

Need to review data in slides
to be sure consistent with final
data analysis.....

This is a test

Collaboration between communities and researchers is:

Fun	T	F
Time-consuming	T	F
Frustrating	T	F
Personally rewarding	T	F
Easy	T	F
A tool for better research	T	F

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

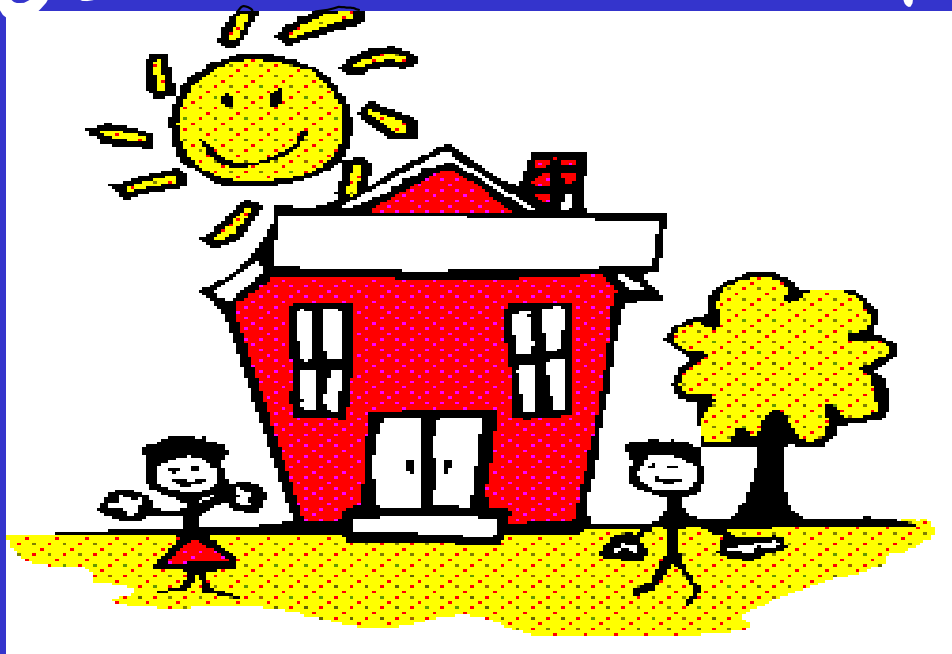
What is community-based participatory research?

- **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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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 (%)

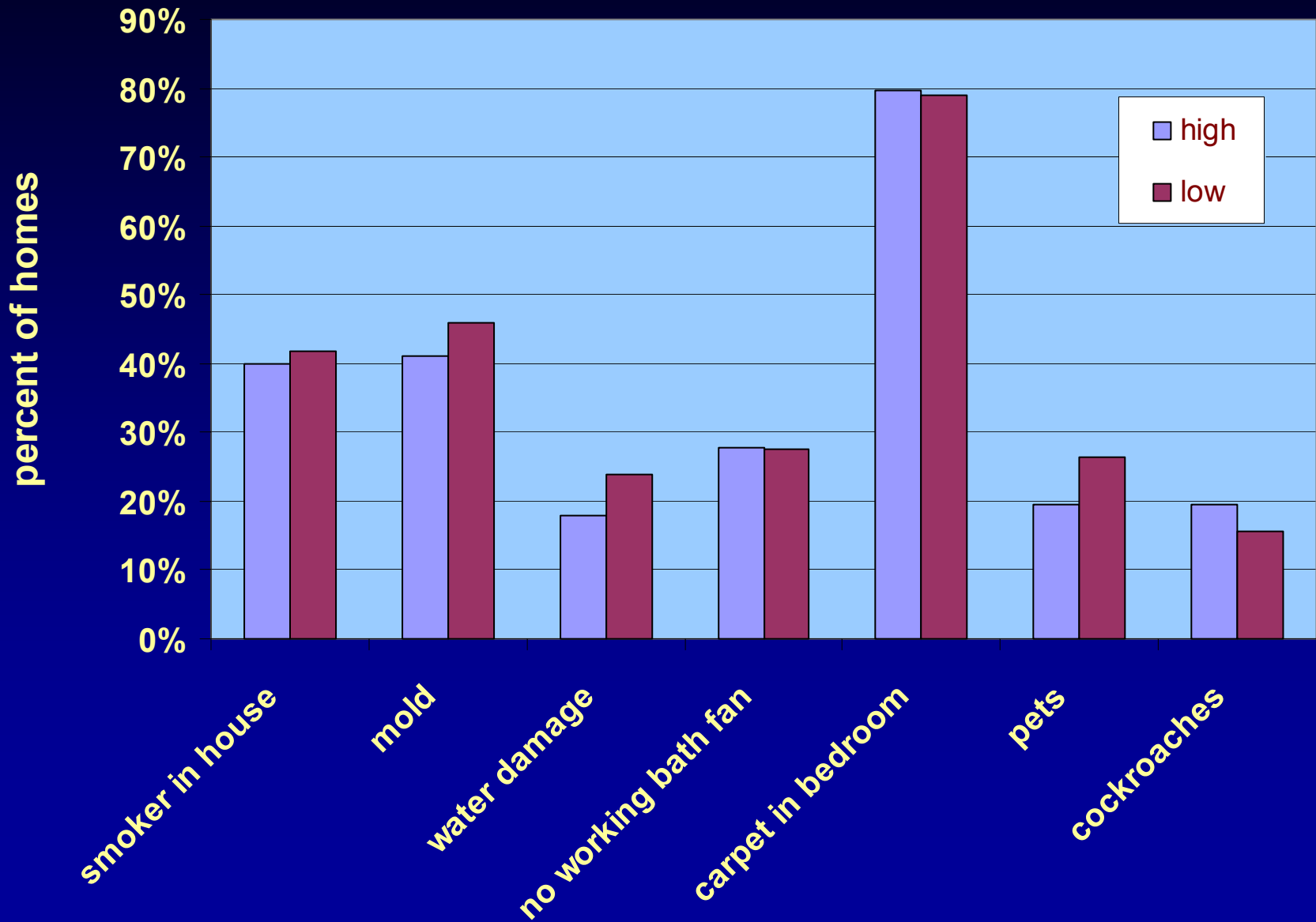
Characteristic	high	low
Number	138	136
Income < 100% poverty	51.9	60.9
Ethnicity		
Asian	34.1	27.3
African American	31.9	27.2
White non-Hispanic	11.6	20.6
Hispanic	17.4	16.9
Other	5.1	8.1
Renter	81.9	83.0
Completed high school	59.1	52.4
Caretaker employed	47.8	57.4

Baseline Asthma Severity

Characteristics of High and Low Intensity Groups

Characteristic	high	low
Asthma Severity (%)		
Mild intermittent	21.0	27.2
Mild persistent	15.9	12.5
Moderate persistent	30.4	36.8
Severe persistent	32.6	23.5
Symptom days/2 week	8.1	7.6
Activity limitation/2 weeks	5.3	4.1
B agonist use/2 weeks	7.2	7.0
Caregiver quality of life	4.1	4.5
Urgent health care use (%)	25.9	21.3

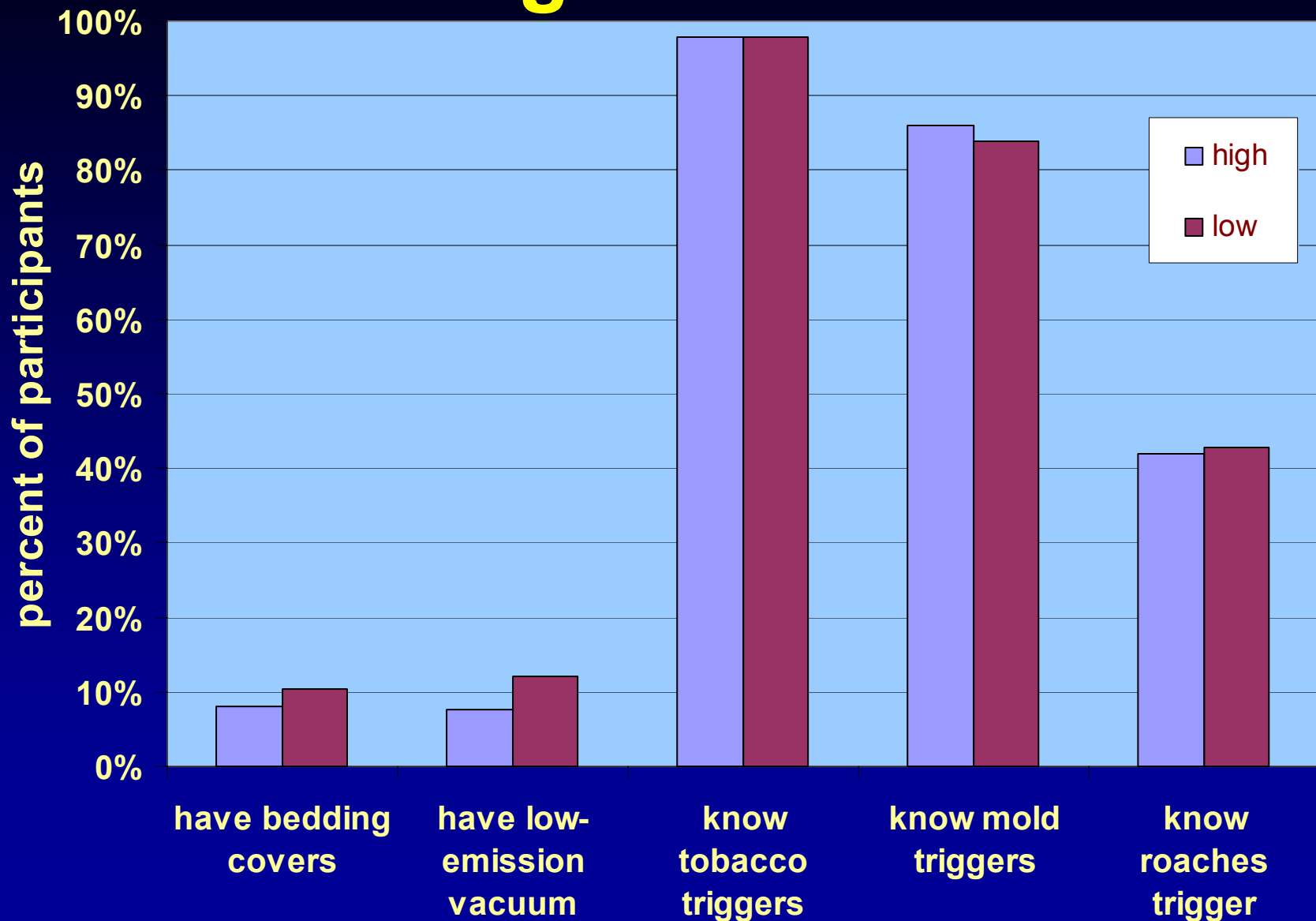
Baseline: The Home Environment



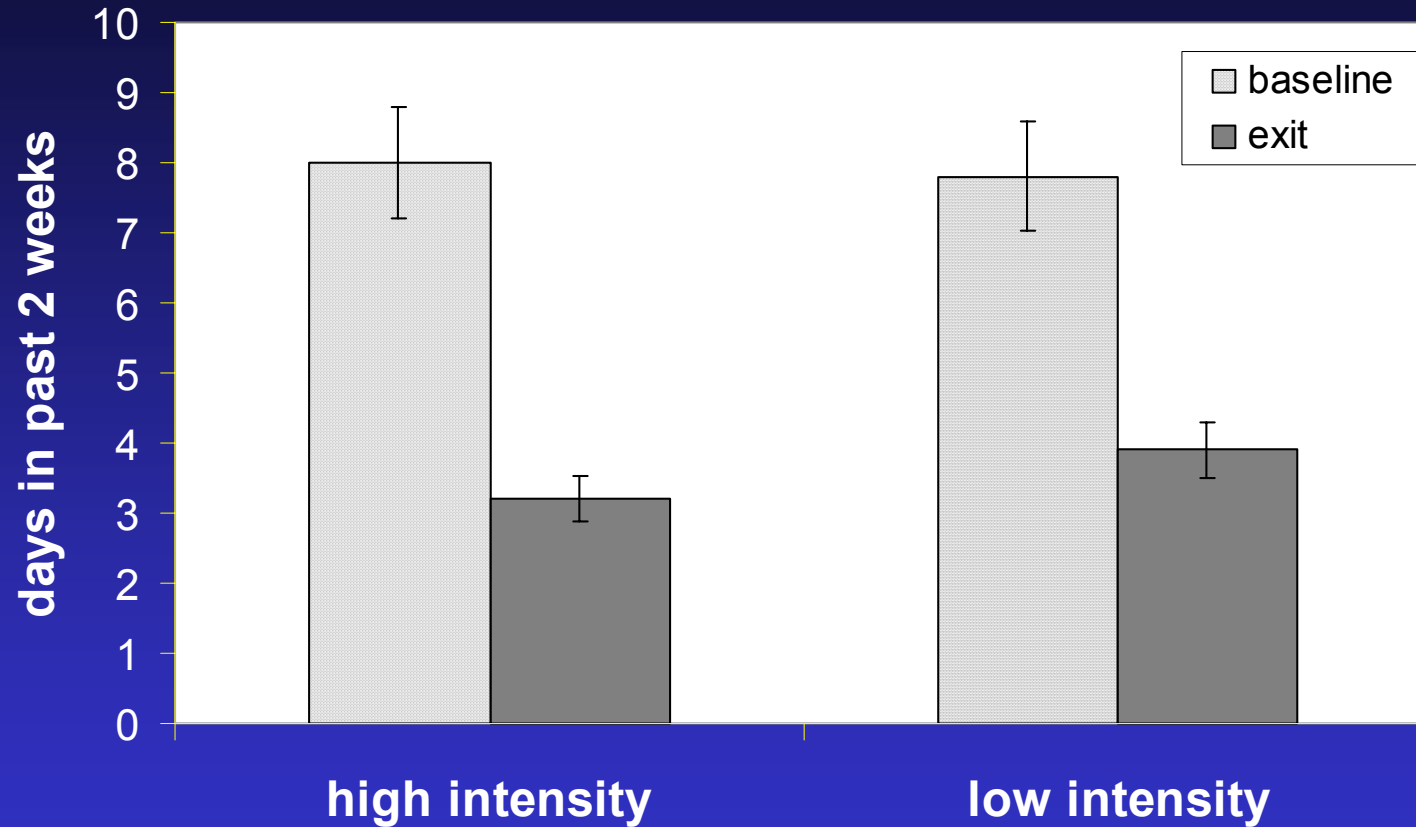




Baseline Findings: Resources and Knowledge



Outcome: Symptom Days



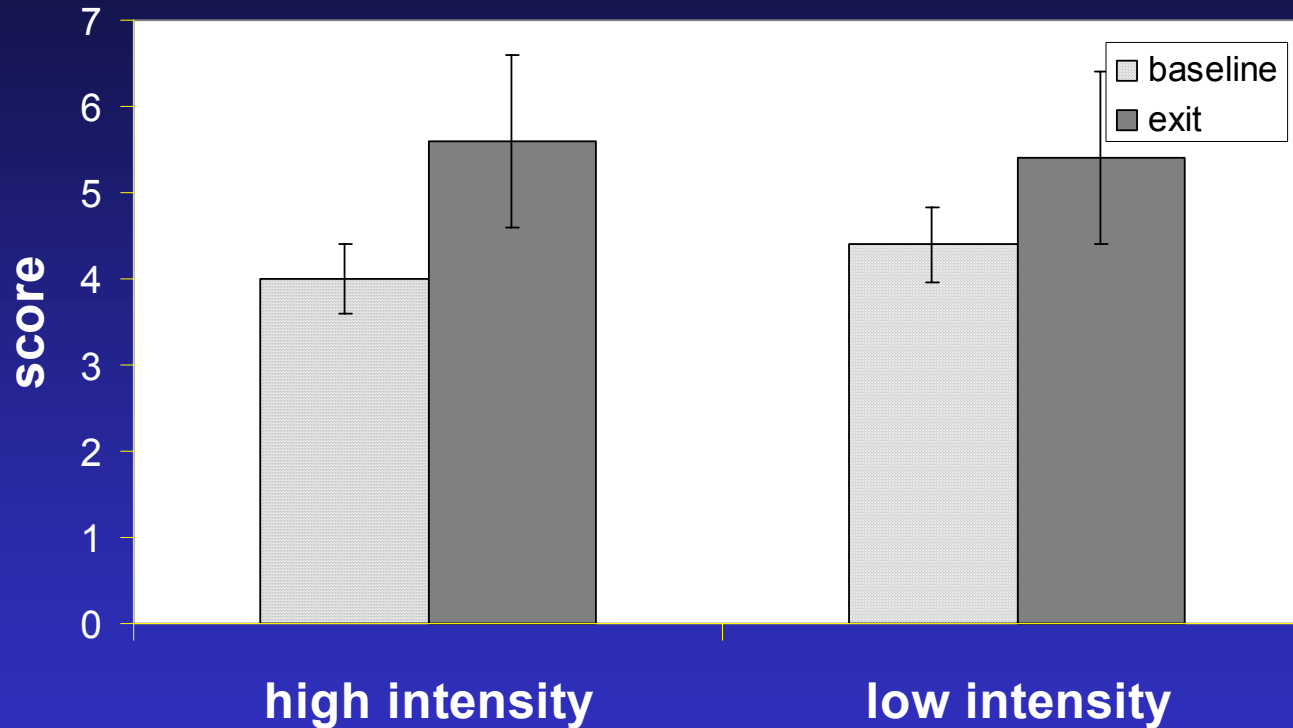
p-values:

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



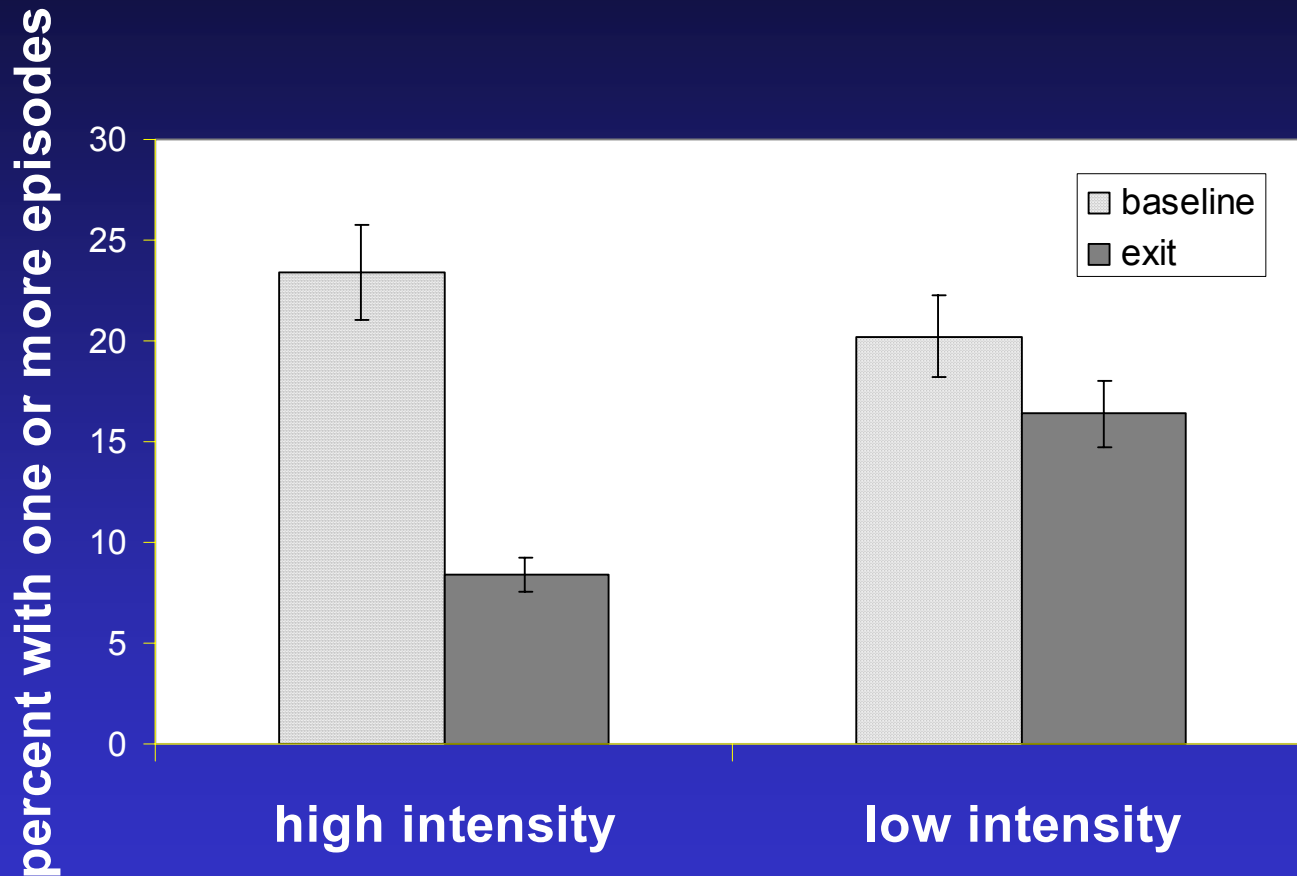
p-values:

0.000 (high intensity, baseline vs. exit, chi-square)

0.006 (low intensity, baseline vs. exit, chi-square)

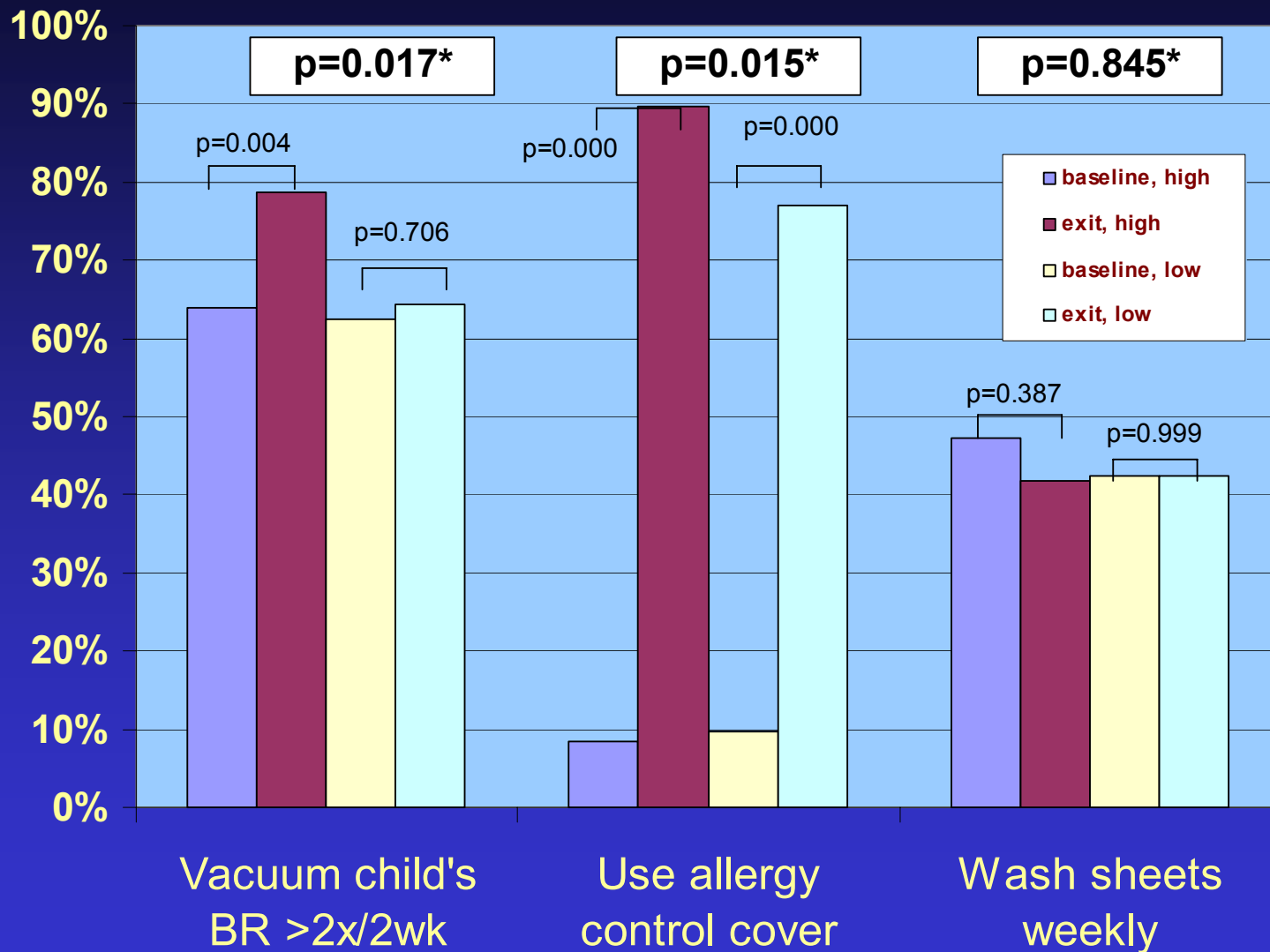
0.001 (exit, low vs. high intensity, regression adjusted for baseline score)

Outcome: Urgent Health Services



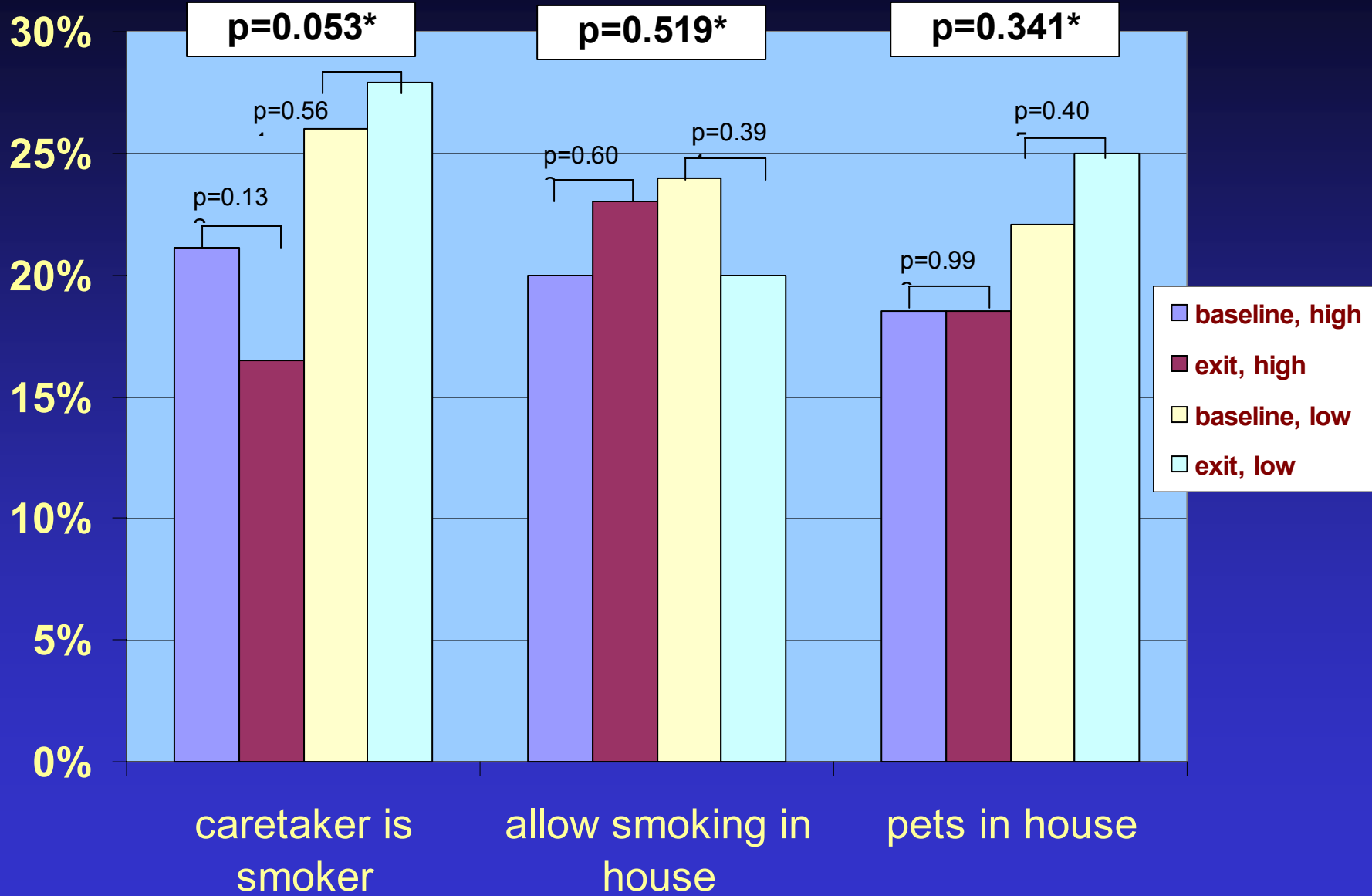
p-values:
0.000 (high intensity, baseline vs. exit, chi-square)
0.414 (low intensity, baseline vs. exit, chi-square)
0.041 (exit, low vs. high intensity, regression adjusted for baseline score)

Outcomes: Participant Actions



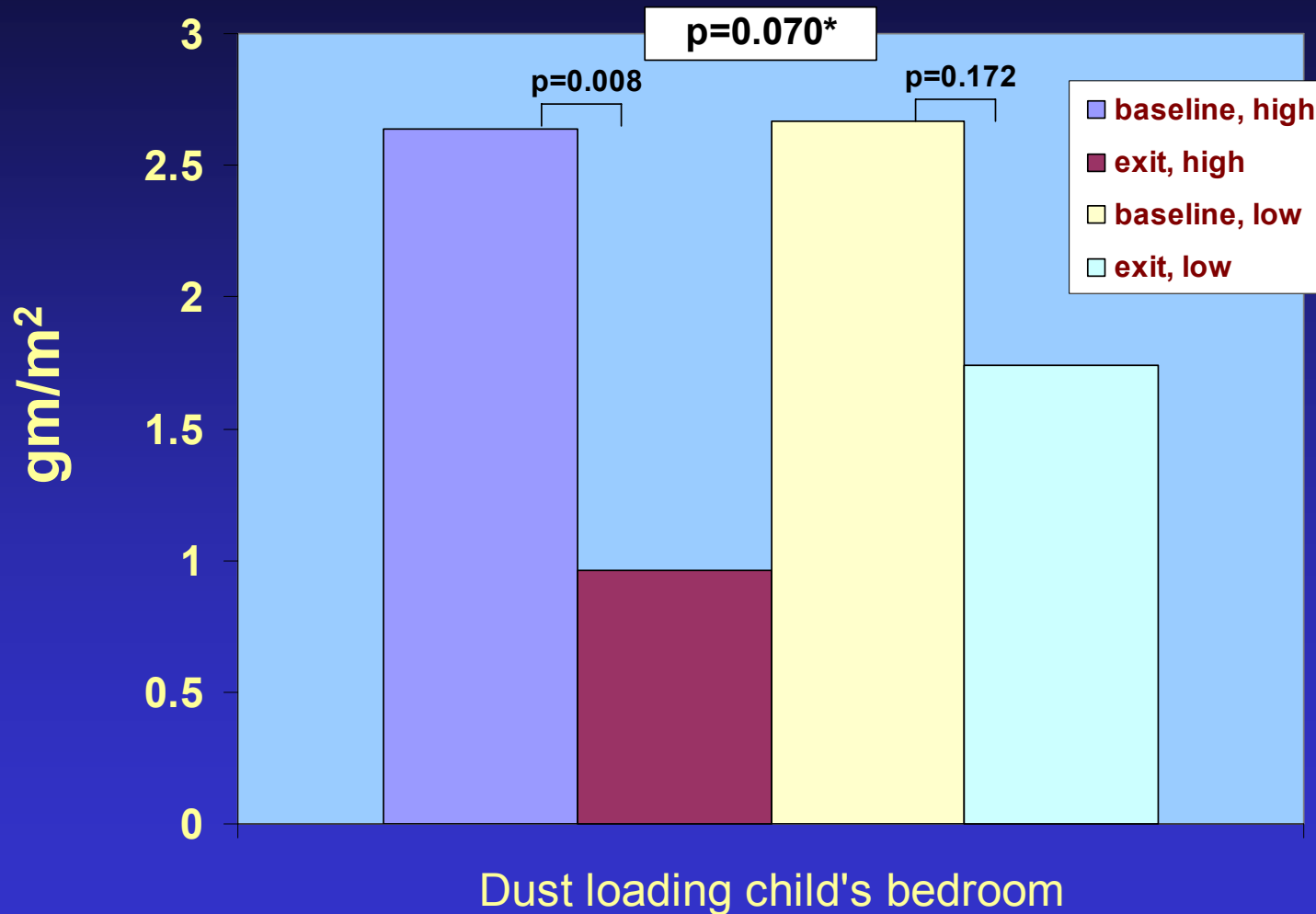
ue comparing high vs. low exit values after adjustment for baseline values using logistic regression

Results: Participant Actions



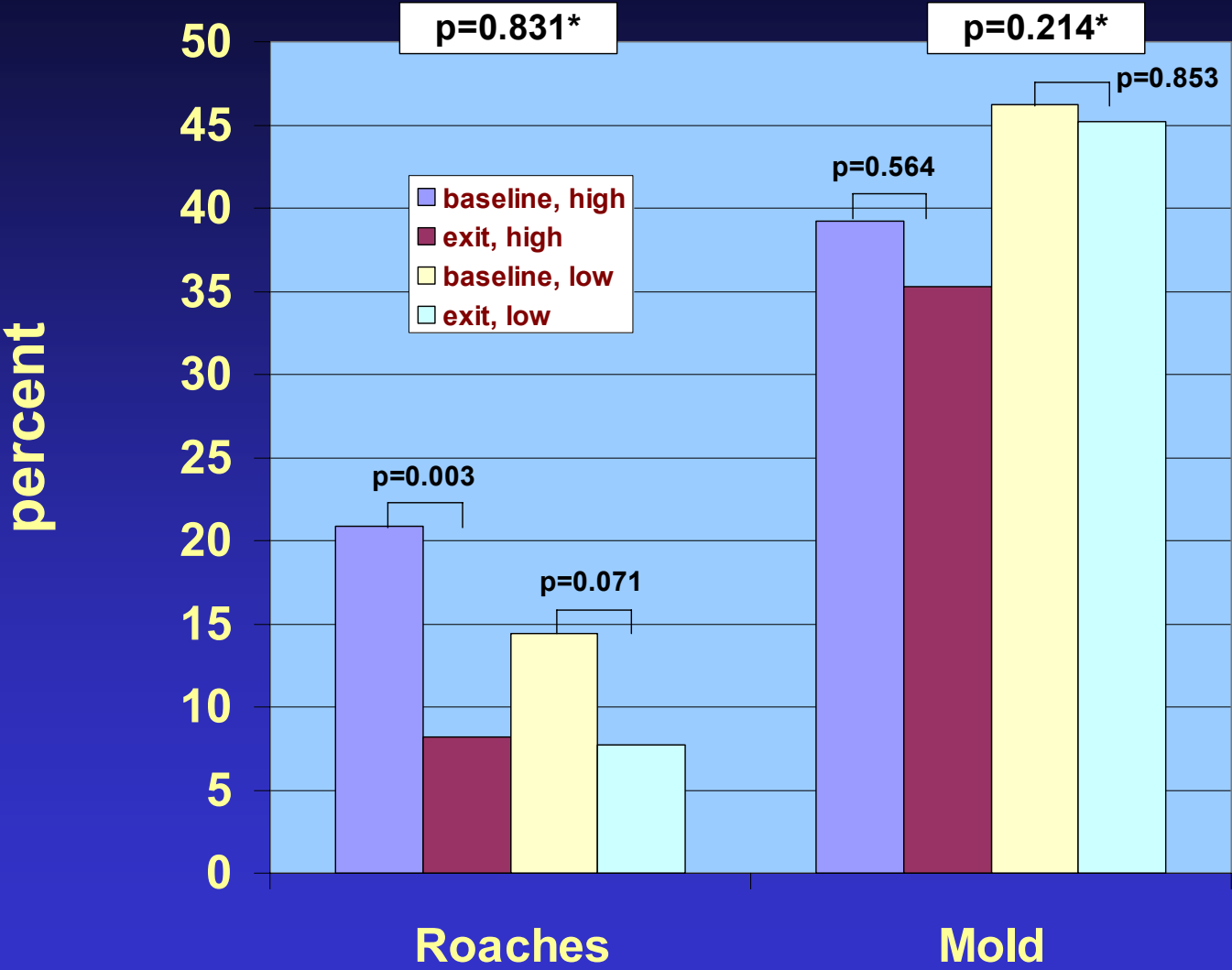
ue comparing high vs. low exit values after adjustment for baseline values using logistic regression

Outcomes: Floor Dust Loading



ue comparing high vs. low exit values after adjustment for baseline values using linear regression

Outcomes: Roaches and Mold



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

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:

Outcome	High Intensity	Low Intensity
Symptoms	↓	↓
Quality of Life	↑	↑
Urgent utilization	↓	

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

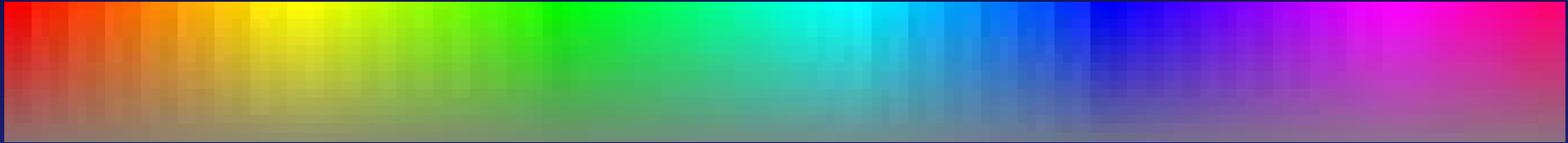
Results in findings that are relevant to community concerns

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