



The need to set explicit goals for human germline gene editing public dialogues

Wendy P. Geuverink^{1,2} · Diewertje Houtman³ · Isabel R. A. Retel Helmrich³ · Sophie van Baalen⁴ · Britta C. van Beers⁵ · Carla G. van El^{1,6} · Lidewij Henneman^{1,2} · Michelle D. Kasprzak⁷ · Danielle Arets⁸ · Sam R. Riedijk³ · the ‘De DNA dialogen’ consortium

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Abstract

Given the potentially large ethical and societal implications of human germline gene editing (HGGE) the urgent need for public and stakeholder engagement (PSE) has been repeatedly expressed. However, the explicit goals of such PSE efforts often remain poorly defined. In this program report, we outline the goals of our Dutch project called *De DNA dialogen* (The DNA dialogues). We believe that setting explicit goals in advance is essential to enable meaningful PSE efforts. Moreover, it enables the evaluation of our engagement efforts. The following four goals, which result from intensive consultations among the transdisciplinary projects’ consortium members and based on the literature, form the foundation for how we will engage the public and stakeholders in deliberation about HGGE: 1) Enable publics and stakeholders to deliberate on “what if” questions, before considering “whether” and “how” questions regarding HGGE, 2) Investigate agreement and disagreement in values and beliefs regarding HGGE in order to agree and disagree more precisely, 3) Involve diverse publics with various perspectives, with a focus on those that are typically underrepresented in PSE, 4) Enable societally aligned policy making by providing policymakers, health care professionals and legal experts insight into how values are weighed and ascribed meaning in the context of HGGE by various publics, and how these values relate to the principles of democratic rule of law and fundamental rights. The effort to describe our goals in detail may serve as an example and can inform future initiatives striving for open science and open governance in the context of PSE.

Keywords Human Germline Gene Editing · Public Engagement · Societal Alignment · Open Science

Introduction

Human germline gene editing (HGGE) introduces heritable genetic alterations to the human germline and has the potential to impact clinical practice by providing a way to

genetically remove severe genetic conditions or modify traits in the embryos of prospective parents (Ormond et al. 2017). One of the frequently mentioned considerations regarding HGGE is that it will change the human gene pool as soon as genetically edited children grow up and reproduce as germline genetic modifications are heritable across generations. Editing the human germline raises many fundamental

Diewertje Houtman and Isabel R. A. Retel Helmrich contributed equally to this work.

✉ Sam R. Riedijk
s.riedijk@erasmusmc.nl

- 1 Department of Human Genetics, Amsterdam UMC, Location Vrije Universiteit Amsterdam, Amsterdam, the Netherlands
- 2 Amsterdam Reproduction and Development Research Institute, Amsterdam, the Netherlands
- 3 Erasmus Medical Center, Department of Clinical Genetics, Rotterdam, the Netherlands
- 4 Rathenau Institute, The Hague, the Netherlands

⁵ Faculty of Law, Department of Legal Philosophy, Vrije Universiteit, Amsterdam, the Netherlands

⁶ Amsterdam Public Health Research Institute, Amsterdam, the Netherlands

⁷ Willem de Kooning Academy, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands

⁸ Readership Journalism & Innovation, Fontys University of Applied Sciences, Tilburg, the Netherlands

questions that are not only relevant for individuals and their offspring, but also for society and even humanity (International Bioethics Committee 2015; Council of Europe 1997; Lander et al. 2019). The potentially large ethical and societal implications urge deliberation about HGGE based on input provided from the scientific community as well as from patients and the public at large (Scheufele et al. 2021; Iltis et al. 2021). The urgent need for public and stakeholder engagement (PSE) on HGGE has repeatedly been expressed by various authoritative (inter)national bodies and committees (Lander et al. 2019; WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing 2021; de Wert et al. 2018; Chan et al. 2015; Nuffield Council on Bioethics 2018; National Academy of Medicine 2020; Commissie Genetische Modificatie (COGEM) and Gezondheidsraad 2017; National Academies of Sciences 2017; Baltimore et al. 2015). The 2023 statement by the Organizing Committee of the Third International Summit on Human Genome Editing underscores that the societal discussion and policy debate is far from conclusion (<https://royalsociety.org/news/2023/03/statement-third-international-summit-human-genome-editing/>).

In the Netherlands, we have been responding to these urgent global calls for PSE about HGGE by organizing public dialogues. The current project called *De DNA dialo-gen* (The DNA dialogues; 2022–2026) follows the previous DNA dialogue project, which was conducted from 2019–2021 and engaged various publics by organizing 27 dialogues about HGGE in the Netherlands (van Baalen et al. 2021). Although this former project involved a variety of publics, some groups were not explicitly engaged. Public acceptance was mapped, as well as the main values related to HGGE that came up during dialogue (van Baalen et al. 2021; Houtman et al. 2022). The identified values were important for *acceptance* and for protection in *practical application* and *in society* (van Baalen et al. 2021). Now, more in-depth knowledge, for example about the weighing of values in the context of HGGE and how these relate to international and national legal frameworks is necessary for political deliberation with the aim of societal alignment (Ribeiro et al. 2018). In the context of our Dutch representative democracy, societal alignment means that a broad variety of perspectives in society is represented, so that governments at national and European level, as well as policy makers in professional societies, could integrate these perspectives in their policy development.

In *De DNA dialo-gen* (2022–2026) we strive to engage a broad range of publics with the specific aim to involve those typically underrepresented in PSE (Table 1). Moreover, we will go beyond arguments related to HGGE, and delve into people's understanding of these arguments, the underlying values, how these values are contextualized by individuals,

and how these values relate to existing and possible systems of governance. Based on our previous experiences with DNA dialogues, we learned that space for emotional and moral arguments is crucial in widening and deepening the dialogue around germline modification.

While there is much agreement on the importance of PSE on HGGE, there is less agreement on the goals of such PSE (Iltis et al. 2021; Scheufele et al. 2021; Baylis 2017). There are for example different perspectives on educating the public as a precondition or goal of PSE and whether PSE should strive for consensus or not (Scheufele et al. 2021; Simis et al. 2016; Baylis et al. 2020).

In *De DNA dialo-gen*, our consortium has formulated four overarching goals that form the foundation for how we will engage various publics and stakeholders on HGGE in the Netherlands (Fig. 1). By describing the four goals in this paper we aim to enable open science and more precise comparisons with other PSE projects in the future.

Goal 1: Enable publics and stakeholders to deliberate

A classic understanding of deliberation is that it is used to resolve problematic situations through the process of exchanging competing reasons, with the goal of making informed and reasoned decisions (Habermas 2001). The yield of such deliberation typically may be shaping policy or making recommendations. However, the idea that a clash of rational arguments will lead to the best outcome or decisions is criticized, especially when it comes to highly complex dilemmas involved in technological developments (Pelizzoni 2001), such as HGGE. A growing body of recent research shows that many of our rational considerations are fed and supported by our emotions and vice versa (Roeser and Pesch 2016; Roeser et al. 2020; van Doorn 2023). Therefore, a more relational approach of deliberation with more elements from dialogue theory in which inquiry dynamics such as exploring, co-creating shared meaning, sharing feelings and building understanding is needed (Escobar 2009). In our project we aim to combine the inquiry dynamics that lead to hearing a wide variety of voices, values and perspectives with the more classic advocacy dynamics of the deliberation process, such as exchanging reasons and being inclusive of all members (Scheufele et al. 2021; Schneiderhan and Khan 2008; Escobar 2011). Based on the above considerations and the various definitions of deliberation cited in the literature, we define deliberation as follows: deliberation is a multi-way communication among the public and/or stakeholders whereby a conversation starter (e.g. scenario, statement, visual, question) is presented, followed by facilitated discussion in which people are willing to engage in both emotional and rational reflection on a multifaceted

Table 1 *De DNA dialogen* project outline


De DNA dialogen 2022-2026:
Join the conversation about modifying embryo DNA

Our Dutch project called *De DNA dialogen* (2022-2026) aims to engage a broad range of publics with the specific aim to involve those typically underrepresented in public engagement.

To reach diverse publics and facilitate deliberation on HGGE we will employ **futures literacy, constructive journalism, art and design** to make conversations about HGGE more accessible, engaging and rewarding. *De DNA dialogen* will go beyond acceptability of HGGE and arguments related to HGGE and delve into underlying **values** related to HGGE. By exploring values in more depth through PSE we strive to encourage publics to ‘disagree more precisely’. The values revealed through PSE will be analysed in relation to **national and international regulations and legislation**. Gathered insights will be used to provide a roadmap for **societally aligned governance**.

We share the vision that transdisciplinary collaboration is needed to broadly engage the public and stakeholders regarding what to do or what *not* to do with HGGE in the Netherlands. We have assembled a transdisciplinary consortium with five workpackages (WPs) that will:

WP1: Prepare the organization of deliberation events and study the impact of these events, and the use of art and constructive journalism on public deliberation

WP2: Engage stakeholders and publics in deliberation and facilitate deliberation through arts

WP3: Conduct constructive journalism to connect internal and external stakeholders

WP4: Reflect on national and international regulations and legislation regarding HGGE

WP5: Provide a roadmap for societally aligned governance of potentially disruptive technologies such as HGGE

issue (here: HGGE). This requires participants’ willingness to both listen to and consider opposing viewpoints on the topic (Scheufele et al. 2021; Iltis et al. 2021; Schneiderhan and Khan 2008). When successful deliberation occurs, it is expected that the generated public insights—that might otherwise be unavailable to elected representatives or policy makers- will enrich and improve policy outcomes (Sirianni 2010).

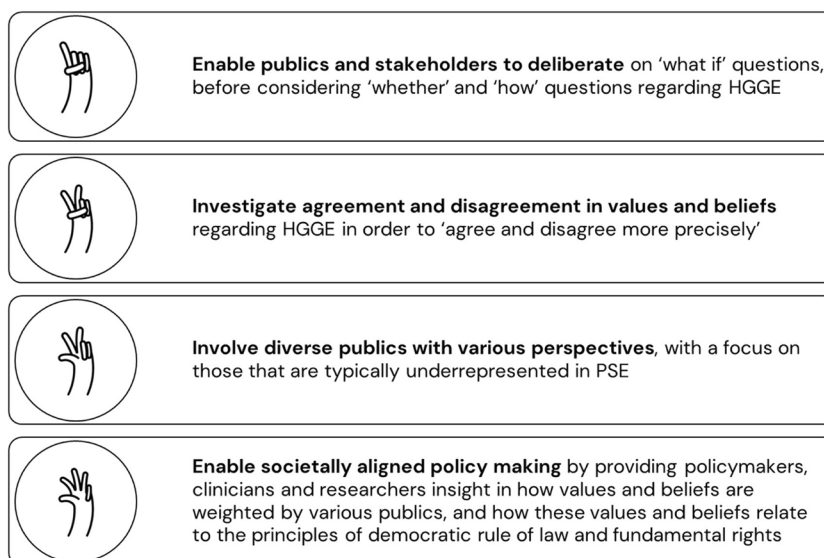
As previously described elsewhere, we recommend starting the deliberation on HGGE with “what if” questions that create time for the audience to reflect, slow down and use their imagination (Houtman et al. 2023). “What if” questions allow the audience to think about the ways HGGE could improve or problematize (their) lives and those of (their) future children, and what future scenarios would be (un)

desirable and (in)consistent with their values. Considering these future scenarios also creates space to exchange values and perspectives. The questions “whether” and “how” thereafter provide valuable insight into how practice and policy around HGGE should be organized, which will become relevant once the “what if” scenarios, of what our society may become, have been deliberated on.

Goal 2: Investigate agreement and disagreement in values and beliefs

After the first International Summit on Human Gene Editing in 2015 it was concluded that “It would be irresponsible to proceed with any clinical use of germline editing

Fig. 1 Public and Stakeholder Engagement Goals in *De DNA dialogen*



unless and until [...] there is broad societal consensus about the appropriateness of the proposed application” (<http://go.nature.com/2pwNV7w>). The call for broad societal consensus provided, at the time, the scope to ask the fundamental question of whether HGGE should be used at all or, in the absence of broad societal consensus, should not be accepted (Almeida and Ranisch 2022; Jezierska 2019; Baylis 2017; Hurlbut 2019; Andorno et al. 2020). The debate on the meaning and importance of this envisaged broad societal consensus has subsequently been conducted extensively. International reports on the future of HGGE published since 2015 have seen a shift in which the call for broad societal consensus on HGGE and the question of its use per se is no longer as loud and seems to have been replaced by a call for clear and strict regulations and for conditions and objectives under which HGGE might be acceptable (Almeida and Ranisch 2022; Van Beers 2020; Greely 2019). In *De DNA dialogen* we believe that many different voices should be included in PSE regarding HGGE and that it is still relevant to ask the question of whether or not to apply HGGE. At the same time, we do not strive for consensus in the sense of unanimity or simple majority, but rather on recognizing and clarifying value differences (Mouffe 2013). In other words, we aim to agree and disagree more precisely. It is precisely the feelings of discomfort, of "not knowing", that need to be heard (Morrison and de Saille 2019). To do so, we strive to gain insight into how values and beliefs are weighed and ascribed meaning in the context of HGGE by various publics. This is especially important in case of potentially disruptive and complex technologies such as HGGE that may have far-reaching societal implications which call for governance and regulatory structures that take into account a variety of perspectives (Scheufele et al. 2021).

Goal 3: Involve diverse publics with various perspectives

Various national and international bodies and committees emphasize the importance of involving the public in broad societal dialogue. They state that PSE should actively involve those who may (likely) be impacted (e.g., persons with a genetic disorder, their parents and families, couples at risk of having a child with a severe genetic disorder and people with reproductive stakes) and those affected by inequities (Nuffield Council on Bioethics 2018; Commissie Genetische Modificatie (COGEM) and Gezondheidsraad 2017). In *De DNA dialogen*, we work with the following definition of diversity: “Cultural differences in values, beliefs, and behaviors learned and shared by groups of interacting people defined by nationality, ethnicity, gender, age, physical characteristics, sexual orientation, economic status, education, profession, religion, organizational affiliation, and any other grouping that generates identifiable patterns” (Bennett and Bennett 2004).

PSE generally involves a relatively homogenous group of participants, namely persons that are highly educated, knowledgeable on the topic, predominantly white, affluent, and have relatively high trust in science (Humm, Schrögel, and Leßmöllmann 2020; Kennedy et al. 2018; Pandya 2012). We aim to involve diverse publics with various perspectives, and we specifically aim to engage those typically underrepresented in PSE, such as people with functional impairment or people who have low trust in science. Therefore, focused engagement efforts will be needed. Inclusivity of PSE is crucial as excluding groups or persons with their own perspectives and lived experiences means that these may not be represented. This underrepresentation of perspectives poses a threat to the development of societally aligned governance

of HGGE. To reach diverse publics and facilitate deliberation we will employ interactive art and design (i.e., fine art, theater, music, photography). Moreover, we will work with key figures in communities to teach us how our engagement efforts may feed into the motives and needs of specific communities resulting in accessible and engaging conversations about HGGE. In addition, these collaborations can establish reciprocal relationships of trust between our consortium and engaged communities, because these key figures have a close connection with the communities and share their values (e.g., a Dutch Christian patient organization). Although during the dialogue activity itself certain shared goals are required, such as listening to other perspectives and being curious, we recognize that the overarching goals that we as a consortium pursue need not be shared by our participants. Those publics that we aim to engage may not be motivated to participate in dialogue to pursue societal alignment for HGGE. For some, a motive to participate in our PSE may be to feel connected and heard, whereas others may feel rewarded if they go home with an exciting experience. We are aware that not everybody will feel gratified in a similar way from participating. Together with social partners we aim to find out about the needs and interests of the target group and align our dialogue strategies with those. In this way we aim to avoid becoming the researchers who, in the eyes of citizens, only come to get something without giving anything back.

Goal 4: Enable societally aligned policy making

Increasingly, also in PSE about HGGE, goals of science communication are moving from educating the public to consulting, involving, and even collaborating with publics (Burall 2018; Dryzek et al. 2020; Houtman, Vijlbrief, and Riedijk 2021; Andorno et al. 2020). Instead of being educated, the goal of PSE becomes to generate a shared understanding of the topic, issues, and perspectives. For PSE to be effective and meaningful it must be consequential. In other words, how do we translate the needs and values of the public into policy development? In representative democracies, as in the Netherlands and across Europe, decisions concerning the regulation of HGGE are in the hands of elected politicians. Therefore, we cannot directly feed the outcomes of the dialogues (i.e., public values) into national or international policies. Instead, we aim to support elected politicians to make careful and well-informed policy decisions. This entails more than simply “informing the policy environment” about the outcomes of the dialogues (Baylis 2019). We aim to stimulate the debate among policymakers about values related to HGGE; i.e., both public values originating from the dialogues and values originating from

their political ideologies and interests. However, policymakers will not only want to be informed about the outcomes of public dialogue on HGGE and the public values that emerge in that process but will also inevitably have to consider various possible regulatory models in order to develop policies in this field based on these outcomes and values. Our approach will therefore also provide policymakers with an overview and analysis of various regulatory models. Presenting policy makers with different options for and reflection on regulatory models for the governance of HGGE can help with finding ways to operationalize the alignment of policy, laws and regulations with the values and needs of the public.

Societal alignment will not take place in a legal vacuum. We consider the relation between law and PSE a two-way street, that is, as part of a circular dynamic: law is not only the outcome of political decision making or legal translation of policy making, but, conversely, law also feeds into decision- and policy making, for example in the form of fundamental rights and legal principles. Given the rule of law, policy making informed by the outcomes of PSE will need to be in line with fundamental rights law (Van Beers 2020; Commissie Genetische Modificatie (COGEM) and Gezondheidsraad 2017; Van Est et al. 2016) as laid down not only in the Dutch Constitution, but also in international and European human rights law. For example, how do the outcomes of PSE compare to various legal interpretations of the principle of human dignity or the right to reproduction, which both have been recognized in European human rights case law? Moreover, to contribute to policy making, it is important to examine how the values and future scenarios that emerge from PSE relate to imaginaries and values underpinning current legal approaches to HGGE (Jasanoff 2015; Klink et al. 2016). The law is after all not just a collection of commands backed up by coercion, but it also tells a certain story and offers an “imaginary” to interpret the world. Legal concepts set the stage for further debate and bring various values to expression. We refer to this as the communicative and expressive functions of the law (Klink et al. 2016; Van Beers 2015; Poort et al. 2016). In addition, various possible regulatory models need to be explored to examine which of these models can possibly do justice to the values, and future scenarios resulting from PSE. These regulatory models may include prohibitions, moratoria, professional self-regulation, regulation through an administrative agency and ‘interactive legislation’ (Van der Burg and Brom 2000).

In conclusion

De DNA dialogen, provides an opportunity to involve the public ‘to participate thoughtfully in imagining the futures we want and governing technological change accordingly’ (Jasanoff et al. 2015). Specifying our goals for PSE has

resulted in a shared understanding as well as a common language to communicate about our goals, as a consortium. This is particularly valuable within the setting of our trans-disciplinary consortium, in which essential terms may carry a different meaning. We highly recommend future initiatives striving for open science in the context of PSE about HGGE or other potentially disruptive technologies to co-create and share their common language, to make their work open access and enable comparison with similar PSE initiatives.

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Declarations

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