Extending the Utility of Biobanks:
Results from the 2024 Indiana Public Deliberation
Deliberative conclusions, reasons and governance

Australalasian Association of Bioethics & Health Law
1-4 December, 2024
University of Sydney

Michael Burgess
Peter Schwartz
Tom Doyle
Kieran O'Doherty

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Indiana University Research Team

- **Peter H. Schwartz**, MD, PhD: *Director*, IU Center for Bioethics;

- **Tom Doyle**, PhD: Post-doctoral fellow

- **Nic Oliver**, MA: Program manager
- **Karen Schmidt**, RN: Study coordinator

Deliberation consultants

- **Mike Burgess**, PhD, Professor University of British Columbia
- **Kieran O'Doherty**, PhD, Professor of Psychology, University of Guelph
- **Colene Bentley**, PhD, BC Cancer Foundation (large group facilitator)

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Collaborators, Funding

- **Funding**: Indiana Clinical & Translational Sciences Institute
  - NIH / NCATS UM1TR004402, PIs: Sharon Moe, Sarah Wiehe, George Wodicka
- **CTSI Co-Investigators**: C Halverson, M Ott, MA; E Cheng
- **Partner Biobanks**: Indiana Biobank, Komen Tissue Bank.
- **Research Assistants**: K Kleiman, J Kline, S Vershaw

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Biobanks

Biobanking is ubiquitous

- many large, formalized biobanks around the world
- non-profit and for-profit organizations
- UK Biobank: 500,000 participants (2006-2010),
- All of Us: 800,000 participants currently

Indiana

- Indiana Biobank: over 50,000 samples linked to EHRs
- Komen Tissue Bank: normal breast tissue

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Policy Ethics Issues

Electronic Health Records

- samples linked to electronic health records (EHRs)
- may access or collect information repeatedly.

Genetic sequencing

- May be genetically sequenced, with many potential benefits for research.

Public-Private partnerships

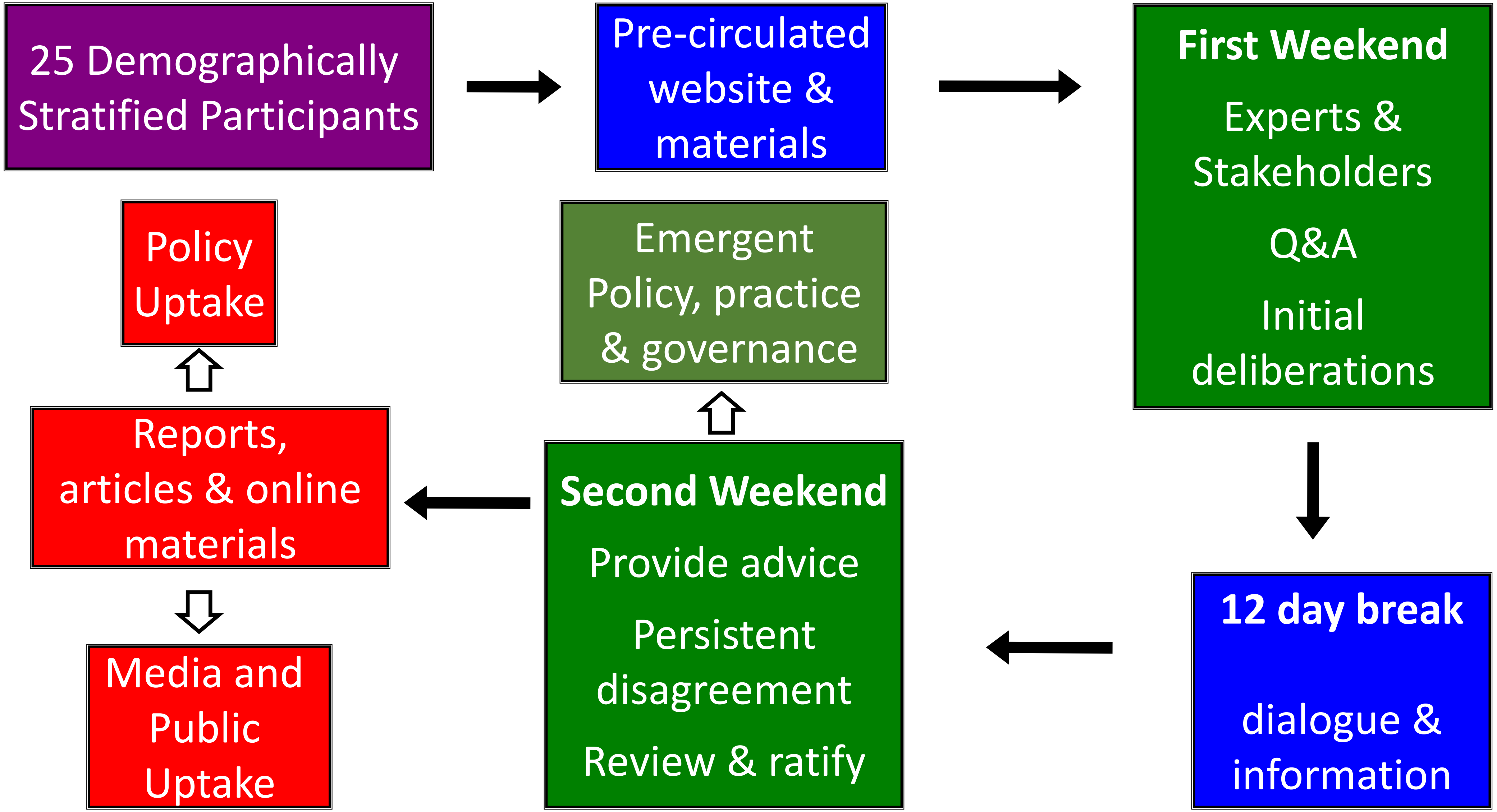
- free sequencing or other services in exchange for access to data

Objective of Deliberative Public Engagement?

“ . . . express a reasoned, informed, consensual judgment forged out of the initially disparate knowledge, values, and preferences of the participants, as these have evolved through the deliberative experience itself.”

Hamlett, PW (2003). Technology theory and deliberative democracy. *Science, Technology, & Human Values* 28 (1): 121-2.

Structure of a Deliberation



25 Demographically Stratified Participants

Pre-circulated website & materials

First Weekend

Experts & Stakeholders

Q&A

Initial deliberations

12 day break

dialogue & information

Second Weekend

Provide advice

Persistent disagreement

Review & ratify

Emergent Policy, practice & governance

Reports, articles & online materials

Policy Uptake

Media and Public Uptake

Four Deliberative Questions

1. What kinds of information about donors should biobanks collect and link to their samples?
2. What projects or researchers should biobanks share information and samples with?
3. When if ever, and how, should biobanks return individual information to participants?
4. How should biobanks make difficult decisions about collecting and sharing information?

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Forming and Reporting Deliberative Outcomes

- 10 of 18 conclusions

- Focus on conclusions critical for biobanks' trustworthiness

- Demonstrate importance of:
  - Reasons in conclusions
  - Framing of propositions
  - Autonomy promotion versus resource commitment
  - Components of trustworthy governance and public representation

Biobanks sharing information and samples

Biobanks should not share information and samples with criminal justice or law enforcement.

Vote: **In favour: 21** Against: 1 Abstain 2

- Main reasons:
  - Research and criminal justice should be kept separate.
  - Law enforcement has other ways of collecting DNA.
  - Might deter donating to biobank

Biobanks sharing information and samples

Biobanks should <u>not</u> be used to improve knowledge in behavioral genetics. (NB: negative wording due to discussion)

Vote: In favour: 5 **<u>Against: 15</u>** Abstain: 4

Against: <u>In favour</u> of sharing data:

- Behavioral research is part of medical research
- Don’t want to rule out a whole class of research
- Information about genetic predisposition could be helpful

In favour: <u>Opposed to</u> sharing data:

- Very strongly held views about danger to participants and society.

Returning individual information to participants?
Resources

Biobanks should commit resources to provide genetic results:

High risk for a disease, with something that can be done to lower risk?

Vote: **In favour: 21** Against: 2 Abstain: 1

High risk for disease, with no effective treatments or cures?

Vote: **In favour: 16** Against: 5 Abstain: 3

Genes that need more research done on them to determine their exact impact on a person's health?

Vote: In favour: 4 **Against: 19** Abstain: 1

Earlier: Returning individual information to participants?
Autonomy:

Consent to donate must include donor’s wishes regarding receiving each of the three types of information.

Vote: **In favour: 22** Against: 1 Abstain: 1

Biobanks must provide counseling and/or guidance

- to support disclosure and interpretation of results
- reflect on possible response for those who have requested return of results.

Vote: **In favour: 21** Against: 2 Abstain: 1

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Biobank Governance

A suitably constituted community advisory board is important to advise biobank experts and administrators when community and/or donor input is needed.

Vote: **In favour: 24** Against: 0 Abstain: 0

Community advisory must reflect diverse people / perspectives and not be selected to support a predetermined conclusion

Vote: **In favour: 21** Against: 0 Abstain: 3

Implications for biobanks and deliberation

1. Controversial uses of biobank collections need nuanced discussion to determine when donors and public are in favour, against, and why.
    - Behavioural genetics and criminal justice
2. Deliberants supported of choices for donors, but were less willing to spend resources with fewer direct benefits.
    - Reworded propositions demonstrated differences in support
3. Deliberants came to appreciate the role of public and diversity in governance.
    - Supports broader call for participatory governance of biobanks

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