A Family Health History Project in Urban Appalachian Communities

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Conference Objectives

- Apply concepts of empirical research design to bioethical issues
- Describe the bioethical issues in research that are amenable to empirical analysis
- Identify critical ethical issues when designing and implementing clinical research studies
Disclosures - multiple codes of ethics

- Genetic counseling
  - www.nsgc.org

- Public health practice
  - www.apha.org/about/

- Human subjects research
  - www.hhs.gov/ohrp/
Principles of the Ethical Practice of Public Health

- 12 principles
- Essence of community is a key belief that underlies many of the principles
  - Public health seeks to assure health of whole communities and recognizes the health of individuals is tied to their life in the community
Public Health Principles and Community

Public health should:

- Achieve community health in a way that respects the rights of individuals in the community
- Advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all
Public Health Principles and Community

Public health policies, programs, and priorities should:

- Be developed and evaluated through processes that ensure an opportunity for input from community members
- Incorporate approaches that anticipate and respect diverse values, beliefs, and cultures in the community
Public Health Principles and Community

Public health institutions should:

- Provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community’s consent for their implementation.
- Protect the confidentiality of information that can bring harm to an individual or community if made public.
- Engage in collaborations and affiliations in ways that build the public’s trust and the institution’s effectiveness.
Project Background

- U.S. Surgeon General Family History Initiative
  - Encourages all American families to learn more about their family health history (FHH)
  - FHH tool “My Family Health Portrait” accessible online

http://www.hhs.gov/familyhistory/
My Family Health Portrait

- Available electronically or in print to those with computers connected to the web with a major Internet browser
Education and Community Involvement Branch, NHGRI

- A model demonstration project and support materials to educate and engage a targeted community or community group about the collection and use of their own family health history information
Project Goal

- Develop a model program to educate urban Appalachian women about the collection and use of their FHH
- Create low literacy FHH resources
Higher poverty rates related to:
- High-school drop out rates
- Unemployment

Appalachian whites reported higher rates of:
- Lung disease
- Heart trouble
- Diabetes
- Hypertension
- High Cholesterol
- Stroke
Community Partners

- Urban Appalachian Council, Cincinnati, OH
- Lower Price Hill Community School, Cincinnati, OH
- Brighton Center, Newport, KY
- Sunrise Center, Dayton, OH
- Voices of America, Dayton, OH
- Life Enrichment Center, Dayton, OH
Family History Working Group

Eleven members

- Three representatives from community organizations
- Experts in health literacy, genetic counseling, nursing, Appalachian studies, environmental health, cultural competence, family history education, public health

Helped develop all resources for project
Understanding and engaging the urban Appalachian community

- A conference call was held with the Family History Working Group and members from each participating community organization to discuss cultural aspects unique to the urban Appalachian community and the best way to engage them
Recommendations from Community Partners

- Be prepared to listen
- Value the community and the information they can provide
- Don’t stigmatize – “we are trying to develop materials that everyone can understand”
- Be sensitive to culture of community
  - Fatalism
  - Powerlessness for selves but not for children
  - Strong family bonds
Inclusion Criteria

- Women over the age of 18
- Less than a college education
- Appalachian heritage
Appalachian Heritage Criteria

- Participant, parent or grandparent
  - Self-identify as Appalachian OR
  - Born in a federally designated Appalachian county
Project Components

1. Two focus groups (n=24)
   - Importance of FHH, how want to learn about FHH

2. Education session 1 (n=100)
   - Record FHH, importance of FHH, access FHH on internet, questions to ask relatives

3. Education session 2 (n=92)
   - Problems encountered, intended use of FHH, confidently ask questions of HCP

4. Follow-up phone calls (n=58)
Community Partners

- Engaged the community
  - Recruitment
- Informed us of cultural values and beliefs
- Facilitated the transfer of trust to academic partners
  - Participation in education sessions
- Identified missing elements of the project
  - How to talk to healthcare provider about FHH
Community Members

- Specified format for education sessions
- Recommended topics for fact sheets
- Evaluated fact sheets
- Identified “benefits to children” as a critical element of education sessions
Results

After one education session, women were able to:

- Complete "My Family Health Portrait"
- Identify the importance of FHH in disease prevention and health promotion
- Identify four relevant questions to ask family members about FHH
Access to the FHH tool

- Not all women felt they could find the Surgeon General’s tool on the internet, suggesting access may be a barrier.

- Have to be able to print the FHH to take it to provider.
Ability to Access Tool

- Enough training to find form on web?
- Able to teach relative to find form on web?

Bar chart showing the percentage of respondents who could find forms on the web, with categories for Total, Paper, and Electronic.
Intended use of tool

- Most participants intended to share their FHH with their family and their children.

- In general, participants completing the electronic tool tended to report being more likely to use their FHH than those completing the paper tool. This was especially notable with intent to share FHH with a HCP.
### How intend to use information?

<table>
<thead>
<tr>
<th></th>
<th>Paper</th>
<th>Electronic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Share with family</td>
<td>70%</td>
<td>83%</td>
</tr>
<tr>
<td>Save for children</td>
<td>89%</td>
<td>85%</td>
</tr>
<tr>
<td>Share with HCP*</td>
<td>65%</td>
<td>91%</td>
</tr>
<tr>
<td>Eat healthier</td>
<td>67%</td>
<td>72%</td>
</tr>
<tr>
<td>Increase activity</td>
<td>46%</td>
<td>63%</td>
</tr>
<tr>
<td>Get check-up</td>
<td>30%</td>
<td>50%</td>
</tr>
<tr>
<td>Stop smoking</td>
<td>35%</td>
<td>41%</td>
</tr>
</tbody>
</table>

*p<.05
Other challenges with engaging community in research

- Community identifies problem
- Insider-outsider tensions
- Sharing and release of findings
- Sustainability when funding ends
Partners

Academic:
- Melanie Myers
- Margaret Au
- Carol Baugh
- Katie Brown
- Sandy Cornett
- Judy Jarrell
- Todd Nick
- Cindy Prows
- Jody Wallace
- Yu Wang
- Nancy Warren

Community Organizations:
- Paula Houston
- Bonnie Hood
- Norma Ryan
- Steve Christensen
- Tim Nolan
- Brandon Sirbu
- Jeff Sorrell
- Tom Stegmeier
- Maureen Sullivan
- Joanne Hale

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References


