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Human Germ Line Gene Editing: Why Comparative, Cross-National Studies of Public Viewpoints are Important?

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Introduction

New technologies for the genetic alteration of living organisms are being developed, that can be used for heritable genetic modifications in humans. A first study that reported genetic editing in human embryos was published by researchers in China in April 2015 [1]. Subsequent calls for a global temporary moratorium on human germ line editing were rejected in an International Summit on Human Gene Editing, which was organized by the US National Academy of Sciences together with the UK Royal Academy and the Chinese Academy of Sciences in December 2015 [2]. The Summit concluded that basic and preclinical research that involves the genetic editing of human gametes and embryos should be permitted, while the clinical use of human germ line editing should temporarily be suspended, but periodically reviewed until relevant safety and efficacy issues have been resolved [2]. The suspension of the clinical use of embryo gene editing, was echoed in a decision of the US congress on December 16, 2015, which summoned a provisional ban for the US Food and Drug Administration to review or approve investigational clinical interventions that involve the genetic modification of human embryos [3]. The decision to proceed with human germ line editing for research purposes has been reconfirmed by regulatory authorities in various countries, including the UK, where the Human Embryo and Fertilization Authority has approved a license application to use gene editing in research on February 1, 2016 [4].

Human germ line gene editing research is associated with new opportunities to prevent and cure human diseases, new insights in fertility research, as well as novel understandings of the biology of human embryos and germ line cells [5]. However, the prospect of human germ line editing has also raised public controversy and given rise to widespread concerns. These range from fears regarding potential misuse, to the creation of designer babies, to the emergence of new types of social inequalities, changes in human and cultural values as well as transformations of political priorities, such as changes in health care and reproductive policies [6].

Irrespective whether these concerns are justified, it is a fact that there is a widespread lack of citizen deliberation on human germ line gene editing, and that empirical insights into the perceptions of lay people are absent [5,6]. It is currently not clear how publics in different societies view these emerging genetic technologies, what kinds of concerns and preferences people have, which kinds of moral dilemmas they expect to experience, and whether and in which ways these technologies should be used in practice. Critical appraisal and commentary of this new technology field comes at present primarily from the side of experts such as bioethicists, scientists, and policy specialists. In China, for example, where the first two studies on human embryo gene editing were published [1,7], various bioethicists and geneticists have expressed concerns on human embryo and germ line gene editing. The geneticist Professor Hongqi Wang, for example, has suggested that Chinese researchers should not conduct the basic research of gene editing in human germ cells and embryos at will, and especially not proceed with clinical research since this research field is in an extremely immature phase [8]. The bioethicist Professor Renzong Qiu has argued that at present the application of gene editing in human germ lines should be discouraged and that research that aims for human enhancement should be ruled out. According to Qiu, also the use of gene editing in non-human living organisms requires further regulation and systematic oversight [9]. Professor Xinqing Zhang, who is the second author in this paper, has cautioned that due to the lessons learned from the early development of gene therapy clinical trials and embryonic stem cell research – hype and scientific misuse of human embryo and germ line gene editing should be avoided from the beginning. China and other countries ought to establish a model regulatory framework to meet the technical and ethical demands specific to these clinical trials [10]. However, despite vital debate among scientists and bioethicists a more systematic examination of public opinions has not yet happened. This is the case in China, as in most other countries. A challenge in this regard is that many citizens and laypeople may not fully understand what gene editing is, and how its use can impact societies. Many people may simply be uninterested in this technology field and they are unlikely to follow the ethical and legal debates around it.

The creation of new spaces of deliberation and calls for public participation in political decision-making processes of new technologies have become widespread in recent years [11]. This line of thinking is reflected, for instance, in recent European Union policies, which aim to provide new opportunities for the democratization of science and politics [12]. But calls for more inclusive forms of decision-making, and the need of public consultation in the context of technology governance exist also in other societies, including in non-democratic societies like China [13] albeit to a lesser extent and within the constraints of a centralized government system. However, the methodologies and procedures that are used for public deliberation, the types of publics and stakeholders that are consulted, and the purposes of these consultations vary widely across societies [14].

Public deliberation in an interconnected global science system

In view of the fact that science is an increasingly global enterprise

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and that developments in one country influence the situation in other countries, processes of national deliberation fall increasingly short. Human germ line gene editing, for instance, does not stop at national boundaries and will have a global impact. However, the perceptions, debates and the religious, cultural, and political concepts and values through which emerging technology applications are implemented, made sense of and experienced, differ across societies. Moreover, differences in political, socio-economic and health care contexts do profoundly shape the ways in which new technologies are used: in research, medical practice, health care arrangements and commercial applications. These disparities also impact the ways in which citizens can get access to new technologies, or alternatively, whether they will be able to contest, resist or avoid technology developments such as the genetic modification of human embryos or germ lines.

Considering this multifaceted situation, more inclusive and international forms and forums of public deliberation are required. Public viewpoints are currently clearly under-represented in public debates on human germ line gene editing. However, an understanding of the opinions of lay people and citizens in different societies is crucial for political decision-making and the realization of responsible research innovation as well as international research collaborations. It is also a prerequisite for the development of technology applications that correspond closely to the actual needs, values, preferences and concerns of people. Moreover, an awareness of the perceptions of lay people can play an important role in the problematization and deconstruction of ideological or politicized discourses on the economic, scientific and medical benefits of new health care technologies, which are often biased by powerful interests and exaggerated or one-sided claims.

The need for comparative studies on public viewpoints and processes of public deliberation

This situation calls for comparative cross-country studies and the need to focus on transnational developments and debates. The comparative analysis of public viewpoints, attitudes and expectations of gene editing in different societies, and in international and transnational arenas, can contribute important insights to the ongoing public, academic and policy debates on human embryo gene modification. Such studies can generate new knowledge on the challenges of public participation in international contexts, and provide new ideas on making life science governance public, in the context of the complex global assemblages in which science and technology research is conducted today. Comparative studies on the range of attitudes and perceptions that exist among citizens and lay people in different countries can also play a crucial role in science education. They can alert researchers, policy makers, corporations and the media of the impact of religious, cultural, socio-economic and political differences, within and between countries and communities. By providing comparative insights into the spectrum of attitudes on gene editing, such studies can provide evidence of both, shared and dissimilar concerns of citizens in different countries and world regions. In doing so, they have the potential to strengthen demands for more inclusive forms of science governance and citizen participation. These types of study can employ quantitative and qualitative methodologies, or ideally a combination of both, including ethnography and participant observation, in order to grasp the conceptual, emotional and relational complexities that surround the use of human embryo and germ line gene editing technology. Another possibility is the use of digital technologies to detect and analyse emerging issues, viewpoints and controversies, and to compare these across social boundaries and borders [15].

A related field of inquiry is the comparison and analysis of the methodologies and procedures of 'public deliberation', which policy institutions or scientific and corporate stakeholders employ in different societies, and how the insights that come from these exercises are used to legitimize scientific, political and economic agendas. A crucial question is in this regard, which kinds of representations (of citizen perceptions and publics) public engagement exercises create, and in which ways these representations are used to justify divergent commercial, research or health care applications of genetically modified gametes, embryos, and germ lines. It is an important question, to understand why and how representations of publics and public opinions do often significantly differ across societies, and whether and in which ways these differences can be traced back to methodological differences and differences in the underlying interests or questions that shape processes of public deliberation in different societies and contexts.

Conclusion

Science and technology research and related real world applications are an increasingly global enterprise. Developments in one country influence the situation in other countries and the emergence of transnational market opportunities often undermines national legislations. In view of this situation, more inclusive and international forms of public deliberation are required that involve comparisons between multiple countries and groups of citizens. In currently emerging debates on human germ line gene editing, public viewpoints are currently under-represented and insufficiently explored. An understanding of the attitudes and perceptions of lay people and citizens in different countries is a crucial element for political decision-making. It forms a prerequisite for the realization of responsible research innovation and the development of technology applications that correspond to the needs, values and preferences of people in the societies in which human embryo gene editing shall one day be used and brought to the market. This situation calls for comparative cross-country studies and the need to analyze transnational developments and debates. The comparative study of public attitudes, perceptions and expectations of gene editing can generate new insights into the challenges of public participation in transnational or global contexts. These studies can also provide new ideas on making life science governance public, in the context of the complex global assemblages in which science and technology research is conducted and commercialized. Comparative studies on the range of attitudes and opinions of citizens can alert researchers, policy makers, corporations, and the media of the impact of cultural, religious, socio-economic and political differences. These insights can important insights to the ongoing public, academic and policy debates on human embryo gene editing and play a crucial role in science education.

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