

# What Does the Public Want to Know About Health-Related Research?

**Lynn Waishwell, PhD, CHES**

waishwly@umdnj.edu

Laura Hemminger, MPH CHES

Jennifer Campbell, MPH

UMDNJ-School of Public Health

Piscataway, NJ



Department of Health and Human Services • National Institutes of Health

Supported by a Science Education  
Partnership Award (SEPA) from the  
National Center for Research Resources  
(Grant No. R25 RR018490)



**SCHOOL OF  
PUBLIC HEALTH**

University of Medicine & Dentistry of New Jersey



# Acknowledgements

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- Supported by Science Education Partnership Award (SEPA) from the National Center for Research Resources (NIH R25RR018490)
- Jennifer Campbell and Diane Lucas-MPH graduate students who helped coordinate the management and reduction of data

# HOPE Partnership: Partners

Oregon State University

UMDNJ-SPH

University of Southern  
California/U. of California

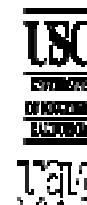
University of Texas M.D.  
Anderson Cancer Center

University of Wisconsin-  
Madison

Vanderbilt University

University of Arizona

University of North Carolina



Health Observances & Public Education



THE UNIVERSITY  
OF NORTH CAROLINA  
AT CHAPEL HILL



# Health Observances and Public Education – HOPE Partnership

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- To enhance the public's scientific literacy
- Overall mission of project is to improve public understanding of the biomedical and health-related sciences and impact of research on human health – determine the most effective outreach methods
- Focus is on three health issues: Cancer, Asthma and Allergies, and Lead Poisoning Prevention



# Background

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- The public's lack of knowledge about basic scientific facts and process can have far reaching implications (National Science Board, Science and Engineering Indicators, 2006)
  - Adversely affect level of gov't support for research
  - Choice of careers
  - Knowledge of science can help people evaluate the validity of various claims
- Science communication is important and not particularly well done (Treise & Weigold, 2002)



# HOPE Partnership

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- Three national health observances
  - Asthma and Allergy Awareness Month
  - Cancer Control Month
  - Lead Poisoning Prevention Week
- Materials designed to raise public awareness as to how research is influencing prevention, detection and treatment of disease with three target groups
  - Middle and High School Teachers
  - General Public
  - Students
- Dissemination methods assessed: Community forums, formal education, informal education, media, non profit organization events and science centers and museums

# Methods: Needs Assessment



- Focus Group Discussion Guide Development
- Training of focus group facilitators
  - Provided structure for screening, recruiting and discussion guide
- Each institution conducted focus groups
  - Six focus groups assigned- 3 with two different populations
- Target Populations:
  - Middle school and high school students
  - Middle school and high school teachers
  - General Public
- Recruitment of Focus Group Participants
  - Diverse methods; typically worked with partner agencies
- Analysis
  - Professionally transcribed a subset of focus groups (N=15)
  - Coded using Atlas.ti
    - Trained coders for consistency of concepts



# Focus Groups

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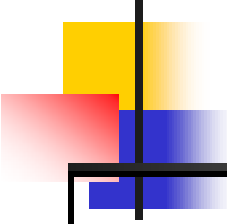
- Qualitative research

Not intended to meet assumptions of quantitative research

*"Groups of 12 or fewer persons who are asked a series of in-depth questions by a trained facilitator to elicit perceptions and opinions on a particular issue, product or service"* (Morgan and Krueger)



# Focus Group Participant Characteristics (N=15)



	Teachers	Public	Total
Females	34	48	82
Males	16	13	29
Hispanic	4	17	21
Asian	1	4	5
Caucasian	40	31	71
Black	4	12	16
Native Am.	0	2	2
Mixed Race	3	5	8
Unknown	1	8	9



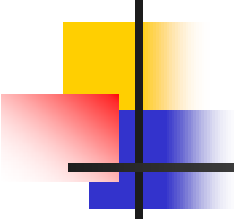
# Results

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- Perceptions of Cancer, Asthma/Allergy and Lead Poisoning Prevention Research
- Information about health related-research desired
- Preferred methods of receiving information

# Common themes across health topics: *When you think about research on XXX, what comes to mind?*

- **Reporting of health-related research in the media is confusing for the public**
  - *"I think about all the news articles that come out about what you shouldn't eat and all the new studies that they come out with and it makes you sometimes wonder what they are doing."*
- **Health research is perceived as treatment focused. Research on causes and prevention mentioned less.**
  - *"[on general health research] I know there is a cure for it. I mean...I know someday there is going to be a cure that is going to take it all away."*
- **Research is influenced by companies, politics and process.**
  - *"I also think about the fact that lots of research is hired by companies who would like to make a profit, and sometimes the research results are manipulated."*

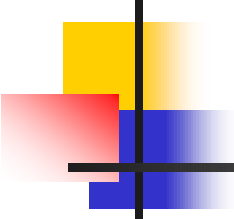


# Differences Between Health Topics:

## *When you think about research on Cancer what comes to mind?*

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- It's personal.
  - *What comes to mind immediately is my Mom. She died of cancer of the kidney...that was in 1980 and then we had to rely totally on the doctor's suggestion as to go ahead and work through this."*
- Finding the cause is a greater part of the discussion.
  - *"My sister had cervical cancer and it was treated successfully with surgery. Now there have been some advances in...the discovery that cervical cancer is caused by a virus...you get a shot to prevent something."*



# *When you think about research on Asthma and Allergies, what comes to mind?*

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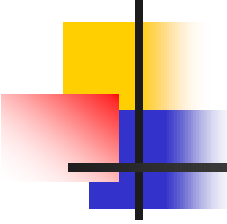
- Children
- Efficacy of treatment
  - "...I don't even know if she got the best treatment."
- Seems less important than cancer because its not as life threatening
  - "I don't think that it has the same kind of emphasis and importance as some of the other illnesses do."
- Environmental determinants
  - *"I am wondering about the environment. We have more allergies today than we've ever had, and I think we have more reactions. And that concerns me about the environment. What are we doing to cause that, or what can we do to stop?"*



*When you think about research on Lead Poisoning Prevention, what comes to mind?*

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- Lead Poisoning Prevention
  - *“Is it really an issue any more? From the paint?”*
  - *“Do pencils have lead?”*



*Imagine that a new study on cancer (etc) is recently completed and is ready to be shared with the public. What would you want to know about it? Themes across health topic areas.*

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■ ***Results***

- Long term effects of treatment
- If the results were a treatment, how much would it cost?
- What were the results, and do they add to what we what we already know? (benefits versus risks)

■ ***Credibility of the study***

- Who funded the study?
- Who conducted the study?

■ ***Study design- emphasis on who was studied***

- Characteristics of population, particularly with when concerned about environmental causes
  - If the health problem is on blacks – Was there a got placebo?
  - If using animals, why?

■ ***Communication of results***

- All groups called for better communication of research results in understandable, simple terms – “comfortable”

# Favored Sources of Information

	<b>Cancer</b>	<b>Asthma &amp; Allergies</b>	<b>Lead Poisoning Prevention</b>
Teachers	<b>Health Care Professionals**</b> Internet	<b>Health Care Professionals</b> Internet	<b>Media* /Internet</b> Public agencies
Public	<b>Magazine/Journals/Friends &amp; Family</b> Internet/HC Prof.	<b>Friends &amp; Family/HC Profs.</b> Media	<b>Health Care Professionals</b> Public agencies/Library

\*Newspapers, TV, Radio

\*\* Doctors and Nurses





# Conclusions

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- Health-related research is often perceived as finding a treatment. The value of prevention research should be more strongly communicated with demonstrated relevance.
- Framing (Nisbet & Mooney, 2007) Health-related research as personal and relevant to family/community could increase its perceived value.
- While people may not know the scientific process, they ask good questions about the quality of a study.



# Limitations

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- Focus group process across many institutions
  - Can't control setting – some inability to transcribe files
  - Diverse skills of focus group moderators
  - Complexity of the discussion guide
- Qualitative data
  - May be differences of people within focus groups, but cannot characterize easily