Parent Perspectives on Pediatric Biobanking

Research in progress

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Parent Perspectives on Pediatric Bio-banking

Study Overview
Pediatric Bio-bank: Definitions

• **Bio-bank**: a repository of biological tissue, which could be further classified by a variety of characteristics, including tissue type, purpose, ownership, volunteer group, and size (Swede, Stone & Norwood, 2007)

• **Bio-banking research**: genetic research that utilizes bio-tissues from a bio-bank
Pediatric Bio-bank: Significance

The promise of bio-banks

Bio-bank at Coriell Institute, NJ
“I will do your study, but I told my son…never let them take your blood because they’ll be able to track you wherever you go”

(said mom of pre-teen aged boy to Diana during data collection for another study)

Catalyst for Our Research

With every opportunity comes a challenge
Parent Perspectives on Pediatric Biobanking: Research Questions

1. What are some **ethical and social issues** from the perspective of parents who made a decision about whether to enroll their child(ren) in a pediatric biobanking research study?

2. How does **race and parental trust/distrust** in the research enterprise influence decision-making about participating in a pediatric bio-bank?
Research Questions

1. What are some ethical and social issues from the perspective of parents who made a decision about whether to enroll their child(ren) in a pediatric biobanking research study?

2. How does race and parental trust/distrust in the research enterprise influence their adolescent child’s decision-making about participating in a pediatric bio-bank?
Ethical Context of Pediatric Bio-banking

- Parental consent and child’s assent
- Return of results
- Re-consent (once children reach 18)
Parent Perspectives on Pediatric Biobanking: Research Questions

1. What are some ethical and social issues from the perspective of parents who made a decision about whether to enroll their child(ren) in a pediatric bio-banking research study?

2. How does race and parental trust/distrust in the research enterprise influence decision-making about participating in a pediatric bio-bank?
Historical Context of Race and Distrust

- Pre-Civil War medical experiments
  “As early as the 1920s, African Americans feared that they would be research subjects if they entered hospitals.” (Gamble, 1993)
- Tuskegee
- Eugenic ideologies: 1960s sterilization initiatives, 1970s sickle cell screening initiatives
- Henrietta Lacks
Research Method: Study Population

- 32-40 parents of adolescents (aged 12-17) who recently made a decision about participation in a pediatric bio-bank at CHOP (PI: Hakon Hakonarson)
- 50% African American, 50% Caucasian American
- 50% participants, 50% decliners
Research Method: Data Collection

- Decision-making Participation Scale (adaptation)
- The Health Care System Distrust Scale
- The Trust In Medical Research Scale
- Open ended telephone interviews
Health Care System Distrust Scale example items

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<tr>
<th>Item</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
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<tr>
<td>1. The health care system does its best to make patient’s health better.</td>
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<td>2. The health care system covers up its mistakes.</td>
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<td>3. Patients receive high quality medical care from the health care system.</td>
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Interview guide covers relevant domains:

- Nature of consent interaction
- Re-consent
- Return of results

*It is possible that as more research is done on your child’s samples, that they may find that your child is at an increased risk for developing some sort of medical condition in the future. Based on what they find, do you think that researchers are obligated to tell you results about your child? Why or why not?*

- Privacy
- Trust and Distrust
My Involvement and Next Steps

- Interview and Data Management
- SPSS Data Entry
- NVIVO Coding
- Data Analysis and Feedback
- Manuscript Preparation

Flowchart:
- Literature Review
- Data Collection
  - Materials Development
- Recruitment
- Interview and Data Management
  - SPSS Data Entry
  - NVIVO Coding
  - Data Analysis and Feedback
  - Manuscript Preparation
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References
