Need to review data in slides to be sure consistent with final data analysis.....
Collaboration between communities and researchers is:

<table>
<thead>
<tr>
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<th>T</th>
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<tbody>
<tr>
<td>Fun</td>
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<td>Time-consuming</td>
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<td>Frustrating</td>
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<tr>
<td>Personally rewarding</td>
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<tr>
<td>Easy</td>
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<td></td>
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<tr>
<td>A tool for better research</td>
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</table>
What is community-based participatory research?

- **Partnership** of community and researchers who jointly develop projects for mutual benefit
- Research focuses on a **defined community** and brings **benefit** to the community
- All partners have **real influence** on all project phases
  - project focus and objectives
  - implementation (including budget, hiring)
  - evaluation design, data collection and analysis
  - interpretation and dissemination of research findings
- The values, perspectives, cultural backgrounds and contributions of all partners are **respected**
- Research process builds **trust** and nurtures long-term relationships
What is community-based participatory research?

- Research process strengthens trust and collaboration
  - recognizes the expertise and resources of all collaborators
  - builds collaboration infrastructure
  - promotes mutual respect and trust
  - encourages open communication
  - depends on mutual accountability and follow-through
  - supports reciprocal learning
  - develops long-term relationships and commitments
What is community-based participatory research?

• Research benefits the community by
  – providing desired services
  – producing knowledge that promotes change
  – bringing resources (jobs, money, technical assistance)
  – developing capacities
  – giving community partners a share of project activities and funds
  – sharing findings
  – sustaining useful projects
Seattle-King County

Healthy Homes Project

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Community Interviewer

Matthew Ha Nguyen
Outreach Worker

Lin Song
Epidemiologist

Tianji Yu
Systems Analyst
Background

- Prevalence of pediatric asthma increased by 75% from 1980-1995.
- Higher asthma morbidity in low-income, minority, urban populations.
- Exposure to indoor asthma triggers is a major contributor to asthma morbidity and contributes to health disparities.
- The “Healthy Homes” approach reduces multiple exposures but effectiveness has not been rigorously evaluated.
- Community Health Workers are widely used, but effectiveness has not been rigorously evaluated.
Methods: Community Health Worker Home Visits

- Make 5-9 visits over one year
- Assess home environment & develop specific Action Plan
- Offer client education and encourage behaviors to implement plan (e.g. dust control, ventilation)
- Review Action Plan at each visit, provide feedback on control efforts
- Counsel about smoking, refer to free telephonic smoking cessation program (Free and Clear™), provide nicotine patches
- Provide social support
- Offer advocacy/referral (housing, food, furniture, jobs, etc.)
Methods: Provision of Trigger Control Resources

- Allergy control bedding covers
- Low-emission vacuum cleaner with dirt finder sensor
- 1-Year supply of microfiltration vacuum bags
- Commercial doormat
- Cleaning supplies (green kit, mop, pail, scrub brushes, bleach)
Methods: Intervention

- Protocols developed for the following topics:
  - Basic asthma education
  - Dust mites
  - Moisture and mold
  - Roaches (IPM)
  - Rodents
  - Tobacco smoke
  - Dust control
  - Household cleaning
  - Pets
  - Landlord-tenant relations
  - Lead
  - Hazardous home products

Using a low-emission vacuum  Putting on a mattress cover
CHW characteristics

- Ethnicity: African American, Vietnamese, Latina
- Gender: 5/6 female
- Residence: in target community
- Asthma: CHW or family member affected
CHW recruitment and training

- Recruitment
  - Word of mouth
  - Networking with CBOs
- Training
  - 40 hour classroom
  - Field experience
  - Continuing education
  - Case discussions
CHW management

- Close supervision
- Weekly work schedules
- Flexibility to accommodate personal needs
- Clear protocols
- 40-80 clients per FTE (50 is reasonable)
- Provide emotional support
- Incorporate periods of less intensive activity
Project Collaborators

- Seattle Partners for Healthy Communities
- Public Health – Seattle & King County
- Center for MultiCultural Health
- Master Home Environmentalist Program / American Lung Association of WA
- Washington Toxics Coalition
- University of Washington
- Community Coalition for Environmental Justice
- Seattle Tenants Union
- Seattle Housing Authority
- King County Housing Authority
- Group Health Cooperative of Puget Sound
- Engineering Plus
- Community clinics, hospitals and emergency departments
- Seattle Public School District
- Neighborhood House Parent & Child Center
- Institute of Neurotoxicology and Neurological Disorders
- Additional support from CDC, Hoover Vacuum Company, Nesholm Foundation, Seattle Foundation, Seattle Solid Waste Utility
What was it like to participate in the project?
Recruitment and Research Design

- **Eligibility**
  - household income below 200% poverty
  - child age 4-12 with asthma

- **Randomized controlled design:** participants randomized into high (n=138) and low (n=136) intensity intervention groups.
  - High group: full intervention
  - Low group: one visit, follow-up call, bedding covers only
  - Low group crosses over to high group after one year

- **Community-based participatory research methods**

- **Main outcome measures**
  - Child’s asthma symptoms
  - Caregiver quality of life
  - Asthma-related health services utilization
## Participant Demographics

### Characteristics of High and Low Intensity Groups (%)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>high</th>
<th>low</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>138</td>
<td>136</td>
</tr>
<tr>
<td>Income &lt; 100% poverty</td>
<td>51.9</td>
<td>60.9</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>34.1</td>
<td>27.3</td>
</tr>
<tr>
<td>African American</td>
<td>31.9</td>
<td>27.2</td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td>11.6</td>
<td>20.6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>17.4</td>
<td>16.9</td>
</tr>
<tr>
<td>Other</td>
<td>5.1</td>
<td>8.1</td>
</tr>
<tr>
<td>Renter</td>
<td>81.9</td>
<td>83.0</td>
</tr>
<tr>
<td>Completed high school</td>
<td>59.1</td>
<td>52.4</td>
</tr>
<tr>
<td>Caretaker employed</td>
<td>47.8</td>
<td>57.4</td>
</tr>
</tbody>
</table>
## Baseline Asthma Severity

### Characteristics of High and Low Intensity Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>high</th>
<th>low</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asthma Severity (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild intermittent</td>
<td>21.0</td>
<td>27.2</td>
</tr>
<tr>
<td>Mild persistent</td>
<td>15.9</td>
<td>12.5</td>
</tr>
<tr>
<td>Moderate persistent</td>
<td>30.4</td>
<td>36.8</td>
</tr>
<tr>
<td>Severe persistent</td>
<td>32.6</td>
<td>23.5</td>
</tr>
<tr>
<td><strong>Symptom days/2 week</strong></td>
<td>8.1</td>
<td>7.6</td>
</tr>
<tr>
<td><strong>Activity limitation/2 weeks</strong></td>
<td>5.3</td>
<td>4.1</td>
</tr>
<tr>
<td><strong>B agonist use/2 weeks</strong></td>
<td>7.2</td>
<td>7.0</td>
</tr>
<tr>
<td><strong>Caregiver quality of life</strong></td>
<td>4.1</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>Urgent health care use (%)</strong></td>
<td>25.9</td>
<td>21.3</td>
</tr>
</tbody>
</table>
Baseline: The Home Environment

- Smoker in house: 40% high, 60% low
- Mold: 40% high, 60% low
- Water damage: 30% high, 70% low
- No working bath fan: 20% high, 80% low
- Carpet in bedroom: 30% high, 70% low
- Pets: 20% high, 80% low
- Cockroaches: 20% high, 80% low
Baseline Findings: Resources and Knowledge

- Have bedding covers: 10%
- Have low-emission vacuum: 10%
- Know tobacco triggers: 100%
- Know mold triggers: 80%
- Know roaches trigger: 40%

Legend:
- Blue: high
- Red: low
Outcome: Symptom Days

days in past 2 weeks

p-values:
0.000  (high intensity, baseline vs. exit, chi-square)
0.000  (low intensity, baseline vs. exit, chi-square)
0.123  (exit, low vs. high intensity, regression adjusted for baseline score)
Outcome: Caregiver Quality of Life

p-values:
0.000 (high intensity, baseline vs. exit, chi-square)
0.006 (low intensity, baseline vs. exit, chi-square)
0.001 (exit, low vs. high intensity, regression adjusted for baseline score)
Outcome: Urgent Health Services

p-values:
0.000  (high intensity, baseline vs. exit, chi-square)
0.414  (low intensity, baseline vs. exit, chi-square)
0.041  (exit, low vs. high intensity, regression adjusted for baseline score)
Outcomes: Participant Actions

p value comparing high vs. low exit values after adjustment for baseline values using logistic regression

Vacuum child's BR >2x/2wk

Use allergy control cover

Wash sheets weekly

* p value comparing high vs. low exit values after adjustment for baseline values using logistic regression
Results: Participant Actions

- caretaker is smoker: p = 0.053*
- allow smoking in house: p = 0.519*
- pets in house: p = 0.341*

* p value comparing high vs. low exit values after adjustment for baseline values using logistic regression
Outcomes: Floor Dust Loading

Dust loading child's bedroom

- baseline, high: p = 0.008
- exit, high: p = 0.172
- baseline, low: p = 0.070*

* p value comparing high vs. low exit values after adjustment for baseline values using linear regression

gm/m²
Outcomes: Roaches and Mold

* p value comparing high vs. low exit values after adjustment for baseline values using logistic regression

Roaches
- baseline, high: 0
- exit, high: 0
- baseline, low: 0
- exit, low: 0

Mold
- baseline, high: 0
- exit, high: 0
- baseline, low: 0
- exit, low: 0

p = 0.831*
p = 0.214*
p = 0.564
p = 0.003
p = 0.071
p = 0.853
Conclusions

- Many low-income urban children with asthma in King County are exposed to indoor asthma triggers.

- Substandard housing, lack of knowledge and resources, and caretaker’s actions often underlie exposures.
Conclusions

A community health worker intervention addressing multiple exposures reduced asthma symptom days, improved caretaker quality of life and reduced urgent health services utilization:

<table>
<thead>
<tr>
<th>Outcome</th>
<th>High Intensity</th>
<th>Low Intensity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Urgent utilization</td>
<td>↓</td>
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</tr>
</tbody>
</table>
Conclusions

- The degree of improvement in quality of life and utilization was greater with the higher intensity intervention.

- The intervention increased caretaker knowledge and actions, and reduced exposures more, in the high intensity group.
Conclusions

- Policies to reduce exposures are needed:
  - Availability of healthy housing for low income families
  - Insurance coverage of exposure control resources and CHWs
  - Further development and implementation of “Healthy Homes” housing standards
Challenges

• Setting boundaries with clients
• Flexibility to accommodate changing protocols
• Logistical hassles
  – Traffic
  – Clients not home
  – Evening and weekend work
• Self-management
• Documentation
CBPR: Project development

- Community (Seattle Partners Board) and Public Health staff identified asthma as priority
- Public Health staff developed initial ideas
  - Experience
  - Evidence in the literature
  - Consulting with experts
- Steering committee provided oversight
  - Reviewed and modified proposal
  - Defined roles on project
- Parent Advisory Group offered advice
- Staff from communities brought experience, developed details
CBPR: Evaluation

- **Study design**
  - Community concerns with controlled design
    - Compare high intensity group to low intensity group
    - Low intensity group receives high intensity benefits after 1 year

- **Data collection**
  - Review, edit and shorten questionnaire
  - “Does your child have asthma?”
  - Validity of data collection may have been improved

- **Qualitative evaluation collects data from partners**
  - Formative feedback at midcourse
CBPR: Project Implementation

- Protocol development and modification
  - “This is way too complicated and won’t work!”
  - Reduce outreach visit frequency and duration
  - Weekend and evening home visits
  - Expand capacity to address non-asthma client needs

- Recruitment facilitated
CBPR: Project Implementation

- Access to homes
- Cultural competence and respect for community values
  - Intervention was flexible in meeting needs of diverse cultures and therefore better accepted and more sustainable
  - “What, the community health worker gave vacuums to the low intensity group?”
  - Electric candles instead of burning incense
  - Provide bleach
CBPR: Researcher-Community Communication

• Parent Advisory Group
  – Genuine influence over project
  – Needs support (transportation, childcare, dinner, stipend)
  – Ongoing relationships: active in HH-II and HUD

• Newsletter
• Health Fairs
• Celebrations
CBPR: Sustainability

- Sustaining community benefit after grant funds finish
- Ongoing funding
  - More grants
  - Public sector
  - Private sector (e.g. insurers)
- Integration into existing practice
- Policies and advocacy
Sustainability: Research

● Healthy Homes II
  ◆ Compare effectiveness of CHW in-home asthma support to clinic-based education
  ◆ CHW intervention combines support for medical aspects of asthma self-management with reduction of indoor triggers
  ◆ RCT of 380 low-income households with children with asthma funded by NIEHS
  ◆ Wait-list control group
  ◆ Sponsored by local asthma coalition
Sustainability: Dissemination

- Expand locally
  - Local asthma coalition supports two CHWs
  - Local health department supports one CHW
- Diffuse to other cities
- Work with health services payers to support Healthy Homes approach
Sustainability: Housing Policy

- Partner with public housing agencies
  - Incorporating Healthy Homes and Healthy Communities design principles in new public housing construction
  - Assisting public housing tenants with special health needs in obtaining appropriate units (e.g. dry and above grade for households with asthma)

- Housing and Health Work Group
- Update housing code to reflect Healthy Homes principles
- Advocate for availability of healthy and affordable housing for low income families
Sustainability: Housing Remediation
Better Homes for Asthma

- Ongoing research demonstration project funded by HUD
- Tim Takaro, PI
- Remediate 70 substandard homes with conditions associated with asthma and other health risks:
  - improve ventilation
  - remove old carpet
  - eliminate water intrusion
  - install lighting and barriers to prevent falls
  - address lead paint if present
- Assess impact of remediation on health of occupants
- Compare marginal value of remediation relative to community health worker intervention
CBPR: Conclusions

- Community involvement in the project was beneficial:
  - Intervention was culturally competent, acceptable to community, and more sustainable
  - Recruitment was facilitated
  - Validity of data collection may have been improved
  - More likely that findings will shape practice
Why Collaborate?
Benefits for Researchers

• Hypothesis generation
  – new ways of looking at issues
  – access to community knowledge and experience
  – questions relevant to community concerns

• Data collection
  – improved questionnaires
  – more valid and reliable responses
  – less intrusive measures
  – greater cooperation with data collection

• Subject recruitment
  – access to community members
  – more effective recruitment and retention, especially among minorities
Why Collaborate?
Benefits for Researchers

- Study design and implementation
  - novel intervention ideas
  - community acceptability
  - practical, feasible protocols
  - cultural competence
  - ability to address health problems that result from complex interactions of individual, social, cultural and political factors

- Interpretation and application of findings
  - understanding *how* an intervention works or *how a causal association* operates
  - project sustainability
  - increased likelihood that findings will shape practice
Why Collaborate?
Benefits for Researchers

• Builds connection to communities
  – facilitates communication with community members
  – builds relationships and opens door to future projects
  – breaks down barriers and overcomes distrust
  – increases community support for research
Why Collaborate?
Benefits for Communities

- Improves health
- Brings resources to community
- Provides access to technical expertise and credibility
- Results in findings that are relevant to community concerns
- Helps improve programs, gives feedback on effectiveness, provides data for policy makers
- Recognizes lived experience and knowledge of community members
- Provides opportunities to acquire new skills and knowledge
How Collaborate: Spectrum of participation

- Fixed, predetermined protocols
- Standardized data collection tools
- Professional staff
- Institutional fiscal agent

- Flexible, process-derived protocols
- Specific, customized data collection tools
- Community staff
- Community fiscal agent
How Researchers Can Collaborate

- Develop relationships with community partners
- Spend time in the field with participants
- Project empowers participants and staff
- Be flexible and willing to adapt protocols and data collection tools
- Listen a lot and speak little
- Learn from partners (don’t assume you know best)
- State your perspectives clearly and openly, but don’t assume it is the last word
- Assure the project meets participants’ needs (e.g. addresses other issues, provides resources)
Conclusions

• Collaboration appropriate to some (not all) projects: couldn’t have done Healthy Homes without it

• Different forms of collaboration appropriate for different projects

• Requires adequate resources and defined structure and processes

• Requires good communication and continuity of relationships
Conclusions

Collaboration is

- fun
- time-consuming
- frustrating
- personally rewarding
- a tool for better research