Participation of Minorities in NIH Research:  
--thru Clinical Trials  
--thru Engagement of the Community  
UC Davis-Hmong Women’s Heritage Association  

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NIHMD Session on: Ethics of Community Engagement  

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Presentation Outline:

Clinical Trials

Benefits vs Challenges: Changing the Culture

Community

Perspectives-----Processes-----Products

Conclusions

Lessons Learned-----Take aways
Clinical Trials: the Benefits

- Patients enrolled in clinical trials receive better care than non-participants.

- Patients enrolled in clinical trials live longer.

- Advancing the field is possible when clinical trials that are properly powered are completed. This is particularly relevant to prevention and behavioral research.
Projected Cases of All Invasive Cancers in U.S. by Race & Ethnicity

- 142% increased incidence for Hispanics of any race
- 132% increased incidence for Asian/Pacific Islanders
- 101% increased incidence for multiracial
- 76% increased incidence for American Indian/Alaska Natives
- 64% increased incidence for Blacks

NCI Clinical Trials by the Numbers

10,000 NCI Clinical Trials

< 150 focused on racial/ethnic minority

- Black/African American
- Hispanic/Latino
- Asian American
- Native American
- American Indian, Alaskan Native
- Pacific Islander

ClinicalTrials.gov, 1/13
Changing the culture starts with being at the table
Comparison of Therapeutic Clinical Trials Accrual Rates at UCDCCC by Race/Ethnicity, Average 2011-2014

National Range of adult accrual for clinical trials (2-5%)
Engagement of the Community in Sacramento, CA

Hmong Women’s Heritage Association
WHO ARE THE HMONG?

- American ally from the Vietnam Conflict
- Fastest growing population in Sacramento County, 195.3%
- Only 2.8% of Hmong Americans have at least a bachelor’s degree
- The per capita income for Hmong Americans is $4,885
## Socio-demographics of Hmong P01 Participants

<table>
<thead>
<tr>
<th>Socio-Demographics Characteristics</th>
<th>Total % (n=260)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>No Formal Education/DK</td>
<td>63.85%</td>
</tr>
<tr>
<td><strong>BMI (Asian Cut Point)</strong></td>
<td></td>
</tr>
<tr>
<td>23-27.5</td>
<td>43.08%</td>
</tr>
<tr>
<td>&gt;27.5</td>
<td>35.77%</td>
</tr>
<tr>
<td>Overweight and Obese</td>
<td>80.77%</td>
</tr>
<tr>
<td><strong>Country of Birth</strong></td>
<td></td>
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<tr>
<td>Laos</td>
<td>73.08%</td>
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<tr>
<td>Thailand</td>
<td>21.54%</td>
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<tr>
<td><strong>Language of Survey</strong></td>
<td></td>
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<tr>
<td>Hmong</td>
<td>91.02%</td>
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<tr>
<td><strong>English Fluency</strong></td>
<td></td>
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<tr>
<td>So-So/Poorly/Not at all/DK</td>
<td>84.23%</td>
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<tr>
<td><strong>Health Insurance</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>90.77%</td>
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</tbody>
</table>
Approach

Utilize list of Hmong households

Determine eligibility

In person interview to:
1. Collect baseline data

Random Assignment

Intervention: Hepatitis B
With CBO #1 LHW

Control: Diet & Exercise
With CBO #2 LHW

Follow-up interview: self-reported testing

Verification of testing by checking medical records
Partner with Hmong Women’s Heritage Association in CBPR approach
Challenges and Barriers to Health

Some of the health challenges that Hmong community faces:

• 60% of community are Limited English Proficiency
• Low health literacy
• Socioeconomic status (65% qualify for SNAP)
• Cultural (East vs. West, Shaminism vs. modern health care, etc.)
• Challenges with adjusting from farming to sedentary lifestyles

• Diseases that are prevalent
  • Gout
  • Type II diabetes
  • Hypertension
  • Hepatitis B
Activities in Community Research

- Lay Health Worker Home Visits
- Group Sessions
- Diagnostic Testing
Examples of nutrition flip chart and the HBV flip chart
Conclusions
Abraham Maslow’s Hierarchy of Needs

- Physiological Needs
- Safety Needs
- Love and Belonging Needs
- Esteem Needs
- Self Actualization
“And just as you want people to treat you, treat them in the same way.”
—Luke 6:31
Essentials for ethics in Engagement of the Community

**Time**
- Understand community issues and concerns
- Build relationships
- Outreach and education

**Trust**
- Ensure community is involved in every step

**Transparency**
- Culturally appropriate ethnically specific outreach and education
- Continuous community input and feedback
- Community ownership
“Longest journey begins with a single step....”