

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



Moon S. Chen, Jr. & Kendra Thao
UC Davis & Hmong Women's Heritage Association
Sacramento, CA

NIHMD Session on: Ethics of Community Engagement



October 7, 2015

Presentation Outline:



Clinical Trials

Benefits vs Challenges: Changing the Culture



Community

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



Conclusions

Lessons Learned-----Take aways

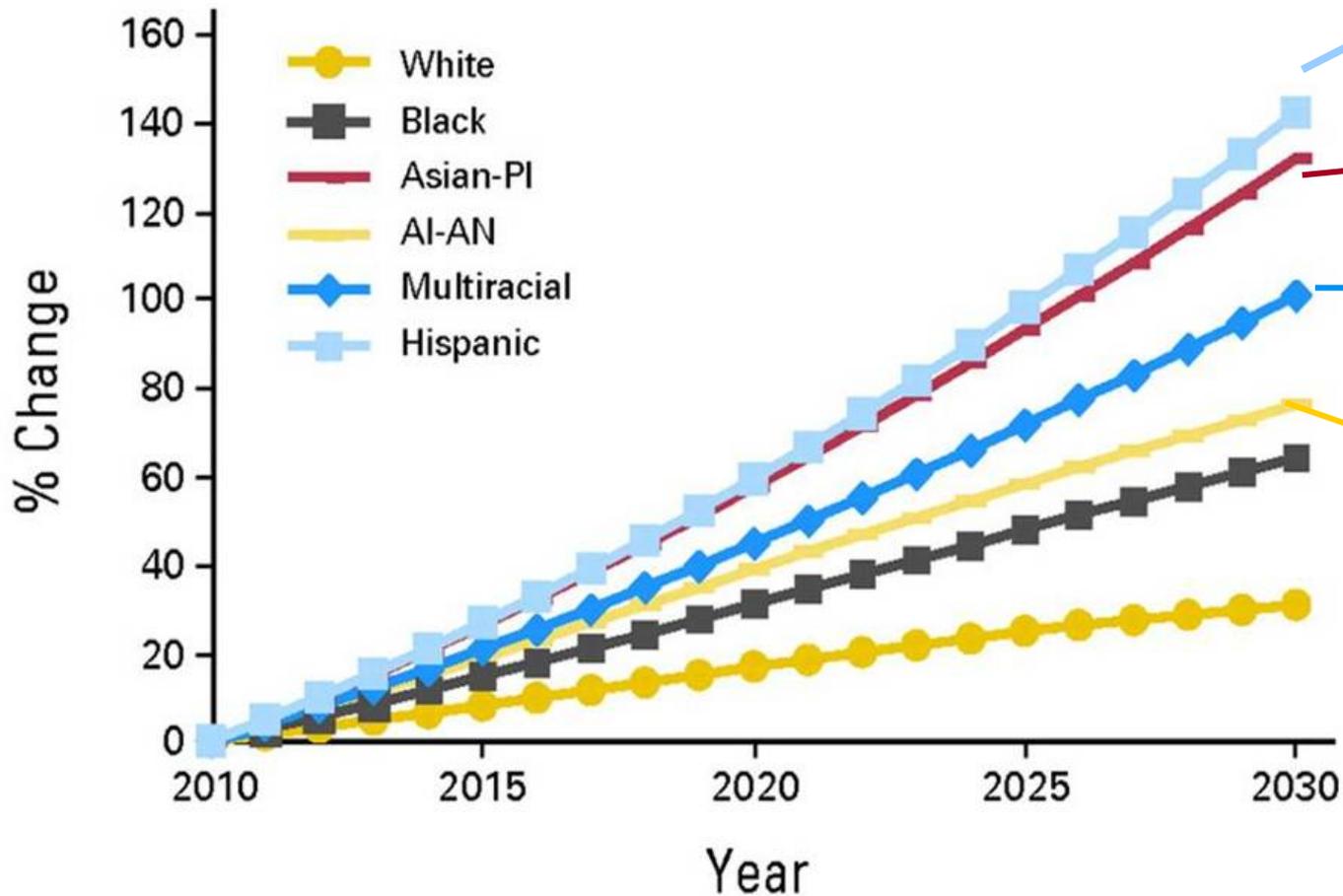


Clinical Trials: the Benefits

- 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

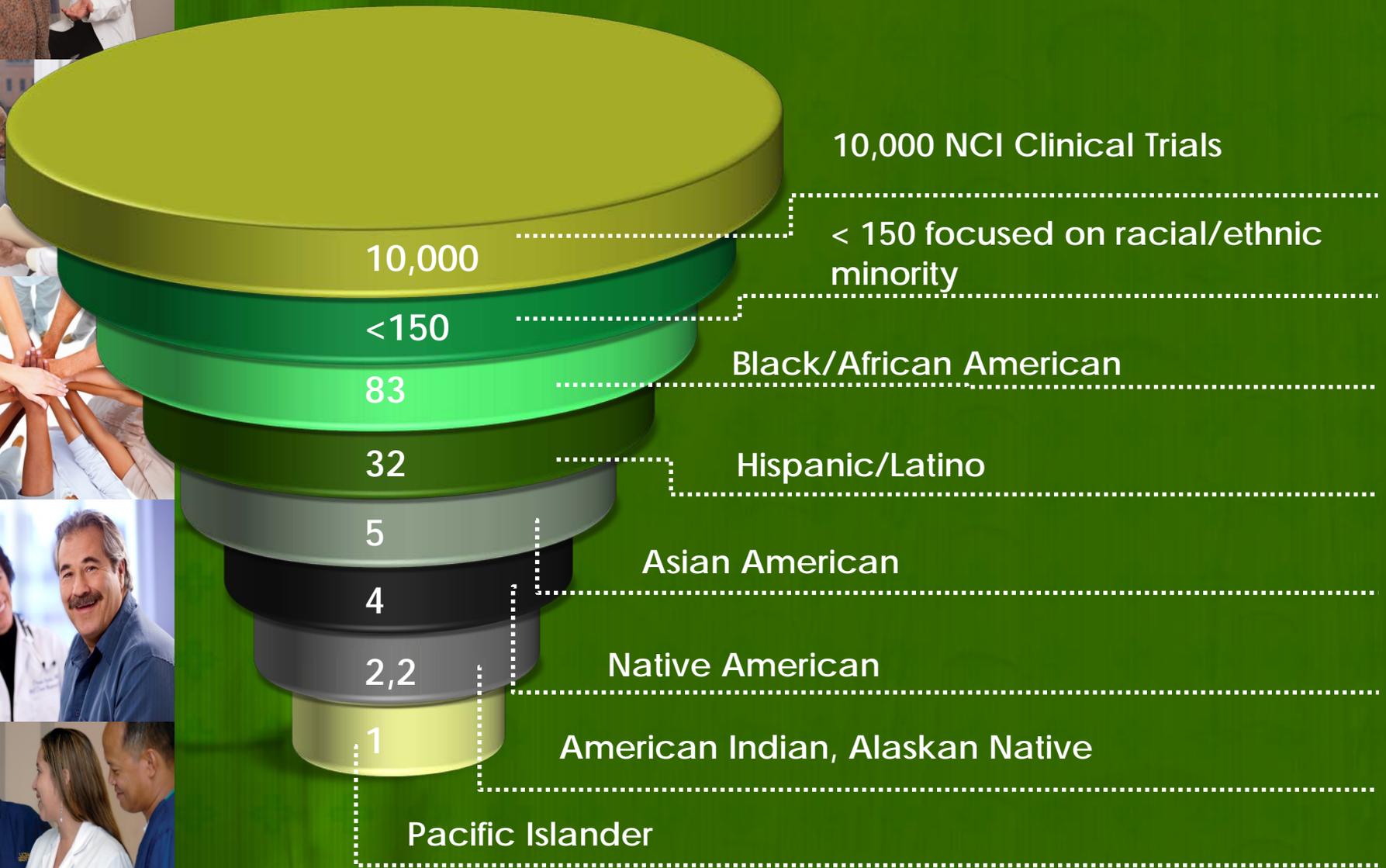
132% increased incidence for Asian/Pacific Islanders

101% increased incidence for multiracial

76% increased incidence for American Indian /Alaska Natives

64% increased incidence for Blacks

NCI Clinical Trials by the Numbers





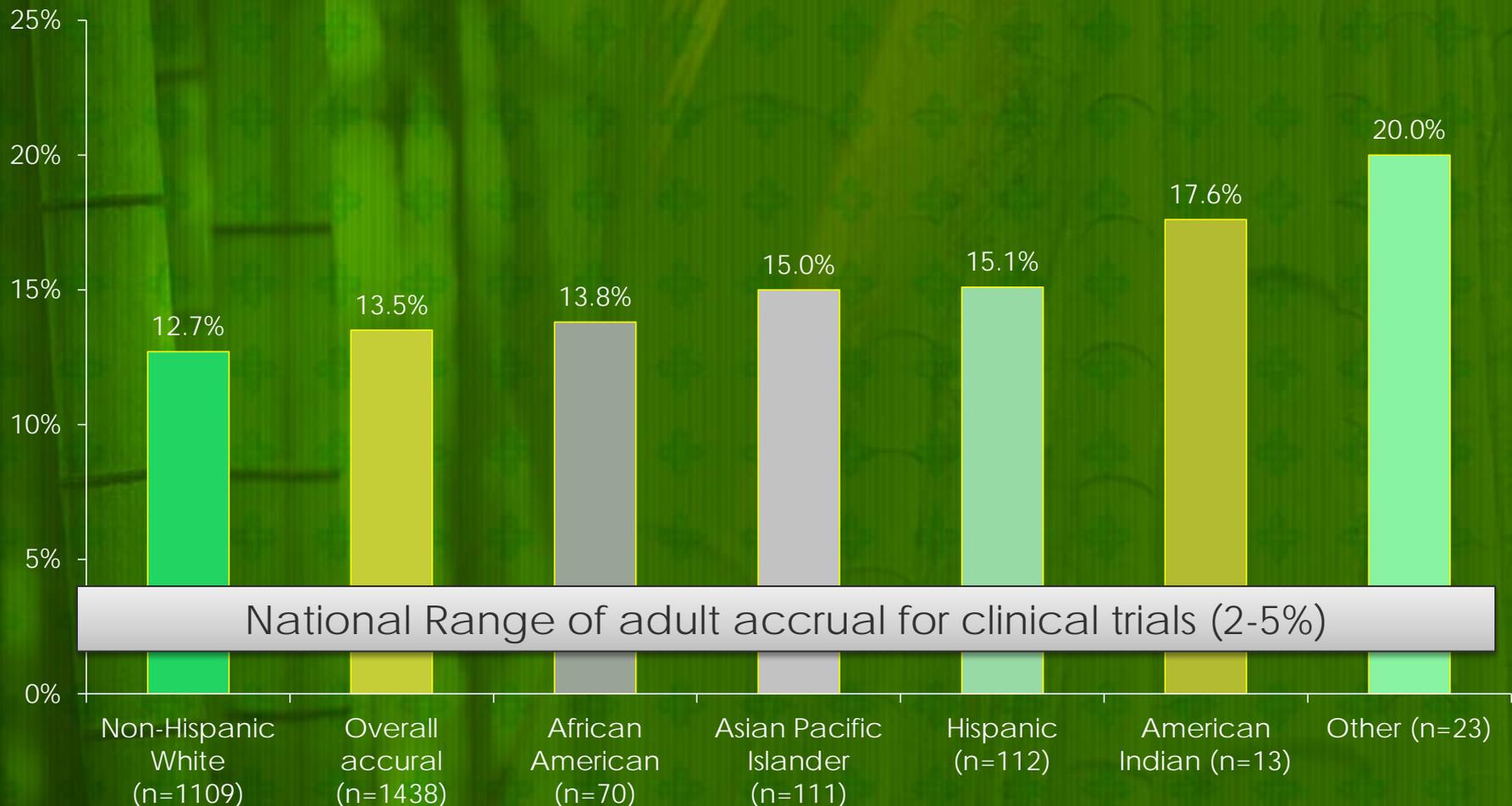
Moon S. Chen Jr.
Chinese
Male

Personalized
Treatment



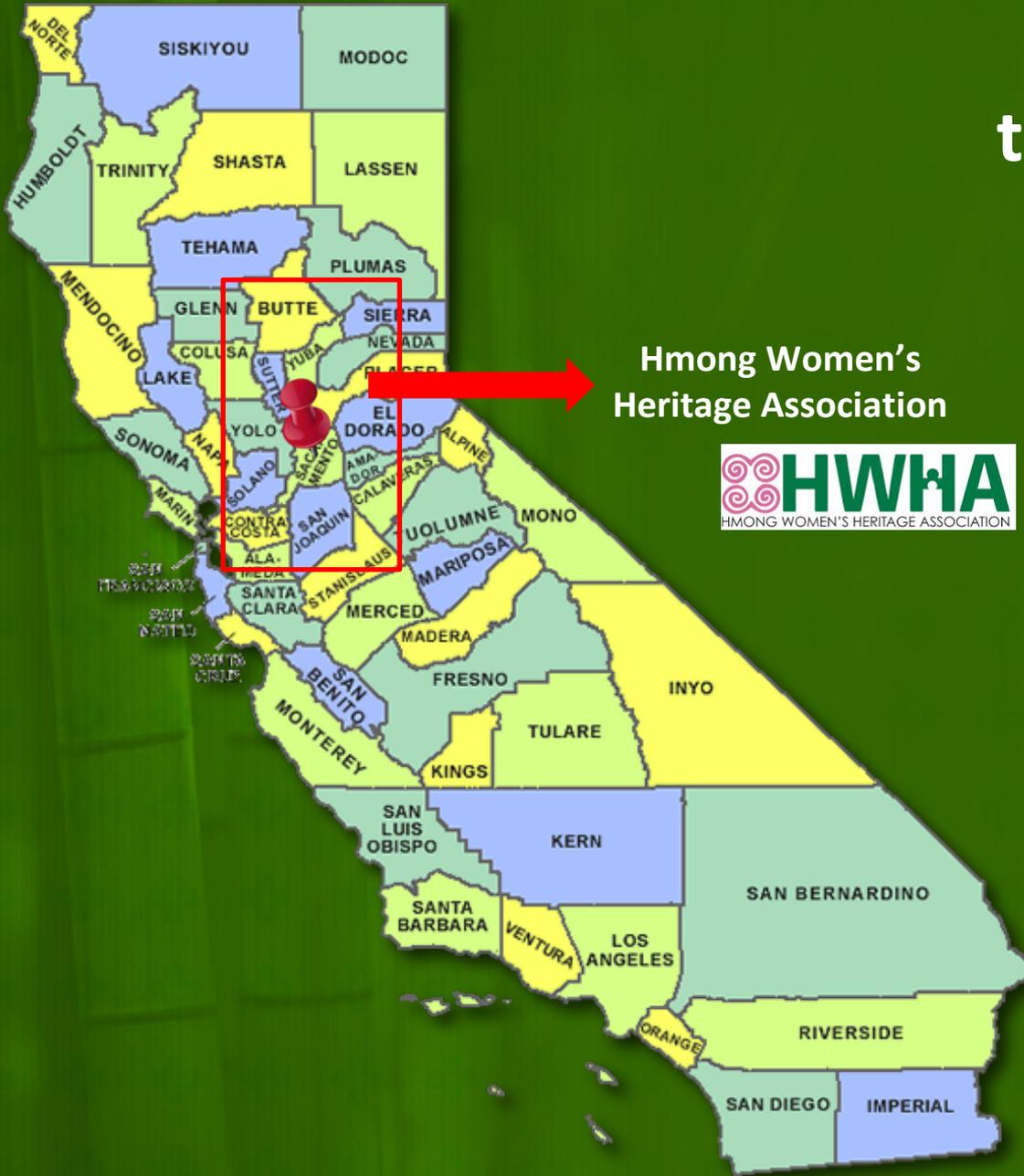
Changing the culture starts with being at the table

Comparison of Therapeutic Clinical Trials Accrual Rates at UCDCCC by Race/Ethnicity, Average 2011-2014



Engagement of the Community in Sacramento, CA

Hmong Women's
Heritage Association



The
SPIRIT CATCHES YOU
AND YOU FALL DOWN

*A Hmong Child, Her American Doctors,
and the Collision of Two Cultures*

ANNE FADIMAN

WINNER OF
THE NATIONAL
BOOK CRITICS
CIRCLE AWARD



WITH A NEW
AFTERWORD BY
THE AUTHOR

FSG CLASSICS





- 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

WHO ARE THE HMONG?

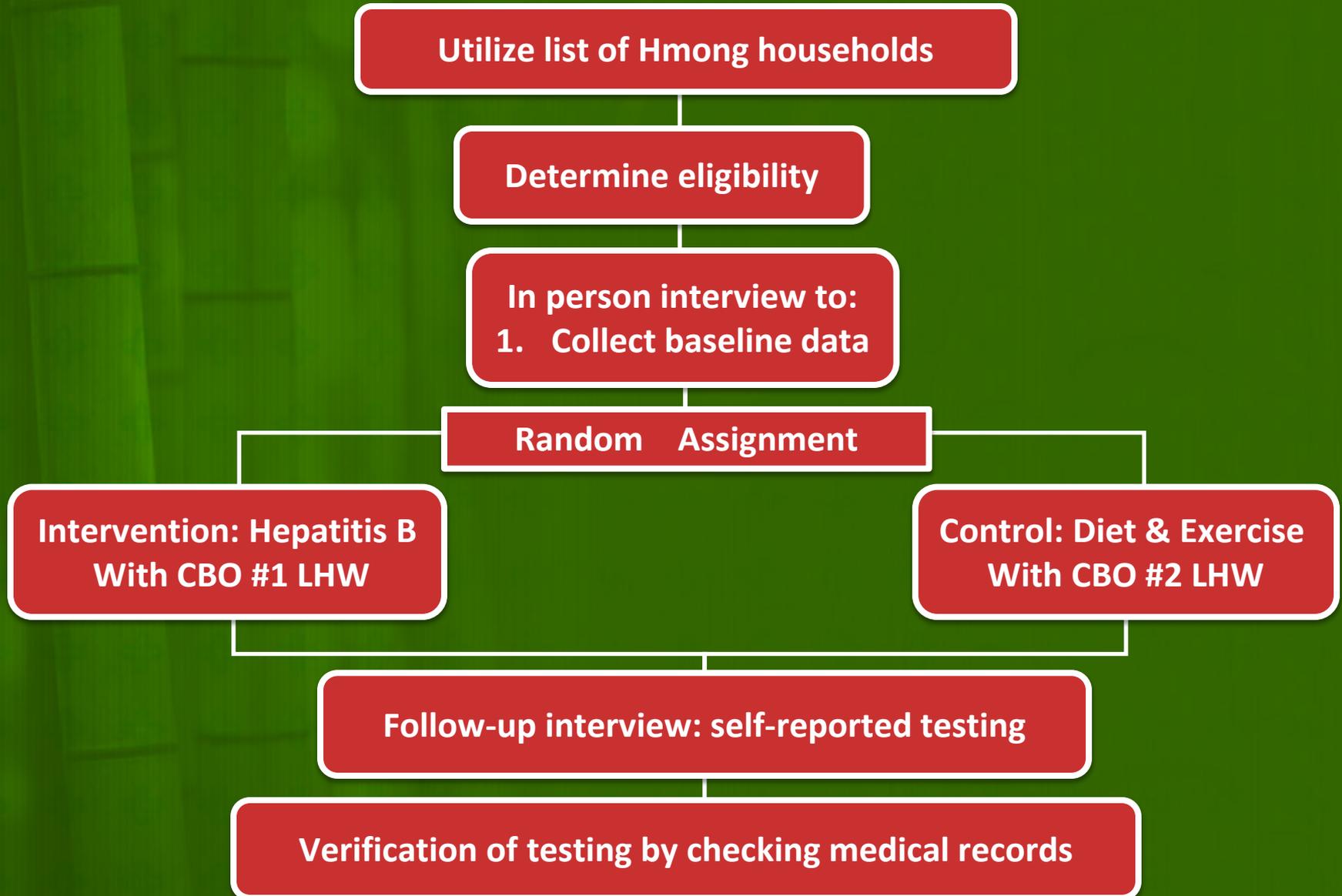


RICH CLABAUGH/STAFF

Socio-demographics of Hmong P01 Participants

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

Approach



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, Shamanism 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



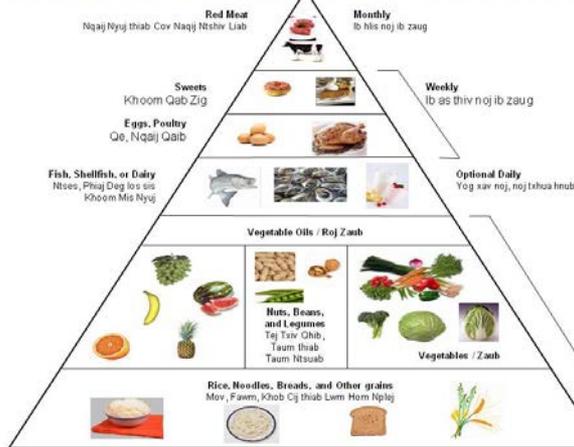
Examples of nutrition flip chart and the HBV flip chart

Kashia Health Program Healthy Eating Education Flip Chart

Why am I here?

You have been chosen to be part of the Kashia Health study. We want to help you eat healthy foods and maintain a healthy weight.

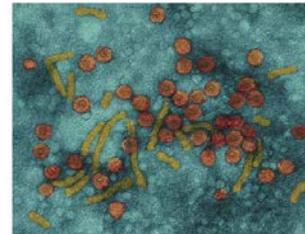
Tell me what you already know about eating



Kashia Health Program A Hepatitis B Education Flip Chart

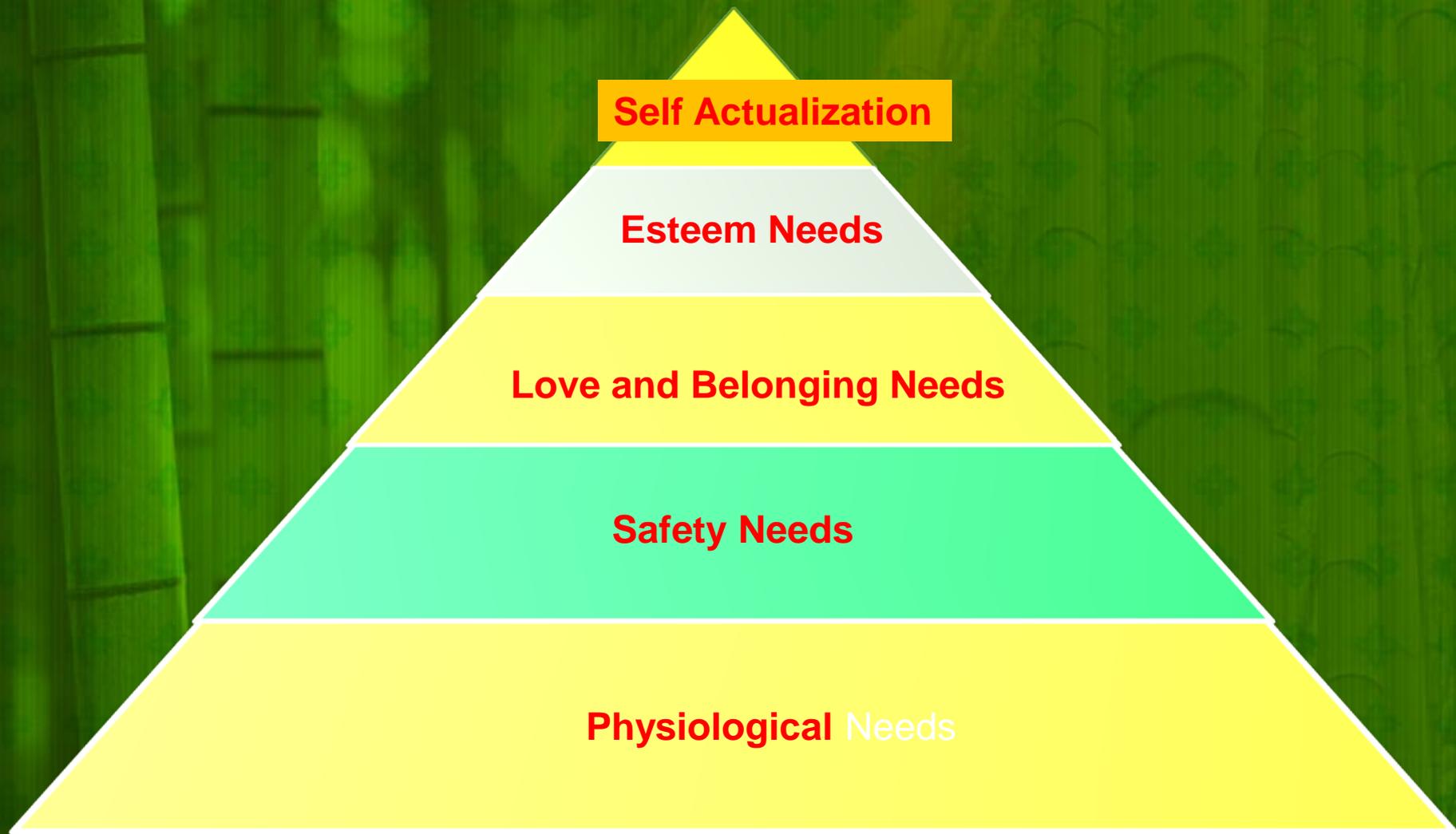
What do you know about hepatitis B?

(Allows some time for participant to explain to you about Hepatitis B)



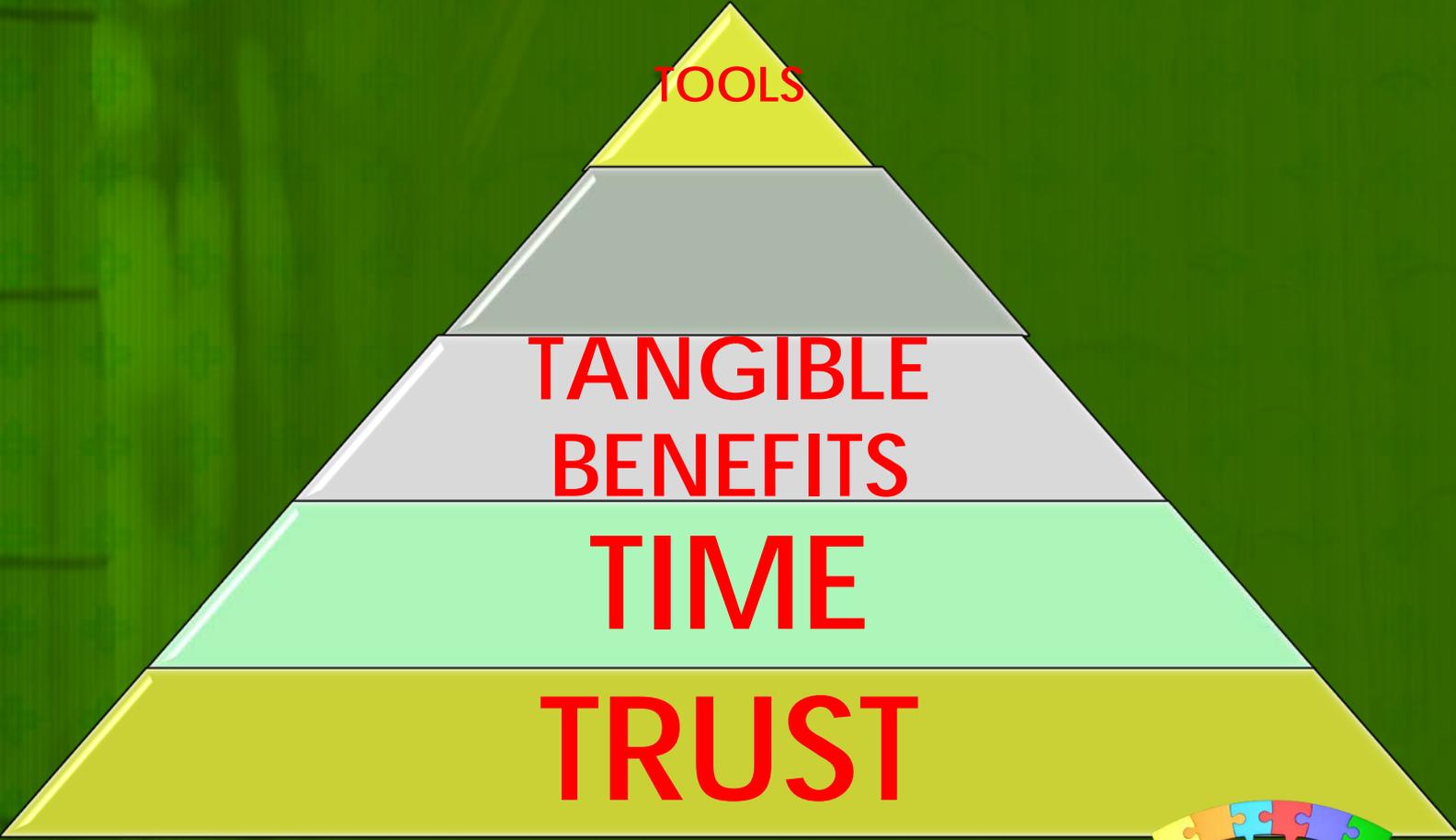
Conclusions





Abraham Maslow's Hierarchy of Needs

PARADIGM



“And just as you want people to treat you, treat them in the same way.”
—Luke 6:31

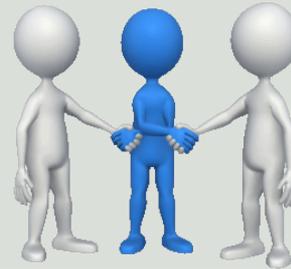


Essentials for ethics in Engagement of the Community



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....”

