



Retention Strategies and Predictors for Urban Cohorts: Experience of the Urban Environment and Childhood Asthma Study (URECA)

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URECA

- Observational birth cohort study to determine factors influencing the development of asthma
 - Immunologic
 - Stress
 - Environmental exposures
- Families live in 4 urban areas in the U.S.
 - Baltimore
 - Boston
 - New York
 - St Louis

Eligibility Criteria

- Parental history of asthma or allergic diseases
- Reside in urban areas >20% below poverty level
- Cord blood collection at site hospital
- No respiratory complications at birth
- Telephone access

Demographics

- 609 children enrolled
- Race/ethnicity
 - 69.8 % African American
 - 20.8 % Hispanic
 - 9.3% Mixed or other
- 68.4 % with income less than \$15,000 yearly
- 57.6% - moved at least once since study start

URECA Timeline

- Recruited over a 2 year period
- Oldest children now 3 years of age



Participant Contact

- Main contact with child's caretaker
- Types of contact
 - Yearly clinical evaluations
 - Yearly home visits for environmental sampling
 - Quarterly telephone interviews
 - Respiratory illness reporting and sample collection

Scheduling

Upcoming Events

Urban Environment and Childhood Asthma

All Events

Boston

Date range: 03/19/08 - 03/26/08

Scheduled visits: 3

Upcoming visits: 35

Scheduled Events

Study ID	Visit	Sched Date	Time	End of Window	Notes
07-02-094-7	21-Month Call	03/19/08	03:05 PM	05/06/08	
07-02-049-2	24-Month Clinic Visit	03/25/08	09:00 AM	04/23/08	2/7/08-Sent out appointment confirmation letter. EA 3/25/08-Called Tiffany to reschedule but she wasn't home and female answered and said she will let Tiffany know to call me. primary phone # is disconnected.
07-02-074-6	Home Eval Years 1 and 2	03/26/08	09:30 AM	04/19/08	10/26: mother lives in a shelter in Brockton. EG 2/27/08-Sent out confirmation letter. EA 3/25/08-Called to reschedule and male said he will give her the message. 3/28/08-Called to reschedule and female said she left and will give Maryann the message.

Monitoring

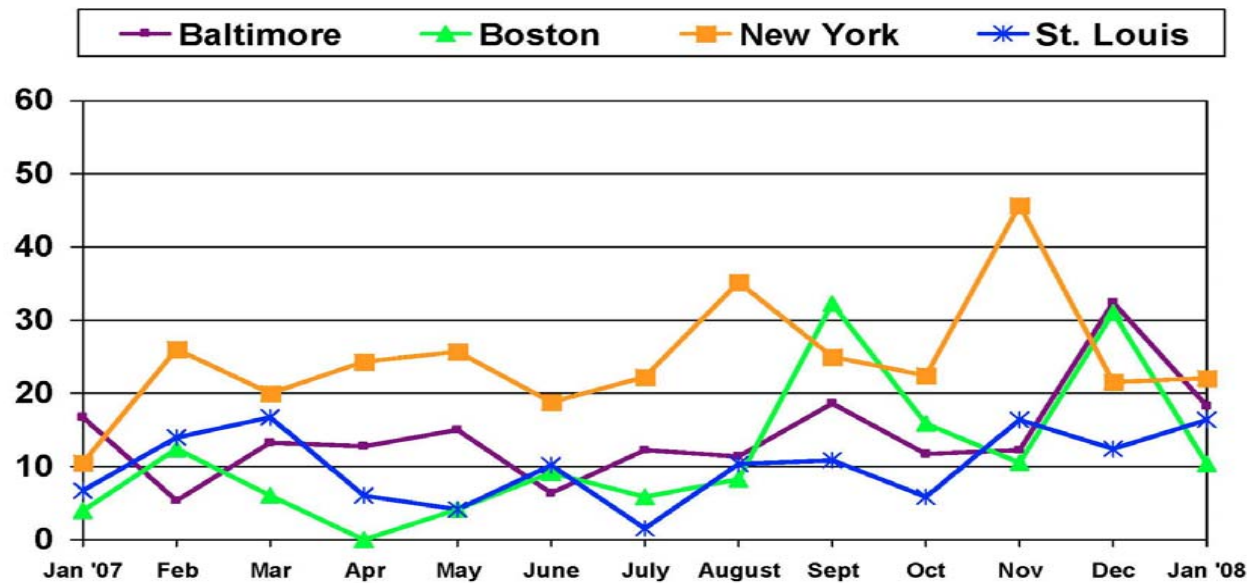
Weekly Status Report

9 Month Visit	BA	BO	NY	SL	Total
Deactivated	0	3	7	3	13
Missing	14	26	24	18	82
Pending	0	0	0	0	0
Occurred	146	112	85	145	488
Occurred Late	4	2	9	2	17
12 Month Visit					
Deactivated	1	7	2	8	18
Missing	21	16	30	20	87
Pending	0	2	0	1	3
Occurred	138	113	77	134	462
Occurred Late	2	3	3	3	11

Monitoring

Percent of Quarterly Assessments Missed by Month and Site URECA Study through 04-08-08

(2007 and on – results displayed through January 2008)



Importance of Early Events for Subsequent Participation

Participant characteristic	Percent of subsequent events completed	ANOVA p-value
If 3-month visit:		
Completed	87.3%	<0.0001
Missed	57.6%	
If 12-month visit:		
Completed	92.4%	<0.0001
Missed	34.4%	

Characteristics Not Related to Subsequent Participation

- Maternal education
- Marital status
- Maternal age
- Household income
- Cell phone reimbursement
- Age child entered daycare
- Maternal depression or stress score

Reasons for Deactivations

Reason	Number
Lost contact with family	27
Consent withdrawn	18
Other (custody issues, incarcerations)	14
Family moved from area	6
Medical reasons	4
Total	69

Deactivation Rate by Age of Child

Age	Number deactivated	Cumulative deactivation rate
0 - 12 months	43	7.1%
12 - 24 months	26	11.7%

Characteristics Related to Deactivation

	Percent deactivated	Chi-square p-value
If 3-month visit: missed	34.0%	p < 0.0001
completed	4.9%	
If Mother's age: < 18 yrs. old	22.7%	p = 0.02
18 + yrs. old	10.7%	
If Child in daycare at 3 months: enrolled	10.9%	p = 0.01
not enrolled	3.8%	

Characteristics Not Related to Deactivation

- Maternal education
- Marital status
- Household Income
- Maternal depression score
- Maternal stress score

Retention Strategies

- Essential
- Helpful
- Effectiveness Unknown

Retention Strategies - Essential

- Full-time staff
 - Effective task delegation
- Staff characteristics
 - Strong interpersonal skills
 - Culturally competent and sensitive
 - Flexible

Retention Strategies - Essential

- Information for alternate contacts
- Telephone calls
 - Evening/week-end calls, as needed
 - Guidelines for call attempts
 - Documentation of date/time of calls
 - Use of site cell phone for some calls

Retention Strategies - Essential

- Event Reminders
 - Appointment letter
 - Phone call the day before visit
- Reimbursements
 - Short and reliable turn-around time
 - Several payment method options
 - Transportation or parking costs for clinic visits

Retention Strategies - Helpful

- Encouragement
 - Incentive gifts
 - Mother's day gift and card
 - Holiday cards
 - Quarterly study newsletter
 - Thank you notes

Newsletter



URECA News

URBAN ENVIRONMENT AND CHILDHOOD ASTHMA—INNER CITY
ASTHMA CONSORTIUM

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Nasal Wash Results

Sometimes, when your child is sick, we may ask to do a nasal wash on your child. The reason we do this is to learn if your child's symptoms were caused by a virus. We check every URECA nasal wash sample for viruses, but it can take several months to get the results since the samples are analyzed in a research laboratory in Wisconsin. By the time we receive the exact results, your child has probably gotten over the illness.

This research is very important because we are learning more about the viruses that infect inner-city children. The most common virus we've found in the URECA samples so far is a common cold virus called Rhinovirus. About one third of the illnesses were caused by this virus. This is important because scientists are working on new treatments for this virus.

When your child is sick, remember to call the URECA staff. We will try our best to answer your questions and give you the information you need to help your child. For more severe illnesses, we might recommend that you call your doctor, schedule an appointment, or even go to the emergency room. If you would like, we would be glad to help you get these appointments scheduled. We will keep you updated on the types of viruses we find in the study as we get this information.

Clinic Visits - We Need Your Help



In a few months, the youngest URECA children will be celebrating their first birthdays! That means the URECA staff will soon be completing the final 12-month visits. Because of you, these clinic visits have been very successful.

We are now in the middle of our 24-month clinic visits and we will be holding our first 33-month and 36-month visits this winter. It's extremely important that you bring your child to your appointments when they are scheduled.

At all these visits, we collect important information about you and your child that we can't get from a phone call. We have the opportunity to check your child's height and weight, do a physical exam, and collect a blood sample.

Beginning with the 33-month visits, we will also begin two new tests. At the 33-month visit, we will do a skin test to see which things your child might be allergic to - we will also give you the results of this test during this clinic

appointment. At the 36-month visit, we will be doing some breathing tests to begin learning about your child's lungs.

We greatly appreciate everything you parents are doing to make the URECA study an important study. In order to continue our success, we need every parent and child to continue to come in for their regular study visits.

If you ever have questions about the visits or study procedures, the URECA team is glad to answer them.

Sleeping Tips



As you parents know, getting a child to go to sleep can be a real challenge. It can be even more difficult as children's sleeping habits change over time. The baby that slept peacefully may grow into a toddler that refuses to go to bed.

Here are a few tips to help your child - and you! - sleep better at night:

-Put your child to bed before he falls asleep: Children need to learn to fall asleep on their own. If you wait until your child falls asleep in your arms to put him to bed, he may not learn to go sleep on his own as he grows older.

-Start a routine: Help your child get into a nightly routine before going to bed and follow it every night. Depending on the age of your child, the routine might include a bath, putting on pajamas, brushing teeth, and reading a story. The main thing is to do the routine every night.

-Avoid TV and caffeine: Television is stimulating for children and may actually lead to nightmares in toddlers and preschoolers. Try to avoid watching TV just before bedtime. Also avoid giving your child any food or drinks that contain sugar or caffeine.

-Keep the light dim: It is normal for children to want a nightlight but too much light can keep your child awake. Keep the light dim. If necessary, use lower wattage bulbs.

-Be firm if necessary: Try not give in if your child wants to stay up past his bedtime. Setting a bed time schedule is important for your child as well as you.



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Address Line 1

Address Line 2

Address Line 3



Get to Know Your URECA Staff!



You may not recognize her picture, but most of our URECA families recognize her voice! Lanaya Daniels is a Research Program Assistant with our study. Lanaya is usually the first person you talk to when you call the URECA office. But she does a lot more than answer the phones. Lanaya handles most of the "behind the scenes" responsibilities that really contribute to the success of the URECA study.

Lanaya grew up in Baltimore in a small family - she has one younger sister. However, she is the youngest member of the URECA staff. Lanaya has a Bachelor's degree in Psychology and has a lot of experience volunteering and working with children and adolescents. She has served as a tutor, mentor, and site coordinator for several mentoring programs. She has also volunteered as a mentor for middle-school children to help them prepare for college. She has watched many of these children grow into responsible young adults - in fact, many of them are now in their first and second years of college!

Besides working with adolescents, Lanaya's interests include: fashion, fine arts, bowling, studying and teaching others about the Bible, spending time with family and friends, and playing board games. She describes herself as the "Board Game Queen!" and loves word games like Scrabble.

Some day, Lanaya would like to start an after-school program in Baltimore that would expand into a community center offering literacy and life skills training, homework help, and classes in the arts. Lanaya values humility and mildness and applies these values to her everyday routine. She enjoys working on the URECA study and loves the chance to interact with all of the URECA families.

Retention Strategies - Helpful

- Efforts for “hard to reach” participants
 - Follow-up letters
 - Unscheduled home visits
- Event/study reminders
 - Monthly postcards
 - Phone call week before clinic visit
 - Phone call day of clinic visit

Retention Strategies - Effectiveness Unknown

- Cell phone reimbursement
- Internet searches for contact information
- Child health discussions and pamphlets
- Retention events

Retention Events



Summary

- Operational considerations
 - No single strategy
 - Persistence with a variety of methods
 - Staff patience and flexibility
 - Emphasis on study participation during recruitment interview is critical

Summary

- Maternal characteristics
 - Early compliance predicts future compliance
 - Mother's age is related to deactivation
 - Early daycare attendance is related to deactivation
 - Changing life circumstance and variety of factors affect participation

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