

ROLES AND CHALLENGES IN PUBLIC ENGAGEMENT

ARRIGE: Association for Responsible Research and Innovation in Genome Editing

(<https://arrige.org>) Lluís Montoliu

ARRIGE is a non-for-profit association founded in France. Its scope is international with a focus in the global South, including South Asia, Africa and South America. ARRIGE promotes the responsible use of genome editing tools in biology, biomedicine and biotechnology applications. Our objectives are to: (1) promote a global governance of genome editing through a comprehensive setting for all stakeholders; (2) push forward the scientific, ethical, social, legal and political reflection in the field of genome editing; (3) foster the development of genome editing technologies within a safe and ethical framework for individuals and for our societies, and; (4) disseminate reliable information regarding genome-editing technology for experts, politicians and citizens throughout the world. ARRIGE includes more than hundred active members and nearly five hundred supporters worldwide. Launched in 2018, ARRIGE activities include: (1) seven international meetings, both in-person and online, on diverse topics beyond the clinical use of CRISPR including, for example, CRISPR in gene drive strategies and in modern livestock and agriculture practices; (2) five newsletters (publicly available on our website), including articles on human somatic and germline genome editing, public engagement, governance, and base editing; (3) three statements on the self-reported first gene-edited babies, gene drive technology, and the regulation of gene editing for crop breeding; and (4) a joint statement by ARRIGE, the Genome Writers Guild (GWG) and the Japanese Society for Genome Editing (JSGE) on the use of genome editing techniques in human embryos leading to live births.

Global Observatory for Genome Editing (<https://global-observatory.org/>) Sheila Jasanoff

Recognizing that genome editing, especially of the human germline, raises fundamental questions about the dignity and integrity of human life, the Global Observatory for Genome Editing (established in September 2020) seeks to expand the range of questions arising at the frontiers of emerging biotechnologies and to explore and encourage alternative framings and solutions. Acknowledging that this scientific and technological frontier is also a moral frontier, with implications for all life on the planet, the Observatory seeks to draw upon a wide range of human knowledge, experience and moral imaginations to foster international, interdisciplinary, and cross-sectoral dialogue. It convenes communities that have not otherwise been in a position to reflect upon each other's perspectives on issues that concern all humanity. The Observatory is particularly interested in fostering and increasing exchange between scientists who are working at the technological frontiers and communities with intuitions and understandings derived from different cultural and political histories, life experiences, and disciplinary expertise. In pursuit of such interactions, the Observatory has hosted convenings on issues such as the sources of limits on research and the comparative politics of defining where life begins. To date, the Global Observatory has hosted a number of Convenings. The 2023 Convenings include: *In Search of Limits: Human Integrity at the Frontiers of Engineering Life* (San Diego, February 2023) and *Toward Inclusion: Genome Editing and Social Justice* (London, March 2023).

Global Citizens' Assembly on Genome Editing (<https://www.globalca.org/>)

Simon Niemeyer

The central goal of the Global Citizens' Assembly on Genome Editing (GCA) project is to contribute to meaningful public engagement at the global level, enacting what will be the world's first in-person Global Citizens' Assembly. In doing so, it will address numerous calls by the World Health Organization, national scientific academies, and others to engage the public on key questions about genome editing, especially at the crucial global level—questions that have yet to be translated into practical designs. Importantly, GCA will feature centrally in a three-part 'deliberative documentary' film series about genome editing and how citizens of the world can weigh in on principles for its use. The series will document the citizens' voyage of discovery, and help foster discourse in the wider public sphere. The Assembly's conclusions will also be amplified in a social media campaign, and mainstream media coverage.

The GCA will bring together upward of 100 ordinary people from around the world using an innovative '3D inclusion' process that is developmental (in making use of prior participation in a national-level deliberative event), demographic (in representing geographic origin and other social characteristics), and discursive (in capturing the relevant variety of opinions and perspectives). The Assembly will bring together these people to address the key ethical and practical issues, and develop global principles covering use of HGE. With the aid of simultaneous translation and professional facilitation, participants will meet in a week of deliberation, but also be engaged in online interaction both before and after the main event. They will have access to scientists at the forefront of genomic research, as well as ethicists and stakeholders. This will be a practical exercise in deliberative bioethics.

Sama Resource Group for Women and Health (<https://samawomenshealth.in/>) Sarojini Nadimpally

Sama is a feminist, public health, civil society organisation based out of Delhi, India. Sama works at the intersection of public health, social justice, gender equality and human rights. Sama is committed to challenging inequalities that fundamentally determine the distribution of healthcare, with a particular focus on the social determinants of health. Sama uses a range of strategies including research, policy advocacy, knowledge production, building partnerships and coalitions. Sama's decade-long work in the areas of reproductive and biotechnologies, health care technologies (including vaccines), ethics and clinical trials has contributed substantially to meaningful research, policy advocacy and regulatory frameworks. Sama was involved in developing the *National Ethical Guidelines for Biomedical and Health Research Involving Human Participants* of the Indian Council for Medical Research (ICMR). Sama co-organised the 14th World Bioethics Congress in December 2017 with the Forum for Medical Ethics Society (FMES). Sama's engagement with (Human) Genome Editing is informed by this vision and placed within the larger repository of our work on health technologies. Sama participated in the Symposium on Ethical and Scientific Issues of Gene Editing Using CRISPR-Cas9 Technology organised by the ICMR and the Department of Biotechnology, with the aim of fostering global, responsible, and ethical research. With the growth in the intercalation of technology and health, we are keen to form a regional and global solidarity forum to increase engagement with the ethics, equity, and social justice paradigms implicated in human genome editing research. Sama's advocacy aims to ensure ethical, equitable, intersectional and inclusive science, technology and health research.