



# Identifying Issues for Recruitment, Retention, and Community Involvement

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## ABSTRACT:

Better understanding of the most effective recruitment and retention strategies for community-based environmental health research is needed

- ◆ A series of 18 focus groups were conducted across the U.S. in February 2003
- ◆ Additional focus groups were conducted across the U.S. in November and December

Focus group results will help with the plan and design protocols for the NCS to maximize participation while minimizing selection bias and loss to follow-up.

## ISSUES BEING ADDRESSED:

Recruitment and retention for the NCS based on three key themes:

- ◆ Getting you interested
  - ◆ Where best to hear about NCS
  - ◆ Type of information want to know
- ◆ Time commitment and data collection activities
  - ◆ Schedule of participation
  - ◆ Environmental home sampling
  - ◆ List of potential biologic specimens
- ◆ Keeping you interested
  - ◆ Incentives
  - ◆ Stay in touch
  - ◆ Information participants want over time



## APPROACH TO ADDRESSING THE ISSUES:

- ◆ 18 focus groups held across the U.S. February 2003
  - ◆ Pregnant women (10 groups, one with expectant dads) varied by:
    - ◆ Geography
    - ◆ Maternal age (mixed, <35, ≥35)
    - ◆ Population density (urban, rural, suburban)
    - ◆ Maternal education (mixed, ≤HS, >HS)
    - ◆ Health care provider (private, public, specialty clinic)
  - ◆ Health Care Professionals (two groups)
    - ◆ Pediatrics and Family Care
    - ◆ Obstetrics and Gynecology
  - ◆ Parents of school-aged children (Four groups)
    - ◆ Disabled
    - ◆ Non-Disabled
  - ◆ Community Organizations (two groups)



## RESULTS:

### Pregnant women and Parents of school-aged children

- ◆ 10 pregnant women groups ranged in size from 3 to 9 participants
- ◆ 4 parent groups ranged in size from 3 to 8 participants
- ◆ Getting You Interested
  - ◆ Want details of study before deciding to participate
  - ◆ Overall public health significance important
  - ◆ "How will it benefit my child?"
  - ◆ "It's important to help somebody out, not just my child."
- ◆ Being pregnant made first time moms more interested
  - ◆ Women who have children already concerned about child health

### Time Commitment and Data Collection Activities

- ◆ Limit clinic visits infant's first year: maybe more home visits
- ◆ Unwilling/unable to provide some biologic samples
  - ◆ Baby teeth "The tooth fairy takes those."
  - ◆ Nails from disabled children
- ◆ Misinterpretation of some specimen questions "The blood piece is a turnoff."
- ◆ Placenta
- ◆ Baby teeth
- ◆ Convenience, ease of participation
  - ◆ Coordinate with routine MD appointments

### Keeping You Interested

- ◆ Incentives are important
  - ◆ Cash as well as gifts – give choices
- ◆ Researchers need to establish relationship with participants
- ◆ Provide opportunities for networking with other parents in the study, social interactions

"I don't want my child to be a guinea pig."

## Health Care Professionals

- ◆ OB-GYN/Family practice 5 participants
- ◆ Pediatric practice 9 participants
- ◆ Getting You Interested
  - ◆ Want to know what will be required of their practice
  - ◆ Best place to hear about study – professional journals
  - ◆ Possibility to network with peers exciting

### "What's in it for me? Will I be recognized for my participation?"

#### Time Commitment and Data Collection Activities

- ◆ Concerned about liability
- ◆ "What are the risks to my patients?"
- ◆ Participation in study
  - ◆ Private physician offices: saw no problem in actively recruiting participants
  - ◆ Public clinics: prefer to passively support study, do not have staff or time to actively recruit participants
- ◆ Don't have problem with collection of samples per se...
  - ◆ Want to know why and what will test
  - ◆ Worried about genetic testing

### Keeping You Interested

- ◆ Distinct differences between private physician offices and public clinics
  - ◆ Types of incentives
    - ◆ Private physician offices: laptop computer with network card, regularly occurring incentives that could be used for staff luncheons
    - ◆ Public clinics: professional development incentives and subsidize labor cost involved with study



"I am pregnant... Because I have a common bond to women who are pregnant, the spokesperson should also share that bond."

## Community Organizations

- ◆ Each focus group had 9 participants
- ◆ Getting You Interested
  - ◆ Focus on individual community needs
  - ◆ Community organization support would benefit recruitment
- ◆ Time Commitment and Data Collection Activities

### "Expectations of community organizations need to be clear."

- ◆ Involve community organizations from beginning of planning process
- ◆ To aid in recruitment, community needs assessments
  - ◆ Implement effective interventions or programs as a result of the study

### Keeping You Interested

- ◆ Use consistent incentives for participants rather than expensive one-time gifts
- ◆ Community organizations more likely to be involved if there is funding
- ◆ Endorsement of community advisory boards
- ◆ "In order for us to help you, we have to be experts too."

## FOCUS GROUPS PHASE II:

- ◆ Currently being conducted
- ◆ Examining recruitment and retention issues among the following:
  - ◆ Distrust in research among racial/ethnic groups
    - ◆ African American
    - ◆ Other Black
    - ◆ Mexican American
    - ◆ Other Hispanic
    - ◆ Native Americans
    - ◆ Asian
  - ◆ Teen moms
  - ◆ Couples attempting pregnancy
  - ◆ Biospecimen collection



"There must be something to keep you interested 21 years."

## IMPLICATIONS FOR THE NATIONAL CHILDREN'S STUDY:

- ◆ Focus groups provided insights into participants' decision making process
- ◆ Results will be utilized by NCS study planners to help with design protocols

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