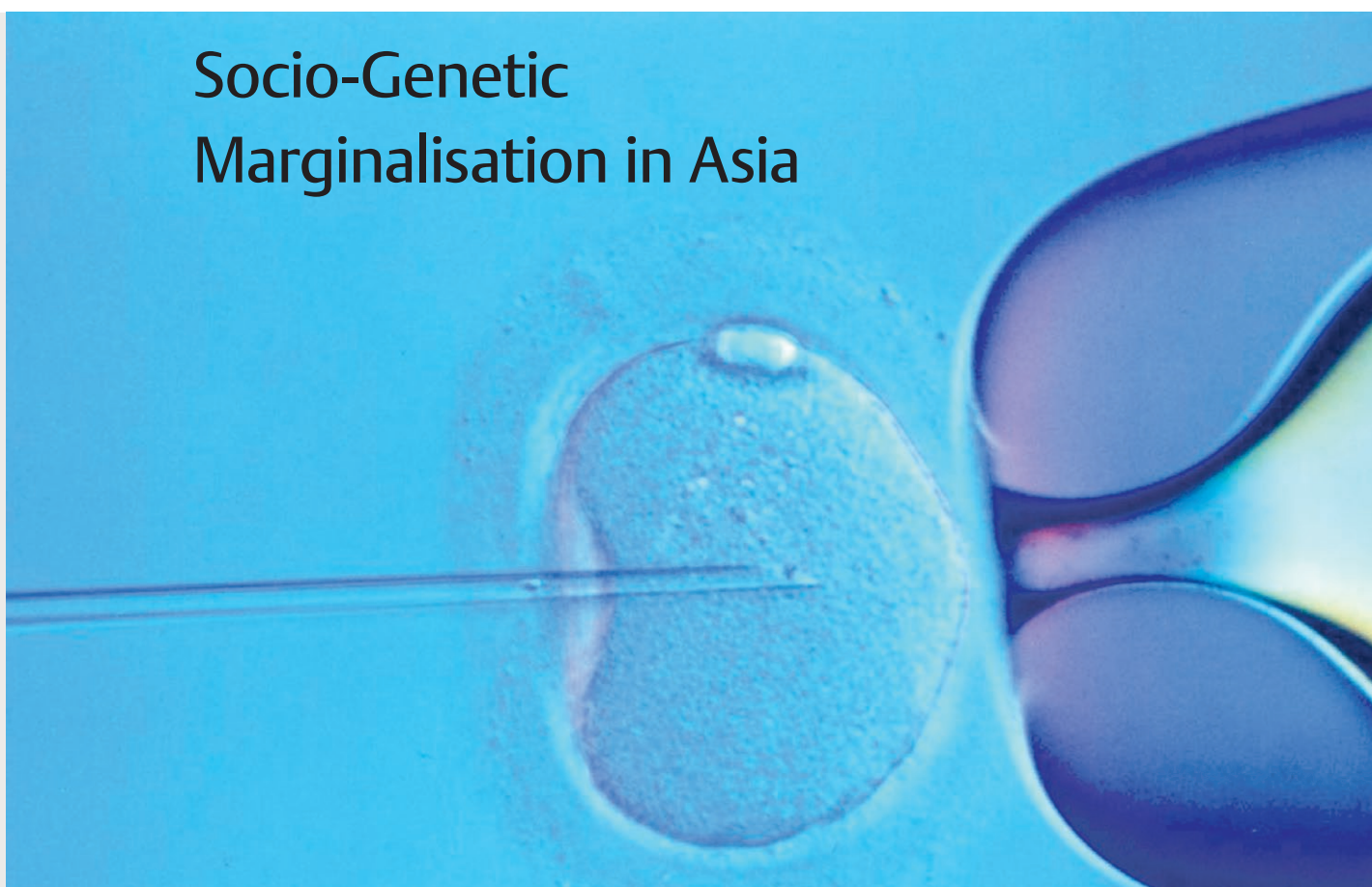


## Socio-Genetic Marginalisation in Asia



### Regulatory governance under institutional void

This programme studies the role of certain actors in fulfilling regulatory functions in the absence of either public institutions or market mechanisms, i.e., under the situation of institutional void. These actors, either public offices performing market functions or market players undertaking regulatory responsibilities, transcend the conventional boundary between public-private and state-market. The programme set to understand under what circumstances and under which forms of governance will institutional void be filled by what type of actors.

### Partnerships and events

The Centre encourages joint research and cross-country cooperation in its research activities. So far it has collaborated with a number of institutions in its research undertakings.

These institutions include:

- Clingendael Institute (the Hague);
- Centre d'études de l'Asie du Sed/EHESS (Paris);
- Erasmus School of History, Culture and Communication (Rotterdam);
- NUS Centre for Governance, Institutions and Organizations (Singapore);
- Tsinghua Center for Industrial Development and Environmental Governance (Beijing);
- Rotterdam School of Management (Rotterdam);
- University of Macau (China).

During the past few years, a number of international workshops and symposiums have been organized by the Centre. Participants from different continents have taken part in the events. As stated above, the workshops were organized around interlocking themes that allow for the accumulation of knowledge and the deepening of research dialogues. These workshops include:

- International Workshop on 'Institutional Voids during State Rescaling', Rotterdam, 6 May 2013.
- International Workshop on 'State Rescaling and Restructuring in Comparative Perspective', Leiden, 3-4 December 2012.
- International Symposium on 'Institutional Voids and the Governance of Developing Economies', Rotterdam, 16 May 2011.
- Young Scholars Workshop on 'Changing Governance in Asia', Leiden, 26-27 November 2009.
- International Symposium on 'Rent Seeking and Industrial Development in China', Beijing, 15-16 May 2009.

In addition to research workshops, the Centre also runs regular seminar series. The first seminar series on 'The State and Economic Development in Asia and Europe' took place in 2011. Another seminar series on 'Subnational and Transnational Actors in a Globalizing World' was organized in 2012. Both series were well attended by government officials, diplomats, business leaders, social activists, and researchers. They served as important forums of exchange between the public and private sectors with regard to issues of regulation and governance.

### Edited book series

Finally, the Centre collaborates with NIAS Press (Copenhagen) in disseminating the research findings by editing the book series on 'Governance in Asia'. The book series explores the problem of governance from an Asian perspective, and encourages studies that are sensitive to the autochthon and hybridity of Asian history and development, and which locate the issue of governance within specific meanings of rule and order, structures of political authority, and mobilization of institutional resources distinctive to the Asian context. The series publishes well-researched books that have the cumulative effect of developing theories of governance pertinent to Asian realities. Information about the series can be found in the website: [www.niaspress.dk](http://www.niaspress.dk)

The Centre is headed by Tak-Wing Ngo, IIAS Professor of Asian History at Erasmus University Rotterdam and Professor of Political Science at the University of Macau. Updates about the Centre can be found at: <http://crg.iias.asia>

ASIA IS A FORCE TO BE RECKONED WITH when it comes to research in the life sciences. It plays a major role both in shaping international research practices and in the formulation of bioethical research regulations in the field of biomedical research and research applications, including stem cell research, genetic testing and screening, reproductive technologies and the banking of biological materials. Not only wealthy welfare societies such as Japan and Singapore, but also large developing countries such as China and India, are strong global competitors at the forefront of biomedical research and biotech applications. These new fields of research, on the one hand, promise to yield revolutionary technologies and biomedical knowledge that could enhance the health and welfare of large patient populations, including diabetes, muscular dystrophy, Parkinson's and Alzheimer's. On the other hand, bioethical concerns have come about due to the novel and global nature of life sciences and the application of resultant technologies in some regions where even the most basic healthcare is poor.

Between 2004 and 2009, there was a large scaled research group entitled 'Socio-Genetic Marginalisation in Asia Programme' funded by the Netherlands Organisation for Scientific Research (NWO). This team was led by Professor Margaret Sleeboom-Faulkner and included three post-doc researchers and Ph.D. students. The team had the three countries India, Japan and China in their scopes. It studied socio-political implications and practices of the development and application of the new biomedical and genetic technologies in Asian religious and secular cultures. It aimed to generate insight into the ways in which the use of, and monopoly over, genetic information shapes and influences population policies, environmental ethics and biomedical and agricultural practices in various cultures.

I was the post-doc researcher looking at Japan, mainly researching into reproductive genetic technologies. How do individuals decide whether or not to use these technologies? What impact do consequences of using such technologies have for an individual's life? How are socio-cultural factors related to these policies, regulations, prices and more? My field research concerned foetus disabilities, and decision-making with regards to termination and genetic testing. I talked with women undergoing infertility treatment, suffering from infertility issues, and those trying to decide whether or not to donate or discard cryo-preserved embryos. Among all, the most important finding is that at all levels, reality does not go as theory teaches us. For example, the principle of self-determination is held high in the field of medicine and bioethics. However, the empirical research, actual conversations between patients and doctors at maternity clinics, taught me that reality does not often allow for patients to practise self-determination. The reality is a lack of time in the diagnosis room, unequal power relations between doctors and patients, as well as an incredible lack of medical knowledge among patients themselves (Kato 2007). Another example is, contrary to a widely held belief that an embryo carries a lighter ethical value of life than those who are already born, or even a foetus, an embryo possesses serious value and meaning for women without children undergoing infertility treatment (Kato and Sleeboom-Faulkner 2011). The value and meaning of an embryo is closely related to cultural concepts of life, which can be understood solely

by talking to those directly concerned, and observing their decision-making regarding what to do with cryo-reserved embryos. Moreover, we found out that value and meaning associated to an embryo is not fixed, but alters in the course of the infertility treatment. We concluded that decision-making (whether to discard or donate embryos 'in-surplus') is related to the ethics of motherhood in Japan. But then, why are all these women's perceptions not being heard by society? Another article analyses women's invisible presence in the process of infertility treatment, critically drawing on Marxist feminist theories, which enabled discussions on the production of embryos and ova, reproduction and ownership and gender (Kato and Sleeboom-Faulkner 2013). One of many important conclusions is that infertility problems are not solely an issue of reproduction, but are deeply rooted in problematic gender relations in society.

The team published extensively in international peer-reviewed academic journals. At present, Professor Sleeboom-Faulkner is publishing the book, *Global morality and life science practices in Asia: Assemblages of Life*, on the final comparisons of findings from this research programme, cross-referencing the cases of China, Japan and India (forthcoming in 2014, Palgrave MacMillan). Having had the privilege to think of genetics and society, genetics and human life before birth, during life and after death, I am now developing the direction of my further research. My interests concern the ways in which nationalism resides in the body, how the genealogy of a population group is practiced in the field of medicine, and international movements concerning bodily parts (e.g., reproductive medical tourism in Asia).

Kato, M. 2007. 'Silence between patients and doctors: the issue of self-determination and amniocentesis in Japan', *Genomics, Society and Policy*. 3(3): 28-41.

Kato, M. and M. Sleeboom-Faulkner. 2011. 'Meanings of the embryo in Japan: Narratives of IVF experience and embryo ownership', *Sociology of Health & Illness*. 33(3): 434-447.

Kato, M. and M. Sleeboom-Faulkner. 2013. 'Ova collection in Japan - Making visible women's experience in male spaces', *Gender, Place and Culture*. 20(6): 737-753.

**Masae Kato was an IIAS research fellow from 2005-2009, during which time she conducted a comparative study on socio-genetic marginalization: Japan in 'Asia' in relation to the 'West' as a reference group. She is the author of: *Women's Rights?: The Politics of Eugenic Abortion in Modern Japan*. Amsterdam: Amsterdam University Press (2009). Currently Masae is involved with the research project 'Dutch-ness in genes and genealogy: following genetic diversity around science and society'. This project is based at the University of Amsterdam ([m.kato@iias.nl](mailto:m.kato@iias.nl))**

### Notes

- 1 This opening paragraph is taken from Margaret Sleeboom-Faulkner's introduction to The Focus section in The Newsletter issue #52 (Winter 2009), entitled "Genomics in Asia"