Clinician Attitudes and Intentions toward DNA Biobanking

SUNY Downstate
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Overview

- Increasing amount of genetic information for both clinicians and patients
- How clinicians perceive the value and utility of a DNA biobank is unknown
- Without clinician assistance, patients may be hesitant to donate their DNA to a biobank
What is a Biobank?

Centralized collections of human blood and tissue samples along with other information including details about health, personal history, and environmental factors, as well as information from DNA, family disease histories and exercise habits.
Types of Biobanks

- Broad vs. disease specific
- Academic vs. national vs. pharmaceutical
- Discard samples vs. acquired specifically for research purposes
- Electronic medical record vs. questionnaire
- Different forms of consent
Some Current Biobanks

- UK Biobank ........................................... 500,000
- Carta@gene (Canada) ............................ 30,000
- Kadoorie Study (China) ....................... 500,000
- Estonia Genome Project ...................... 500,000
- Marshfield Clinic (Minnesota) .............. 20,000
- NUgene (Northwestern) ........................ 100,000
- National Children’s Study (pilot phase)..... 100,000
- **BioGene Bank (NS-LIJ HS)** .............. 25,000
The BioGene Bank will support a broad range of research activities seeking to better understand a variety of illnesses by studying how genes, environment, and lifestyle interact to cause disease.
Purpose of the Study

To describe clinician attitudes and intention to donate medical information and a DNA sample to a biobank.
What is the BioGene Bank Research Program?

- **Recruitment** → inform clinician community
  - form “partnerships” Collect blood samples from 25,000 patients who receive care within the NS-LIJ Health System.

- **Informed Consent** → educate clinicians, staff and patients
  - consenting is a process

- **BioGene Informatics** → “strip” identifiers in a warehouse database separate from genetic information and linked when necessary to patient health data in a very large and diverse patient population in a de-identified manner.

- **Research Focus** → disease and treatment research via academic collaboration
Top Causes of Mortality

- Heart Disease
- Cancer
- Trauma
- Stroke
- COPD/Emphysema
- Diabetes
- Suicide
- Kidney Disease
- Alzheimer’s Disease
- Septicemia

(Complex Genetic Diseases)
What do you need to map genes for a complex disease?

- Large numbers of maximally informative genetic markers distributed across the genome
- Cost effective technologies to carry out large scale genotyping
- Statistical methods to analyze the data
- Large and well-characterized populations of patients and families
Genetic clues to MS

Study Finds Genetic Key To a Kind Of Glaucoma

Genetic clues to ALS

HEALTH & SCIENCE

Linking arthritis, lupus
Translational Research

What are the questions we really want genetics and genomics to answer about complex diseases?
Why are we here?

Genotype → Phenotype
Major issues to consider in genetic association studies

- Phenotype - Define it as precisely as possible.
- Controls – proper matching, especially for ethnicity; controls are as important as the cases!
- Family based association where possible
- Sample size – most studies are too small to detect modest effects (OR in the range of 1.5)
- Replication of results
The Big Picture

Genotype -> Phenotype

- Genotyping
- Phenotyping of “Clinical” Samples
- In vitro functional assays (phenotypes)
• Individual behavior change e.g., diet, exercise, smoking
Cumulative Pace of Disease Gene Discovery 1981-2005

Number of Genes Associated with Disease

Year

Source: Online Mendelian Inheritance in Man
Literature Review

- Many research groups/disease cohorts collect and store DNA linked to clinical data for discovery research
- US and International studies completed with members of the public—who are generally positive toward biobanking
- There remains little information on clinician perception
- Genetic information increasingly available to both clinicians and patients – most applications still “research”
Significance

- Few studies on willingness in US
  - General public
- First US Clinician focused study
  - Stakeholders
  - Attitudes
  - Recruitment issues
PROBLEM

- The success of the Biobank project depends largely on the public support.
Research Questions

1. What are the attitudes of clinicians toward a DNA biobank?
   - 14 Likert-like items scored 1-5

2. What are the intentions of clinicians related to willingness to participate in a DNA Biobank? (2 intention questions)
   - Yes linked to medical records, Yes if anonymous, No

3. What are the relationships between attitude and intention in clinicians as they contemplate a DNA Biobank?
Theory of Planned Behavior (TPB)

- One’s beliefs affects attitude (+/-) and ultimately how one perceives the behavior (+/-)
Study Questionnaire

- Tool
  - Combination of two previously used questionnaires
  - 30 items
- Web based survey - Email request to participate sent with link to survey site
- Dillman (2007) Tailored Design Method for internet/web surveys
- Data collection by SurveyMonkey
Methods

- Descriptive study with online survey design
- Convenience sample from credentialed clinicians with an available email address
- 3 Clinician Groups
  - MD/DO
  - Advanced Practice Nurses
    - Nurse Practitioners
    - Nurse Practitioners with DNP degree
  - CRNA
  - CNM
  - Physician Assistants
Protection of Human Subjects

- IRB approval – exempt category
- Voluntary participation
- Could skip questions and/or discontinue the survey at any time
- No identifying information was requested
- Email addresses were discarded after data collection completed
Survey Limitations

- Surveys have a self-selection bias
  - Web surveys may have unique self-selection biases

*Response:* Dillman Method has introductory email and 4 follow-ups to increase response and reduce non-response rate

- Convenient 10 minute web based survey that clinicians can do at home or in their office

- This is a descriptive study, and the study may not be generalizable to other health systems.

*Response:* this health system is large
Response Rates – Completed Q

- 3 Clinician Groups
  - Overall rate 144/816 17.6%
    - MD/DO (61/415 - 14.7%)
    - Nurse Practitioners (55/193 - 28.5%)
    - Physician Assistants (28/208 - 13.5%)

5/27/2010
STATISTICAL ANALYSIS

- Willingness to donate a blood sample for genetic research (Intention)
- Attitude based on perceived usefulness
- Demographics
Results Research Question 1

Clinician Attitudes toward a DNA Biobank

- No overall score calculated – mean score calculated for each statement

<table>
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<th></th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
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<tbody>
<tr>
<td>Creating biobank</td>
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<td>4.07</td>
<td>.939</td>
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<tr>
<td>Consent pt</td>
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<td>3.84</td>
<td>.979</td>
</tr>
<tr>
<td>DNA bank beneficial</td>
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<td>4.21</td>
<td>.791</td>
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<tr>
<td>Some pop benefit more</td>
<td>143</td>
<td>3.75</td>
<td>.915</td>
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<tr>
<td>Database not secure</td>
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<td>2.75</td>
<td>.991</td>
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<tr>
<td>Info might be sold</td>
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<td>2.80</td>
<td>1.144</td>
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<tr>
<td>DNA for unintended purposes</td>
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<td>2.67</td>
<td>1.134</td>
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<tr>
<td>Part. told of “potential cures”</td>
<td>142</td>
<td>4.29</td>
<td>.830</td>
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<tr>
<td>Part. should profit</td>
<td>141</td>
<td>2.76</td>
<td>1.075</td>
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<tr>
<td>Part. should know results</td>
<td>141</td>
<td>3.91</td>
<td>1.066</td>
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<tr>
<td>Patients would feel coerced</td>
<td>142</td>
<td>2.61</td>
<td>.945</td>
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<tr>
<td>Patients understand</td>
<td>142</td>
<td>3.81</td>
<td>.753</td>
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<tr>
<td>Patients likely participate</td>
<td>138</td>
<td>3.59</td>
<td>.808</td>
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<tr>
<td>I would consent patient</td>
<td>140</td>
<td>3.61</td>
<td>.964</td>
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Results Research Question 2

- Clinician Intention
  - + intention linked
    - Yes 113 78.5%
    - No 13 9%
    - Don't know 18 12.5%  Total n=144
  - + intention linked or anonymous
    - Yes 124 86.11%
    - No 7 4.86%
    - Don't know 13 9.03%  Total n=144
## Results Research Question 2

### Intention by Clinician Group

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Positive Intentions</th>
<th>Linked or Unlinked</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
</tr>
<tr>
<td>MD or DO</td>
<td>53</td>
<td>4</td>
<td>4</td>
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<tr>
<td>Nurse Practitioner</td>
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<td>2</td>
<td>5</td>
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<tr>
<td>NP with DNP</td>
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<td>1</td>
<td>0</td>
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<tr>
<td>Physician Assistant</td>
<td>24</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>n</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Results Research Question 3

- Correlating Attitudes to Intention
- **For 8 of 14 statements the groups were statistically different**
  - “I am receptive to the idea of creating a database of DNA”
  - “I would feel comfortable consenting a patient for a DNA sample for a biobank”
  - “A DNA database would be beneficial in providing information needed in the work to cure disease”
  - “The database would not be secure”
  - “Information from a database might be sold even if the creators say the data is private”
  - “Participants' genetic information might be used for unintended purposes, e.g., notification of their employer”
  - “Patients would feel coerced to donate a DNA sample if asked by a health care clinician”
  - “I would be willing to spend 5 minutes consenting a patient to donate a DNA sample.”
Results Research Question 3

- Are we measuring attitudes with all statements?
- No overall score to correlate to TPB
  - Is there an answer to does attitude affect intention?
  - No clear correlation can be made
Additional Thoughts

- Adventures with trying to acquire a total score
  - First used Cronbach’s to examine reliability
    - Results – CA .62
    - Attempted to see if there was a consistent pattern or + and - values
    - No consistent patterns
  - Unable to develop a total score
Suggestions for Further Research

- Sample clinicians by hospital location
- Investigate possible relationship with race/ethnicity
- Investigate motives such as link between blood donors and positive intention
- Pilot test tool to ensure what is being measured – is it really attitudes?
Overall Conclusions

- Results can be used as framework for larger study to involve community clinicians from all health system sites
- Goal is for patient and clinician partnership in health care
BioGene Bank

Medical Data

“Stripped” Data and Sample Import

Other Data Sources

Genetic Data

Sample Bank

Data Warehouse Management

Genomic Research

Data and Sample Query
Data Management
Request & Inventory Management
Security & Access Control
Thank you