**How do Ethics Committee members and Medical Researchers view public engagement in the ethical conduct of biobanking research? Perspectives from India**

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SUPPLEMENTARY TABLES

Data on ‘public perceptions’ of the ethical issues in biobanking research were sourced from the following studies which were from different countries and used different types of methodology. The table below provides the sources:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Country→**  **Methodology↓** | **N. America (US, Canada)** | **Europe (including UK)** | **Australia/**  **New Zealand** | **Asia / Africa** |
| **Qualitative** (Focus Groups/ In-depth Interviews)  Public Deliberation | Simon CM et al 2011, Iowa, USA), Luque et al 2012,Florida, USA, Reddy DS, 2013, USA, Tauali`i, M 2014 – Hawaii.  O’Doherty et al 2012- BC Canada(21)  Bombard et al 2013 - Ontario, Canada(22) | Haddow 2007, Scotland, UK, Levitt, Weldon 2005, Tutton 2007 UK | Scott et al 2005 (New Zealand)  Molster et al 2012 (Perth, W. Australia) | Asai et al Igbe & Adebamowo, 2012 (Nigeria), Hate K et al 2015 (India) Vaz et al 2015 (India) |
| **Quantitative** (Surveys – online, face to face) | Kaufman et al 2009, (USA), Master et al, 2013 (Ontario, Canada) Page et al 2016 (Alberta, Canada), Erwin D et al (NY, USA, 2013) | Goodson & Vernon 2004 (UK); Hoeyer et al 2004, Johnson et al 2008 (Sweden) Lewis et al 2013 (mixed methods –pan UK) |  | Ahram et al, 2013 (Jordan) Ahram et al, 2014 (Jordan) |
| **Triangulation** (studies comparing multiple perspectives including multiple studies such as reviews) | Goddard 2007  Virani, Longstaff 2015 (BC, Canada) | Hoyer K, 2010 (Denmark)  Machado, Silva 2015 (Portugal)  D’Abramo et al 2015 (Germany)  Tupsela et al 2016 (Denmark) |  | Gottweis et al 2011 (Korea, China, across the word) |

Table \*: Studies reviewed on public perceptions of biobanks / biobanking research

**Meta themes towards a new construct for public engagement**

The meta themes and unified concepts that we see emerging from the primary data are a dynamic movement from specific issues of biobanking to larger ethical premises which constitutes the need for public engagement. Table \* below shows this as a linear progression.

|  |  |  |  |
| --- | --- | --- | --- |
| **Theme** | **Key Public Perception** | **Key MR / EC Perception** | **Meta Theme** |
| 1. Expectations of Biobanking Research | Societal Benefit – individual Therapeutic benefit | Scientific Benefit – Individual/ Private party benefit | Move to ‘Two Way Altruism’ – Public contributes to science and science gives back to public in tangible ways. |
| 1. Risks / Fears | Overcome by transparency and credibility of the researcher and institution | Adhering to regulations, Paternalistic approach to fears | Accountability of researchers to the public |
| 1. Autonomy and Consent | Willing to give up control if motives of the researcher, the implications of the research, and the impact on the greater good are communicated over time. | Driven by principlist, liberalistic, individualistic regulations | Consultative processes and open, ongoing communication, listening to participants and the public. |
| 1. Public Engagement | Sharing of new information, new knowledge back to the public; Have a say in the governance of the biobank, and in policy implications of results. | Limited role. Need public to be educated and aware of research, the purpose of their involvement. Media can be involved. | Public – Researcher –Institution – ECs joint stakeholders. |

Table \*: Meta themes towards a new construct for public engagement

This progression constitutes:

* A moving away from an individual focus to a focus on the ‘collective’, the family, the community;
* Informed consent not from the limited lens of individual autonomy but from the direction of researcher accountability;
* A move from a limited, positivist set of ethics rules to an openness and transparency of research expectations, purpose, limitations and implications;
* A consultative process of public opinion being heard and not just being informed.

The overarching value being propounded is one of ‘trustworthiness’. This has been diagrammatically represented in Figure 1.



Figure 1: Ethical premises for public engagement in biomedical research