HGGE technology. In the Dutch context, however, the role of private parties in the development of fertility research and technology is limited and strictly regulated by government policy, thereby diminishing the commercial influence on HGGE research (Van Dijke et al. 2022). In contrast to other countries, there are only a few commercial fertility clinics in the Netherlands. Fertility clinics are mostly linked to a University Medical Center. Nevertheless, the role of industry in HGGE governance is not entirely negligible, as opportunities in other European countries may encourage researchers and other stakeholders interested in HGGE research to go abroad or push the agenda in the Netherlands, as was the case for non-invasive prenatal testing (Ravitsky et al. 2021).

Media. Finally, traditional and social media have the power to shape the debate on HGGE by highlighting specific arguments for or against HGGE research and, in consequence, can play an important role in agenda-setting. For example, in 2019, He Jiankui caused wide-spread controversy by applying HGGE to genetically modify Chinese twins with the intention of making them immune to Human Immunodeficiency Virus (HIV). The concentration of (social) media reporting and interactions on this event largely shaped the international debate on HGGE in the following years (Chen and Zhang (2021)). While the press and social media can have a strong moderating role between the scientific world and the public, they can, naturally, also have an impact on the perceptions, and decisions, of policy makers.

Politics & governance

In the domain of politics, the Embryo Act is the most important law regulating HGGE research and application. As explained in the introduction, recurrent evaluations of this Act have led to discussions in the political and public sphere concerning the question of whether the ban on creating embryos should be lifted and, if so, for what purposes.

Interviews

A total of twelve interviews were conducted in April and May 2023 with 13 interviewees (1 duo-interview), including 2 research funders, 1 clinical geneticist, 1 embryologist, 1 gynaecologist, 1 fertility doctor, 2 fundamental researchers, 3 researchers working in translational medicine and 2 bioethicists. The interviewee information can be found in Table 3. Below, we describe four key findings from the interviews.

Table 3. Interviewee information, including a short description of their job function, the field of expertise in which they operate, the type of organization and the country in which they work.

#	Job function	Field of expertise	Type of organization	Country
R1	Translational researcher	Genetics	University Medical Centre	NL
R2	Translational researcher	Genetic testing	University Medical Centre	NL
R3	Clinical embryologist	Reproductive genetic technologies	University Medical Centre	NL
R4	Translational researcher	Reproductive genetic technologies	University Medical Centre	NL
R5	Clinical geneticist	Rare diseases	University Medical Centre	NL
R6	Gynaecologist	Reproductive medicine	University Medical Centre	NL
R7	Research funder	Translational research	Governmental funding body	NL
R8	Research funder	Translational research	Governmental funding body	NL
R9	Fundamental researcher	Embryological development	Research Institute	NL
R10	Bioethicist	Reproductive medicine	University	NL/BE
R11	Fundamental researcher	Reproductive medicine	University Medical Centre	BE
R12	Fertility doctor	Reproductive medicine	Non-Academic Hospital	NL
R13	Bioethicist	Reproductive medicine	University	BE

The role of scientists in HGGE governance

Interviewees from all interviews are actively involved in governance. Interviewees mentioned that actors in the scientific domain have a big influence on all three governance processes (agenda-setting, policy formation and policy implementation) compared to actors in the fields of society or laws and regulations. Regarding *agenda-setting*, researchers, medical professionals and research funders explain that technological and scientific developments are important drivers for the creation of new policies. R1 [translational researcher]: 'It's very much technology push. The starting point is: We have this technology and we have to do something with it. And not: We have a societal demand and we have to do something with it.'

Although most interviewees (n = 10) doubted that there is a societal demand for HGGE, considering the existing alternatives, those performing basic science and most medical professionals believed that, in the future, HGGE technologies would be further developed and improved. The speed of scientific development and the importance of the Netherlands in having the chance to contribute to HGGE research were important considerations to advocate against the current restriction on research. This indicates that scientific arguments prevail in foresight activities regarding HGGE research.

Scientists are also involved in the HGGE governance process of *policy formation*. For example, one interviewee explained that scientists are often consulted by policy-makers, for instance to write the scientific background for amendments of laws such as the Embryo Act or to take part in technical hearings in the Dutch parliament to advise policy-makers on the current state-of-the art. When asked what kind of information scientists should provide, R3 [clinical embryologist] explained: 'It is especially important that what is written is correct, that it is no more and no less than what is possible at the moment. And what we as a society all think of that, we [scientists] are only a very small player in that. Above all, we are an important player in ensuring that information is transparent and complete.' The interviewees thus considered themselves to have an important, but narrowly defined role in the process of policy formation. Although they provide information about the science and technology, the integration of the information with other (i.e. ethical, societal and political) considerations is outside of their scope.

Scientists also play an important role in *policy implementation* into research practices. For example, by setting up protocols for working with embryo-like structures (ELS) and performing HGGE research, which relies for a large part on their own values, as R9 [fundamental researcher] explains: 'Now you can do whatever you want [regarding HGGE research with ELS]. If you have scientific morals, you will not do [HGGE] at all. But you never know what will happen elsewhere.'

Moreover, the establishment of consortia for fundamental and translational research and the division of tasks and responsibilities among the collaborating academic centres is up to the scientists themselves. As R7 and R8 [research funders] explained, research proposals are only judged based on their scientific quality and compliance with Dutch laws & regulations. The research funders also indicated that scientists themselves are responsible for reporting problems or addressing new ethical or societal issues.

Values deemed important in the governance of HGGE research

Figure 3 shows the central values that were identified in our interviews and those that were reported in the results of the DNA dialogue (Van Baalen et al. 2021). The figure illustrates that there is quite some overlap

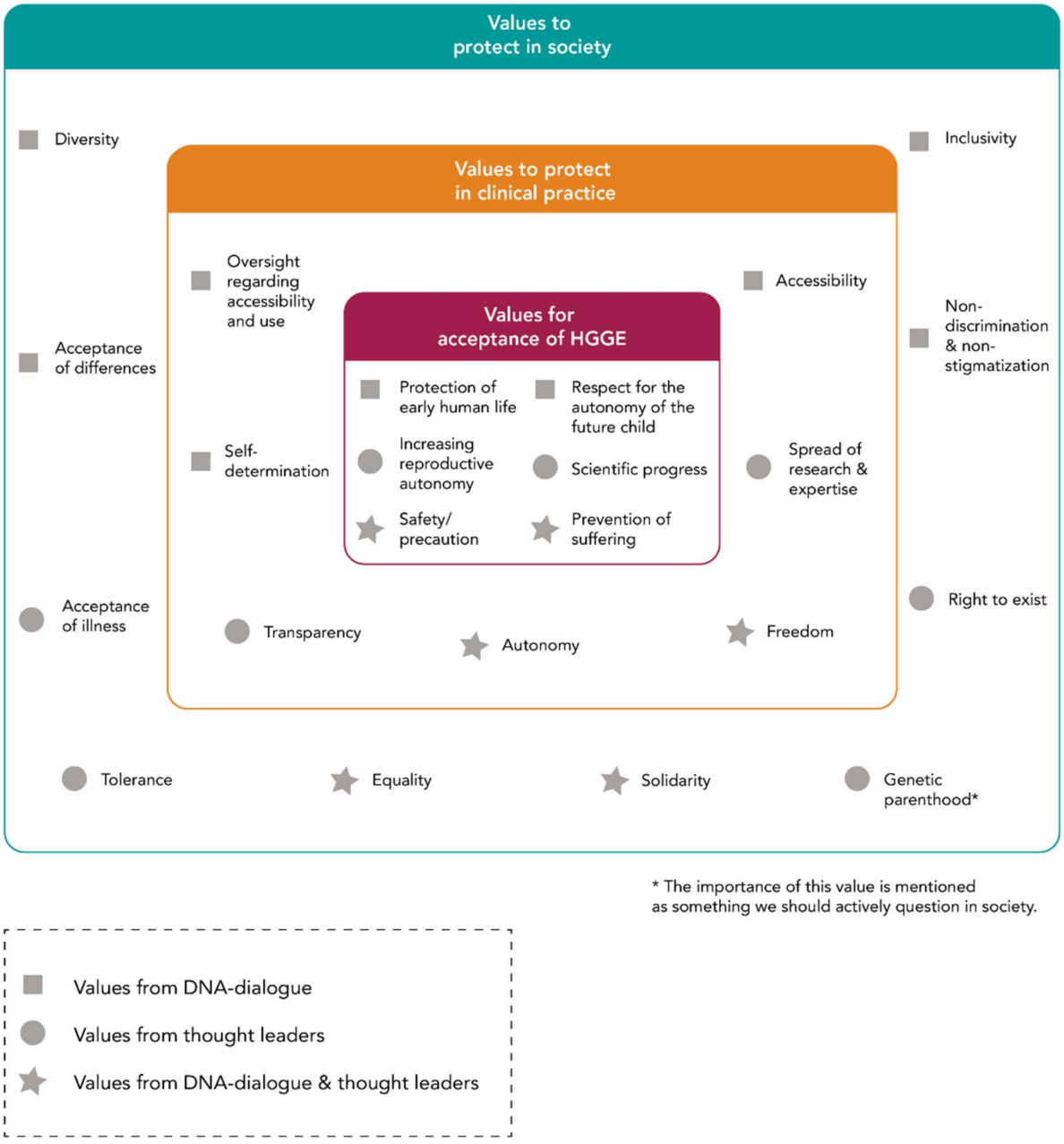

Figure 3. Recurrent values that were mentioned by participants from the DNA Dialogue versus values mentioned by our interview participants. We have organized these values in three groups: (1) values that are important to participants to consider whether HGGE is acceptable or not, (2) values that participants find important to protect when HGGE is used in clinical practice, (3) values that participants find important to protect in society when HGGE is used. Cubes represent values from the DNA dialogue, circles represent values from interviewees, and stars represent values mentioned by both groups of participants.

between the values that were mentioned by citizens in the DNA dialogue and the values that were mentioned by our interviewees, such as the *prevention of suffering*, *equality* and *solidarity* (stars in Figure 3). For the acceptance of HGGE technology, *safety* was mentioned as a basic requirement by both groups. However, there also exists variation.

On the one hand, interviewees considered *increasing reproductive autonomy* (the freedom of prospective parents to make reproductive choices) and *scientific progress* to be important values for the acceptance of HGGE (circles in Figure 3). On the other, participants in the DNA dialogue considered *respect for the autonomy of the future child* and *the protection of early human life* important values for acceptance (squares in Figure 3). It also became evident that interviewees considered other values and responsibilities when

thinking about HGGE application in clinical practice, such as *transparency*; participants from the DNA dialogue favoured *accessibility* and *self-determination*.

Societal alignment: public engagement as a crucial first step for the integration of public values into the governance of HGGE research

All interviewees endorsed the importance of integrating public values in the governance of HGGE research, but several admitted that they were unsure regarding appropriate mechanisms to achieve this goal. When discussing integration, thought leaders primarily mentioned engaging in dialogue with the public, with some terms and conditions. For example, six interviewees emphasized the importance of the public receiving accurate information in such dialogues. And they found it important to listen to the arguments of citizens and make people feel heard. These results show that governance stakeholders might have a limited view of what is proper public engagement, as they focus mostly on informing and hearing citizens instead of mutual exchange and securing impact. This bears the risk of tokenism, in which citizens are informed and consulted, but have no actual power in policy-making (Broerse and de Cock Buning 2012).

Furthermore, interviewees had different interpretations of their own role in this process. Most medical professionals (R3, R6, R12) emphasized that their responsibility lies with providing accurate information about scientific developments. Other interviewees (R1 [translational researcher], R9 [fundamental researcher] and R10 [bioethicist]) remarked that scientific values are not necessarily separate from societal values. For example, R1 envisioned a more active role for scientists in public dialogue, in which their own values are made explicit as well. R1 advocates for a more integrated approach in public deliberation, in which there is no distinction between experts and the lay public.

Policy evaluation is an essential component in the governance of HGGE research

All interviewees spoke about policy evaluation as an essential process for shaping the governance process around HGGE research. According to R3 [clinical embryologist], R4 [translational researcher], R5 [clinical geneticist], and R10 [bioethicist], policy evaluation should be built into the HGGE research governance process. In addition to the evaluation of laws, such as the Embryo Act, the interviewees mentioned several examples of (self-)governance evaluation mechanisms, such as the mandatory evaluation of research programs, and protocols to make the results of evaluations publicly available. For such an evaluation process, R3 considered it important that individuals working on HGGE research determine, in advance, which indicators must be assessed in the future. This is something that can be encouraged by funding requirements. According to R3, R4, R5 and R10, policy evaluation is especially important because public values can change over time. As R10 [bioethicist] explained, 'intergenerational relativism' (i.e. decisions regarding the technology made today can affect future generations, but are not necessarily supported by future generations, who might have a different moral framework) is a challenge for achieving the goal of societal alignment in HGGE governance more generally. This issue is even more important for HGGE, because the clinical application of this technology cannot be reversed for future offspring whose genes have been modified. To start to address this challenge, there should be continuous public deliberation and policy evaluation.

Discussion

Analysis of anticipatory governance gaps in the Dutch governance ecosystem

The aim of this work was to investigate to what extent governance structures in the Netherlands ensure that decisions on HGGE research policy are aligned with public values. Below, we analyse the key findings from the interviews and identify associated gaps regarding the capacities for anticipatory governance (i.e. foresight, engagement and integration) in the governance ecosystem.

Foresight

The interviews show that each stage of the governance process (i.e. agenda setting, policy-making and policy-implementation), interviewees mentioned the significant influence of the scientific field on the governance of HGGE research, vis-à-vis the other domains (society, and laws and regulations).

Scientists are involved in all three governance processes because of their expertise on recent advances in the scientific domain, and the expected speed and direction of future developments. They inform policymakers about what they think are feasible applications and reasonable timelines for when these applications will be clinically or commercially available. Hence, they play an important role in the foresight capacity of the governance ecosystem. However, as alluded to above, foresight requires the involvement of a broad range of expertise. Technical expertise is not enough, as described by Vallor (2016, 5): 'Predicting the general shape of tomorrow's innovations is not, in fact, our biggest challenge: far harder, and more significant, is the job of figuring out what we will *do* with these technologies once we have them, and what they will do with *us*. This cannot be done without attending to a host of interrelated political, cultural, economic, environmental, and historical factors that co-direct human innovation and practice. Indeed, a futurist's true aim is not to envision the technological future but the techno*social* future – a future defined not by which gadgets we invent, but by how our evolving technological powers become embedded in co-evolving social practices, values, and institutions.' Such structural inclusion of a broad range of expertise seems to be lacking in foresight regarding HGGE in the Netherlands, even though many public actors and academics are raising concerns regarding, for instance, human dignity, parenthood, or solidarity (Hurlbut 2020; Sandel 2017; Van Beers 2020). Moreover, a focus on scientific arguments over societal and public values also narrows the timeframe for foresight.[9] Hurlbut (2020) shows that in the current debate, ethical and societal issues are only considered to be relevant after technologies have matured and applications (e.g. in medical interventions) are within reach. He notices a longstanding tendency to focus ethical deliberation about HGGE 'only on the next step, not on where the path ultimately leads', i.e. long-term outcomes (Hurlbut 2020, 180). Hurlbut (2025) calls this a 'science first, ethics later' approach.

Engagement

The interviewees supported public engagement efforts regarding HGGE research and particularly mentioned dialogue as an important method. This is in line with different national and international organizations stating that societal dialogues on HGGE are valuable. In the Netherlands, this challenge was taken up by the DNA Dialogue (Van Baalen et al. 2021). It concluded that Dutch citizens are generally only in favour of HGGE under certain strict conditions, for instance if the technology is used for preventing diseases, but not for improving the life of healthy people. They also generally believe that there should be strict criteria and regulations that ensure that conditions treated are 'severe enough'. However, interviewees described different responsibilities for engaging in dialogue about HGGE, ranging from informing citizens about technological possibilities to integrating different perspectives. Thus, mechanisms and responsibilities are not specified to facilitate the organization of societal dialogue in such a way that societal alignment is sufficiently facilitated.

Furthermore, the fact that there is variety in the values deemed important by different stakeholders indicates that including only a specific set of values (e.g. those of thought leaders) in the governance of HGGE is not sufficient. This underlines the importance of including the diversity of public values in the governance of HGGE and thus the importance of the anticipatory governance capacity of engagement.

Integration

As proposed by multiple interviewees, recurrent policy evaluation can play an important role in the process to facilitate societal alignment, as it provides a concrete and predefined context to reflect on whether the goals and underlying values of the law are still in line with the current scientific state of the art on the one hand and public values on the other. For instance, the committee tasked with the evaluation of the Embryo Act in 2021 refers to engagement efforts such as the DNA Dialogue (Dondorp et al. 2021). However, how the outcomes impact the overall recommendations is not specified. For example, it remains unclear how the conclusions of these engagement efforts were connected to the resulting legal recommendations. The evaluation mentioned that much of the objections to lifting the ban on research embryos are largely[10] based on concerns of a slippery slope towards reproductive technologies that are considered undesirable such as artificial sperm or egg cells and HGGE (Dondorp et al. 2021, 198). The authors stated that this concern is relevant to the discussion of the desirability of these techniques, but not to the discussion regarding the ban on research embryos. As a result, the authors recommended to remove the ban under certain conditions, and the results from public dialogue were not further taken into consideration. We

are also unaware of other efforts to integrate findings from the DNA Dialogue into the broader organization of research and development, such as funding requirements or built-in reflection on public values in research programs related to HGGE. Furthermore, it is unclear who should be responsible for the integration of the outcomes of the DNA Dialogue in governance, research and development of HGGE. This indicates that there is room for improvement for integration in the governance of HGGE research in the Netherlands. In the next section we will provide suggestions to improve societal alignment based on the gap analysis above.

Improving societal alignment by harnessing anticipatory capacities

Based on a review of national and international policy documents, stakeholder analysis and interviews, we found that the influence of public values on the HGGE governance ecosystem is marginal. Despite initiatives such as the DNA Dialogue, which are designed to include a broader range of perspectives in the governance of HGGE, actors from the scientific domain play a dominant role in all three governance processes (agenda-setting, policy-making, policy-implementation). Moreover, despite engagement initiatives and efforts of policy-makers striving to include a broad range of perspectives and considerations into their decisions, scientific arguments are emphasized over ethical or societal arguments. Our results suggest that, in the Netherlands, while (limited) foresight and engagement activities exist, the structural integration of a broad range of public values in HGGE governance is suboptimal. Here, we show how our analysis of the governance ecosystem allows us to develop specific recommendations based on the three capacities of anticipatory governance.

Foresight

Regarding *foresight*, we have identified that, although scientists provide their expert opinion on how they expect technologies will develop in the future, it cannot be expected of them to have an overview of diverse ethical and societal issues. Different approaches can be used to consider the further development of an emerging technology, including 'technomoral scenarios' (Swierstra, Stemerding, and Boenink 2009), (health) technology assessment, emerging risk assessment, or horizon scanning (OECD 2024). All of these approaches are helpful means to think about how the technology and society might co-develop. As alluded to above, it is important that foresight addresses how technology could impact or change norms and values in society. We suggest making foresight a recurrent or structural capacity within the HGGE research governance ecosystem by applying foresight methods that engage a broad range of disciplines (techno-scientific as well as societal) to envision techno*social* futures. This requires the involvement of a broad range of experts to co-create multiple future scenarios about HGGE, including not only scientists, but also individuals living with a disease, (future) parents, etc. Ethicists and social scientists studying science and technology can play a role in connecting scientific and societal perspectives. Foresight exercises can subsequently be used to discuss the desirability of futures of HGGE with the public and other governance stakeholders in *engagement* activities.

Engagement

Regarding *engagement*, the suggestions from interviewees about informing and listening in dialogue with citizens risk to remain passive exercise, the goal of which is to make people feel heard rather than actually identifying their values (Broerse and de Cock Buning 2012). Efforts have been made to identify and include public values in the governance of HGGE research, particularly in the 2021 evaluation of the Dutch Embryo Act. The authors of the evaluation mention several research projects that aimed at stimulating public dialogue on embryo research and HGGE research, among other relevant topics (Dondorp et al. 2021, 67–71).[11] In many of these initiatives, the engagement practice consists of sharing information and asking respondents to rate different aspects of HGGE. Conversely, the committee wrote that further dialogue on research embryos is unlikely to lead to new insights and will mainly result in a delay of decisions. 'All arguments seem to have been exchanged already', they mention (Dondorp et al. 2021, 209). 'The tendency can exist to see a dialogue as a kind of referendum […], which risks deemphasizing the own responsibility of the lawmaker.' At the same time, the authors of the evaluation mention that the societal discussion on the *application* of HGGE has only just started. They do not consider those considerations relevant to policy on

HGGE research, even though the public has expressed serious concerns about allowing HGGE research because it could lead to its clinical application (Gouman, Vogelezang, and Verhoef 2020). These statements in the evaluation show that public values are not being given full consideration.

Therefore, it is crucial that engagement attains a fixed place in the governance ecosystem. To enforce this, engagement could become a required element of the periodical evaluations of the Dutch Embryo Act. This could be facilitated by recurrent mixed-methods studies and dialogues on public values regarding HGGE. In this way, strong structural capacities can be created which will be independent of political directions or trends. This approach could not only be effective in the evaluation of the Embryo Act, but also in the evaluation of related research developments in the fields of genetics or reproduction. In public engagement practices specifically, the focus should furthermore shift from information sharing towards mutual learning, where the role of the experts also entails investing in creating trust relationships and learning through interaction with other members of the public (Reincke et al. 2022).

Integration

Room for improvement is even more significant when it comes to the capacity for *integration*, which requires structural efforts to embed public values in research policy and practices. The results of the interviews in this study indicate that, even though governance stakeholders find it important to integrate public opinions into the governance of HGGE research and development, they are, in many cases, not sure how to do this. This suggests that the lack of integration is not (or at least not only) due to unwillingness, but rather paucity of integration options.

Outcomes from public engagement and deliberations, such as the DNA Dialogue, are referred to in the recommendations by the Dutch Embryo Act evaluation committee. However, building on the anticipatory capacities, we contend that the evaluation of the Embryo Act can play a larger role in the societal alignment of HGGE research. Below, we will provide suggestions on how results from public deliberation can be actively taken into consideration in the ecosystem of HGGE governance.

To improve *integration,* we recommend making scientists and scientific funding organizations aware of the necessity of engaging with public views on HGGE. We have shown that, currently, the scientific domain is dominant in the governance ecosystem and that societal effects of HGGE are insufficiently considered in policy processes concerning HGGE research and development. The choice for a particular research topic is not a value-neutral act, and science and science funders can be made aware of the broader societal implications of the decisions they make. Even conducting fundamental research on the possibility of HGGE signals that this is a direction worth pursuing in comparison to other kinds of research to which effort, time, and money could be allocated. For this reason, it is desirable to engage in public dialogues on potential research topics.

As not all scientists are primarily trained (or can be expected) to align their work with societal values, one recommendation would be to further emphasize the societal effects of research decisions in educational programs. Another option is to involve organizations in research that are more familiar with the challenges of societal alignment. An example of 'good practice' is the PSIDER research program[12], where involvement of a partner pursuing ethical or societal research is required. Research funders could also render such approaches a prerequisite for approval of a research program, making researchers themselves responsible for ethical and societal reflection.

As another means to improve *integration*, we argue that the relationship between policy and the results of foresight and engagement endeavours should be made explicit. This can be achieved by addressing in the Embryo Act evaluation how HGGE policy recommendations relate to public values, and how the different values are weighed to result in specific recommendations. It is thereby crucial that a broad range of values is considered that also encompasses values emphasized by the public, such as, in this case, human dignity, parenthood, or solidarity. For example, Timmis and colleagues demonstrated the feasibility of assessing stakeholder priorities and of the (theoretical) benefits of including them in decision tools such as multi-criteria decision analysis. They have shown, for national vaccine evaluation, how the elicitation (Timmis, Rigat, and Rappuoli 2017) and implementation (Timmis, Black, and Rappuoli 2017) of core values in decision mechanisms can considerably improve their degree of 'accountability', i.e. of alignment towards stakeholder values. Methods like this would result in a more comprehensive assessment of the impact of HGGE, more transparent value trade-offs, and more democratic decisions overall.

Strengths & limitations

These recommendations are intended as starting points for improving societal alignment of HGGE research. Our discussion focuses on the evaluation of the Embryo Act, but a broad range of measures can and should be taken to work towards societal alignment. It remains a challenge to thoroughly consider and reflect upon public views on such a topic in policy. One persisting issue could be that in the ecosystem, there is not one stakeholder that fully represents the interests of the general public, as opposed to patient groups and scientists who have official representation in the form of patient organizations and professional societies. Ethicists and social scientists are well positioned to explain which values, principles or societal issues are at stake, but cannot represent the diverse points of view that exist in society. Therefore, only if the three capacities of anticipatory governance (foresight, engagement, and integration) are structurally embedded in the governance of HGGE research, societal alignment can be properly improved.

Our recommendations on improving societal alignment are catered specifically to the Dutch context. When in other countries evaluation mechanisms or engagement efforts are not in place, this naturally has two consequences: (1) increased efforts are required to setup the kind of policy evaluation required for improving societal alignment; (2) other parts of the ecosystem, like research funding organisations and scientists themselves become relatively more important. Still, we believe, in line with a recent OECD report on anticipatory governance (OECD 2024, 28), that also for other national contexts, evaluation of laws or policies will be a promising direction for improving societal alignment of governance of HGGE and science and technology more broadly. Built-in policy evaluation can provide an excellent structure for transparently integrating public values into HGGE governance.

Applying anticipatory governance after having mapped the governance ecosystem enabled us to critically analyse existing governance mechanisms regarding HGGE in the Netherlands and consequently provide concrete recommendations for improving them. We contend that future anticipatory governance research should also consider combining these two approaches. Our work demonstrates how the governance ecosystem for science and technology and the anticipatory governance framework complement each other to define both context-specific and forward-looking policy recommendations that can be applied to complex innovations beyond the scope of HGGE research.

Conclusion

The anticipatory governance gaps identified in the Dutch HGGE governance system indicate a need for structural mechanisms to improve societal alignment. We recommend (1) that interdisciplinary foresight and engagement activities, for instance mixed-methods studies and public dialogues, are made recurrent activities in every evaluation of the Dutch Embryo Act, (2) to raise awareness of the societal impact of scientists' roles in the HGGE ecosystem and of the necessity of including public values in research policy, and (3) to make explicit how the outcomes of the dialogue can be weighed in policy.

The speed at which HGGE technology evolves, the political efforts to relax Dutch HGGE research policy, and the focus of governance debates on technological arguments rather than public values, underscore the urgency of establishing – as soon as possible – processes and mechanisms to consider and integrate diverse stakeholders' values in HGGE policy decisions. Not achieving this in the very near future, runs the risk of missing the window of opportunity to base HGGE policy on good principles of responsible research and innovation (Ribeiro et al. 2018). We urge those actors who are central to decisions on HGGE policy to critically review our findings and establish mechanisms to ensure that such policies are properly aligned with the values of society at the time of their passing into law.

Notes

1. In the movie "Gattaca," for instance, HGGE is used to create genetically superior humans (Niccol 1997). Aldous Huxley's novel "Brave New World" (Huxley 1932) imagines a future where people are selectively bred for specific societal roles. Although this is embryo selection rather than HGGE, the novel is still important to public imagination of being able to substantively control the genetic make-up of future individuals and generations. While these are some of the most well-known examples, So (2019) points out that there are other relevant literary references that provide more scientifically accurate scenarios and address the societal and ethical issues surrounding HGGE.

2. There have been three evaluations so far – in 2006, 2012 and 2021.
3. www.dnadialoog.nl
4. We acknowledge that in society, there are always conflicting values, and consensus is not always evident. Therefore, we do not promote a 'majority decides' approach. Rather, we aim to encourage transparent engagement with this diversity of public values to substantiate decision-making in HGGE governance.
5. In addition to formal laws and regulations, these also encompass mechanisms or protocols for self-regulation of professionals groups, professional guidelines, steering groups, etc.
6. The reason *foresight, engagement,* and *integration* are called 'capacities' is because they are about facilitating, developing and fostering *continuing* capabilities of relevant actors to perform certain tasks. Foresight, engagement, and integration are not passive sequential steps that result in societal alignment but rather have to be formally integrated in the governance ecosystem as recurrent activities. This leads to the provision of a continuous stream of information on public opinion towards policy-makers and scientists.
7. The DNA Dialogues (DNA dialogen) is a Dutch Research Council funded consortium, bringing together fourteen academic and societal organizations to discuss HGGE with the broad public. See: https://dednadialogen.nl/partners/
8. Also known as the "Oviedo Convention".
9. This focus on scientific arguments can also be observed in Dutch policy discussions regarding HGGE. For example, in a technical hearing about HGGE in the Dutch Parliament, scientists argued that the Netherlands should allow HGGE research because other countries are performing such research already and there is a risk of 'falling behind' (Staten-Generaal 2018). Another common scientific argument, is that HGGE research should primarily focus on preclinical research regarding safety and effectiveness. This argument is mentioned in the evaluation of the Embryo Act (Dondorp et al. 2021, 204), suggesting that only after safety and effectiveness have been established, policy-makers should develop the regulations that citizens desire before approving HGGE. In short, pragmatic arguments based on arguably important yet technical criteria, such as safety or effectiveness, prevail (see also van Bodegom and Vos 2017).
10. Next to general objections to embryo research and objections following from the 'incorrect understanding that creating research embryos necessarily coincides with large risks for egg cell donors' (Dondorp et al. 2021, 198).
11. These are: the DNA dialogue, a survey and focus groups about embryo research (Gouman, Vogelezang, and Verhoef 2020, Schuttelaar & Partners 2020), and viewpoints from patient organizations.
12. https://www.zonmw.nl/nl/programma/psider

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Author contributions

CRediT: **Freek H. van der Weij:** Conceptualization, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing; **Esther A.M. Bührman:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Resources, Visualization, Writing – original draft, Writing – review & editing; **Carla G. van El:** Funding acquisition, Methodology, Supervision, Writing – review & editing; **Danielle J.A.M. Arets:** Funding acquisition, Methodology, Supervision, Writing – review & editing; **James K. Timmis:** Conceptualization, Methodology, Supervision, Writing – review & editing; **Sophie J. van Baalen:** Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing.

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