
Democratic public involvement and social license: Building legitimacy for genomics research in Singapore

Hui Jin Toh

Research Associate / PhD Student
Centre for Biomedical Ethics
National University of Singapore

Genomics research is expanding rapidly, with significant investment in national initiatives worldwide.



Population-scale biobanks

National initiatives collecting genomic data from millions; Singapore's PRECISE aims to sequence 10% of residents' genomes.

Precision medicine

Tailoring treatments to genetic profiles; integrating genomics into routine clinical care and prevention

Reproductive genomics

Carrier screening, prenatal testing, and embryo selection expanding reproductive choices and creating new dilemmas

Ethical implications for individuals, families, and communities

Privacy

Genetic data reveals sensitive information about health risks, ancestry, and family relationships.

Discrimination

Risks of genetic discrimination in insurance, employment, and social contexts

Identity

Findings may challenge personal identity, family narratives, and cultural belonging.

Equity

Benefits and burdens may be distributed unequally across communities.

THE GOVERNANCE CHALLENGE

- Genomics research involves value-laden decisions that extend beyond scientific expertise.
 - E.g. How should we balance reproductive autonomy with public health goals?

RESEARCH GAP

- Limited understanding of how public involvement and engagement (PIE) contribute to legitimacy and public trust in genomics research.
- How should research institutions earn and maintain public trust and acceptance for genomics research that involves profound ethical implications?

This research examines how the following two concepts relate to each other.

CONCEPT 1

Public Involvement & Engagement (PIE) in health research

Practices that facilitate collaboration between researchers and members of the public to co-design research.

Key features:

- Aims to involve public members in all stages of research such as planning, design, analysis, and dissemination
- Increasingly mandated by research funders and undertaken in health research
- Lacks consensus on precise meaning or ethical justifications



CONCEPT 2

Social License to Operate (SLO) in health research

The public's acceptance and trust in research activities— an implied permission earned through ongoing public engagement

Key features:

- Extends beyond regulatory compliance
- Exists on a continuum of acceptance
- Requires ongoing demonstration of trustworthiness

Public Involvement & Engagement (PIE)

TWO JUSTIFICATIONS

DEMOCRATIC

Those affected by research have inherent right to influence it.

PRAGMATIC

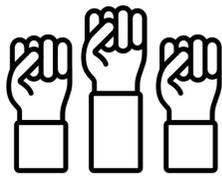
PIE improves research through unique perspectives.

These two justifications have different implications for how we *design* and *evaluate* public involvement—and, I will argue, for which of this type of involvement can *sustain* social license over time.

Democratic justification for public involvement

Grounded in deliberative democracy: Legitimacy derives from informed discussion and reflection among those affected, providing a procedurally fair process for resolving competing values.

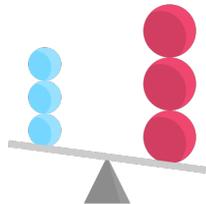
CORE VALUES



Democratic representation



Accountability



Redressing power asymmetry between experts and public



Intrinsic value of involvement (not just for outcomes)

IMPLEMENTATION CHALLENGES

- Slower and more resource-intensive than expert-led approaches
- Tokenistic engagement (e.g. use of public input to legitimize predetermined decisions)
- How to ensure genuine representativeness of diverse publics

Pragmatic justification for public involvement

An outcome-oriented perspective: values public involvement primarily for improving research outcomes through inclusion of unique perspectives

PRIMARY AIMS

- **Improve research quality** (Public provides valuable input that researchers might miss.)
- **Risk management** (Minimize public backlash)
- **Identify controversies early** (Address concerns before they escalate)

CONCERNS

- Treating public involvement as merely instrumental risks reducing it to a **public relations tool**.
- Risks **tokenistic practices** that undermine legitimacy
- **Neglects the rights of research subjects** to have meaningful input into decisions affecting them

Conditions for social license to operate

Based on Carter et al. (2015), the three conditions for building social license in data-intensive research are:

Reciprocity

Shift from one-way communication to genuine co-creation and public engagement throughout the research process

Protection against exploitation

Safeguard participant autonomy; ensure those involved maintain control and are not disadvantaged

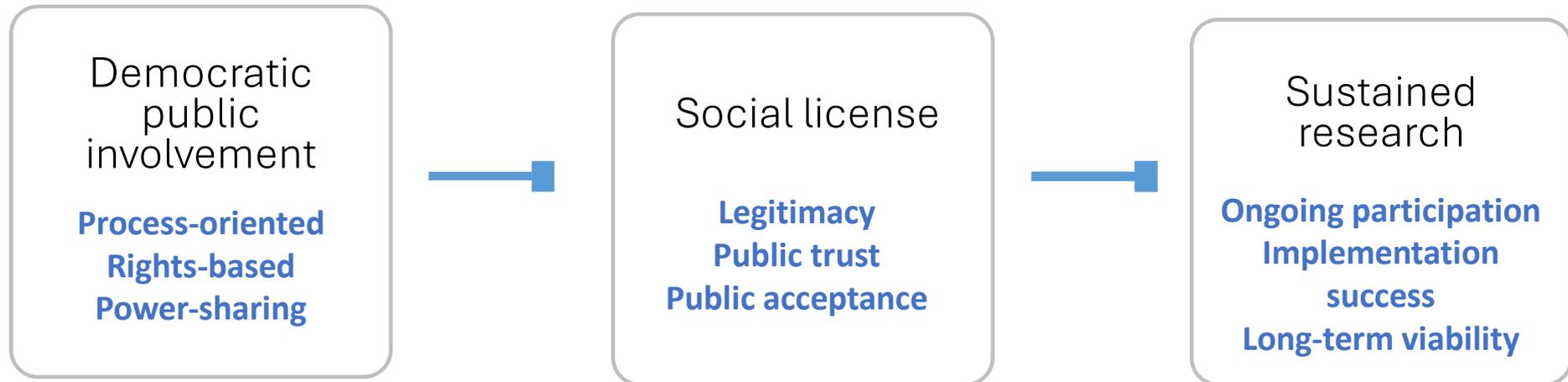
Societal benefits

Delivery of clear benefits to society, supported by robust governance frameworks

Reference: Carter P, Laurie GT, Dixon-Woods M. The social licence for research: why *care.data* ran into trouble. *Journal of Medical Ethics* 2015;**41**:404-409.

The conceptual relationship

The democratic justification for public involvement aligns more strongly with the conditions necessary for sustaining social license in genomics research.



Both democratic public involvement & social license focus on:

01 Incorporating diverse perspectives
Prioritize broader societal values over narrow scientific aims

02 Quality of engagement
Emphasis on genuine participation

03 Responsiveness
Meaningful engagement with public values through transparent processes

- **Pragmatic public involvement** fulfils one condition of social license: **societal benefits** (through improved research outcomes).
- Frith (2023): **Pragmatic benefits** such as improved research quality **are most effectively achieved by democratising health research** and prioritising deliberative quality through inclusion of diverse perspectives.

Reference: Lucy Frith, Democratic Justifications for Patient Public Involvement and Engagement in Health Research: An Exploration of the Theoretical Debates and Practical Challenges, *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, Volume 48, Issue 4, August 2023, Pages 400–412, <https://doi.org/10.1093/jmp/jhad024>

THE SINGAPORE CONTEXT

Governance model

- “Managed” democracy with strong centralized government
- Emphasis on consultation over contestation
- Competitive elections with consultative mechanisms

Genomics research investment

- Major initiatives: PRECISE (Precision Health Research), ACTRIS (cell/gene therapies)
- Genomics research identified as strategic focus

Socio-cultural context

- Multicultural society (Chinese, Malay, Indian)
- Communitarian values
- Cultural emphasis on harmony and deference to expertise
- High institutional trust

Even in high-trust contexts like Singapore, genomics research presents unique challenges for sustaining social license.

Complex value trade-offs	Varying community impacts	Intergenerational implications	Data governance concerns
Decisions about which conditions warrant intervention involve values about what lives are worth living—cannot be resolved by expertise alone.	Genetic risks and cultural attitudes toward reproduction vary across Singapore's ethnic communities	Decisions shape reproductive options for future generations—profound choices requiring broader societal deliberation	Trust varies by institutional context; genomics involves government, commercial, and international actors

RESEARCH QUESTION

Given the preliminary conceptual analysis suggesting democratic public involvement may align more closely with social license conditions than pragmatic public involvement, how can this theoretical relationship be substantiated and operationalized for genomics research governance in Singapore?

Sub-aim 1:

Theoretical development

Develop and defend the proposition that democratic public involvement provides stronger foundations for social license through normative analysis

Sub-aim 2:

Empirical research

Examine stakeholder perspectives on how democratic PIE can be operationalized in Singapore's context

Sub-aim 3:

Framework development

Propose a context-sensitive approach for PIE implementation in Singapore where feasible and beneficial

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By examining Singapore as a case study, it develops a culturally-adapted framework for operationalizing democratic principles in non-Western contexts

Hui Jin Toh - Centre for Biomedical Ethics, NUS