

An Exploration of People
Centred Governance
Mechanisms for Biobanking and
Genetic Research in the Indian
Context

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Investigators and Study Details

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Background

- Growing interest in biobanking and genetic research in India [1].
- Ethical issues in biobanking and genetic research impact its success and sustainability [2,3].
- Public and community engagement can ensure the maintenance of ethical protocol in the conduct of science and enable sustenance of research over the long term [4,5].

Study Aim

- Develop a people-centred framework for the governance of biobanks involved in genetic research in India, through engagement with the public and other key stakeholders.

Study Design

Sample (Purposive)

Potential influencers of public perceptions

Key stakeholders in biobanking and genetic research

Methods (Qualitative)

Data Collection: **Focus Group Discussions** (FGDs) and **In-depth Interviews** (IDIs) with potential influencers of public perceptions and key stakeholders respectively.

Data Analysis: **Thematic analysis** of transcripts using a combination of inductive and deductive coding to identify patterns emerging from the data using NVIVO and R software.

Overview of Participants

Focus Group Participants

	Number (M/F)	Occupation / key area of expertise	Age range
01	9 (7/2)	Public policy proponents	34-80 yrs
02	7 (2/4)	Social activists	24-66 yrs
03	8 (0/8)	Communications practitioners	25-44 yrs
04	6 (5/1)	Legal professionals - Data protection specialists	24-49 yrs
05	6 (1/5)	Students - Masters and PhD Scholars	25-39 yrs
06	8 (4/4)	Patient interest organisation members	25-48 yrs
44 (19/24)		TOTAL NUMBER, AGE RANGE	24-80

Interview Participants

IDI01	44 yrs	Female	Cancer genomics (breast cancer) researcher
IDI 02	33 yrs	Male	Cancer genomics researcher
IDI 03	46 yrs	Male	Biobank manager / immunology -infectious diseases researcher / clinician
IDI 04	30 yrs	Female	Rare disease patient
IDI 05	32 yrs	Female	Population geneticist
IDI 06	54 yrs	Female	Genetic counsellor
IDI 07	68 yrs	Female	Clinician / IEC member
07 (02/05)		TOTAL NUMBER (M/F)	

Results

1. Perceptions of biobanking and genetic research
2. Concerns about biobanking and genetic research
3. Expectations from biobanking and genetic research
4. Ideas towards biobanking and genetic research governance

Framework for People-Centred Governance			
Engagement	Experiences	Values	Expectations
	Curiosity Uncertainty Discrimination Exploitation	Trust Transparency Respect Dignity	Individual benefit Protections Public good Scientific progress
	Negotiating Limits		
	Rights and Restrictions (<i>data access and use</i>)		
	Agency and Accountability (<i>redressal mechanisms</i>)		
	Roles and Responsibilities (<i>inclusive oversight</i>)		
	Openness and Outcomes (<i>sharing study findings</i>)		

Conclusions

1. Engagement facilitates negotiation and enables participants to become partners in biobanking and genetic research.
2. Negotiation is the process through which scientific principles and societal values converge at an equilibrium of governance.
3. Engagement enhances public trust and ensures the sustainability of biobanking and genetic research in the long term. Therefore, it should not be seen as an obstacle.

Related Publications

1. Barbosa S, Paré Toé L, Thizy D, et al.: **Engagement and social acceptance in genome editing for human benefit: Reflections on research and practice in a global context** [version 1; peer review: 1 approved]. Wellcome Open Res. 2020; 5: 244.
2. Warriar P, Ho CWL, Bull S et al. **Engaging publics in biobanking and genetic research governance - a literature review towards informing practice in India** [version 2; peer review: 1 approved]. Wellcome Open Res 2021, 6:5

References

1. Chakrabarty S, Kabekkodu SP, Brand A, et al.: Perspectives on Translational Genomics and Public Health in India. *Public Health Genomics*. 2016; 19(2): 61–8.
2. Vaz M, Vaz M, Srinivasan K: Ethical challenges in biobanking: moving the agenda forward in India. *Indian J Med Ethics*. 2014; 11(2): 79–88.
3. Vaz M, Vaz M, Srinivasan K: Listening to the voices of the general public in India on biomedical research -- an exploratory study. *Indian J Med Ethics*. 2015; 12(2): 68–77.
4. Domaradzki J, Pawlikowski J: Public Attitudes toward Biobanking of Human Biological Material for Research Purposes: A Literature Review. *Int J Environ Res Public Health*. 2019; 16(12): 2209.
5. Lemke AA, Harris-Wai JN: Stakeholder engagement in policy development: challenges and opportunities for human genomics. *Genet Med*. 2015; 17(12): 949–57.