

Lansing (MI) Area Citizens' Deliberative Jury on the "Biotrust"

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Goals and Methods of the Citizens' Deliberative Jury

- Deliberative jury process adapted from use in Great Britain. (Guest expert witnesses; juror time for Q/A with witnesses, group deliberation.) **GOALS:**
- To inform citizen-jurors of the Biotrust proposal (to create a state research biorepository using old and new bloodspots from state newborn screening program).
- To embody democratic goals of inclusivity, deliberativeness, and reciprocity.
- To articulate citizen hopes, concerns, consensuses, and disagreements re preferred bioethical policies.

Who Participated

- 20 Lansing-area residents
- Recruitment deliberately from both general citizens' groups (League of Women's Voters, ACLU, United Way, religious organizations, etc.) and groups that might have a special interest in bloodspots/research (March of Dimes, American Cancer Society, Michigan Minority Health Coalition, etc.).
- About $\frac{1}{4}$ of the jurors from ethnic/racial minorities (compared to about 17% of area population).
- Jurors were asked to express their own views, not to try to represent an organizational perspective.

GENERAL FINDINGS: COMMON WITH OTHER RESEARCH ON ATTITUDES TOWARD GENETIC RESEARCH

- Strong though not universal support for research.
BUT
- People want to be ASKED. Consent deemed critical.
- Greater suspicion among racial/ethnic minorities.
- Questions and concerns about “de-identification.”

Specific Findings: Attitudes about Newborn Screening Program

- Jurors considered both parental and general public understanding of the NBS program an unrealized prerequisite to understanding Biotrust proposal for research use.
- Jurors urged greater education on NBS, including pro-active prenatal education rather than at time of birth.
- Michigan policy of presumed consent for NBS was controversial among jurors. (2/3 supported but 1/3 thought explicit parental consent should be required for NBS screening.)

Specific Findings: Research Use of the Bloodspots

- SUPPORT
- 87% supported general idea of using spots for research.
- That support was conditional upon addressing concerns.
- CONCERNS
- Consent? (Need for distinction between NBS and research use.)
- Consent for what?
- Public purposes of research?
- Consent by whom? (How address consent for old spots? Or child-donators' interests when they become adults?)
- Can DNA be truly "de-identified?" (privacy)
- Commercial development goals of Biotrust? –could they undermine public-minded goals?

Consensus Points: Consent

- Research use requires explicit informed consent.
(Even if bloodspots de-identified.)
- 80% supported an option for consenter to limit the kinds of research for which bloodspots could be used.
- Goals of research and consent for research are ethically related.
(Increased explicitness re criteria or public processes for determining appropriate research goals increased juror comfort with “blanket consent” for future research. Conversely, the less clear those criteria/processes the more important jurors felt it was to be able to constrain consent by personal criteria.)

Other Consensus Points

- An option should be clearly offered to have spot *retained* for possible future *clinical* use but *not research* use.
- Safeguards for de-identification process are important.
- Protection from requisition by criminal justice system or Homeland Security is necessary.
- State should benefit financially from any commercial use. Commercial use should accord with publicly endorsed goals of research.
- A “**Community Values Board**” should be appointed to insure community input into policies governing goals and ethical guidelines of the Biotrust.

Areas of Non-Consensus

- Who “owns” the bloodspots? (Ethically, not legally.) Community, donor, both?
- Should explicit consent for research be opt-in or opt-out model? (2/3 opt-in; 1/3 opt-out.)
- Should donors be contacted if something clinically relevant is discovered? (Affects decision regarding complete versus coded de-identification.)

Citations and Contacts

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Stored Bloodspots: Ethical and Policy

Challenges (East Lansing, Michigan: Michigan State University Institute for Public Policy and Social Research, 2009). Available at:

<http://ippsr.msu.edu/Publications/HPFleck.pdf>

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