Human Genome Center

Department of Public Policy

公共政策研究分野

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The Department of Public Policy contributes to accomplishment of the following major missions: research ethics consultation to help scientists to comply with ethical guidelines and build public trust; public policy science studies of translational research and its societal impact; and promotion of patient and public involvement/ engagement in research and health care. Through qualitative and quantitative social science studies and policy analysis, we facilitate discussion of the challenges posed by the advances in medical science.

1. (Not So) Lost in Translation: Considering the GA4GH Diversity in Datasets Policy in the Japanese Context

The genomics community has long acknowledged the lack of diversity in datasets used for research, prompting various stakeholders to confront this issue. In response, the Global Alliance for Genomics and Health (GA4GH) formulated a policy framework that recognizes the multiplicity of perspectives on diversity and proposed a systemic approach for more optimal data diversity. Given the importance of the research context, assessing this policy's applicability within countries where diversity is less discussed is important. This study investigated the feasibility of implementing the GA4GH policy in Japan, a nation with a smaller genetic diversity than many Western countries. As the proportion of East Asian genomic research is limited internationally, focusing on the Japanese genome contributes to enhancing diversity. Meanwhile, labelling findings as "Japanese" can inadvertently reinforce perceptions of homogeneity and overlook ethnic minorities. Regions and socioeconomic status are also recognized as substantial factors of diversity within academia, yet concerns persist among the public regarding the heritability of stigmatized conditions. Social inclusion of sexual minorities has begun in Japan, but research surveys generally still use binary sex and gender categories, which underscores the need for additional variables. This study found that both academia and the public need to confront the overemphasis on homogeneity within Japanese society and hesitancy in addressing genetic factors. By doing so, more inclusive and diverse datasets can advance the field both ethically and scientifically. Perhaps the most important impact of the GA4GH policy will be to draw greater attention to the complex diversity challenges ahead in Japan.

2. Attitudes of patients with IVF/ICSI toward human embryo in vitro culture beyond 14 days

When the International Society for Stem Cell Research revised its 2021 guidelines, it reversed its ban on the in vitro culture of human embryos beyond 14 days. However, despite widespread recognition of the importance of public debate on embryo research, it remains unclear how patients who have undergone in vitro fertilization (IVF) and/or intracytoplasmic sperm injection (ICSI) perceive this change in the guidelines. Three focus group interviews were conducted with IVF/ICSI patients to understand their opinions on extending the in vitro culture of human embryos beyond 14 days. Thematic analysis revealed a primarily favorable attitude toward the extension of in vitro embryo culture, identifying six reasons for this positive perspective. However, two reasons for negative attitudes were identified, along with some concerns that need to be addressed. To facilitate an open discussion, the following suggestions were made to the government and scientific community. The government and scientific community should provide sufficient knowledge to IVF/ICSI patients about research before discussions. It's important to consider diverse views on embryo models, including distrust and resistance. Ensuring IVF/ICSI patients' psychological safety is essential. "Public conversations" with citizens, including IVF/ICSI patients, should be promoted, and their opinions should be considered as part of a broader public spectrum.

3. Opinions on research involving human embryo models by researchers and the general public

Rules and ethical considerations regarding research on embryo models have been debated across numerous countries. In this paper, we provide insights from our attitude survey conducted among Japanese researchers, including members of the Japanese Society for Regenerative Medicine, and among the general public residing in Japan, the US, the UK, Canada, and Australia. Our survey revealed that many researchers expressed the need for clear guidelines for embryo model research. Furthermore, a minority but significant portion of the general public in each country expressed opposition to research on embryo models but did not oppose research involving real embryos.

Publication list

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