



# Sample of NCS Recruitment and Retention Formative Research – based on NCS Research Day

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NCS Federal Advisory Committee Meeting  
October 2011

# Recruitment and Retention Research at NCS Research Day



- **Oral Sessions**
  - **Community Engagement**
    - Outreach & Engagement Strategies
    - Community Retention
    - Successful Recruitment of Latina Populations
  - **Alternate Recruitment Strategies**
    - Hi/Lo, EHBR, PRiNCeS (provider-based recruitment)
  - **Recruitment and Retention**
    - Provider-Based Recruitment, Provider-Based Sampling
    - Original Vanguard Center Recruitment Experience
    - Completion Rates between In-person versus Telephone Data Collection
- **Posters**



# SUCCESS OF PROVIDER-BASED RECRUITMENT IN THE NATIONAL CHILDREN'S STUDY IN WAYNE COUNTY, MICHIGAN

Nigel Paneth, Kendall Ziegler, Michael Elliott,  
Robert J Sokol, Gwendolyn Norman, Shonda  
Kruger-Ndiaye, Kirsten Alcser, Jean Kerver and  
the MANCS Executive Committee

## CHALLENGES OF HOUSEHOLD-SAMPLED, PROVIDER-BASED RECRUITMENT MODEL IN WAYNE COUNTY, MICHIGAN

- ▣ 24,000 annual live births; large number of prenatal practices and birthing hospitals.
- ▣ Segment women account for **1.5% of live births**
- ▣ We estimate that segment women use **150** prenatal practices and deliver in **28** hospitals.
- ▣ Average Wayne practice sees **one segment woman every four months**, and average Wayne hospital delivers **one segment birth a month**

## WHICH PRACTICES?

- ▣ We prioritized working in the **largest** practices.
- ▣ We used Wayne County birth certificates for 2007-9 to obtain names of birth attendants of segment births, which we linked to clinic addresses to identify practices.
- ▣ We identified approximately 150 practices serving segment women, and rank ordered them by number of births delivered by the practice .
- ▣ We approached largest practices first and began working in **25 practices**, increasing to **57 practices**, covering an estimated **67% of all WC births** .

# STEPS IN PROVIDER RECRUITMENT

- ▣ We ask practices for permission:
  - To recruit (brochures, posters)
  - To address-match prenatal care appointment lists
- ▣ Very few refusals for either request so far
  
- ▣ We identify address-eligible women, highlight their charts, and request that provider offices ask permission **in person** for our staff to discuss the study when the women come in.
- ▣ The Obstetrics (OB) core staffer tries to be **present in the practice** at the time of the visit.

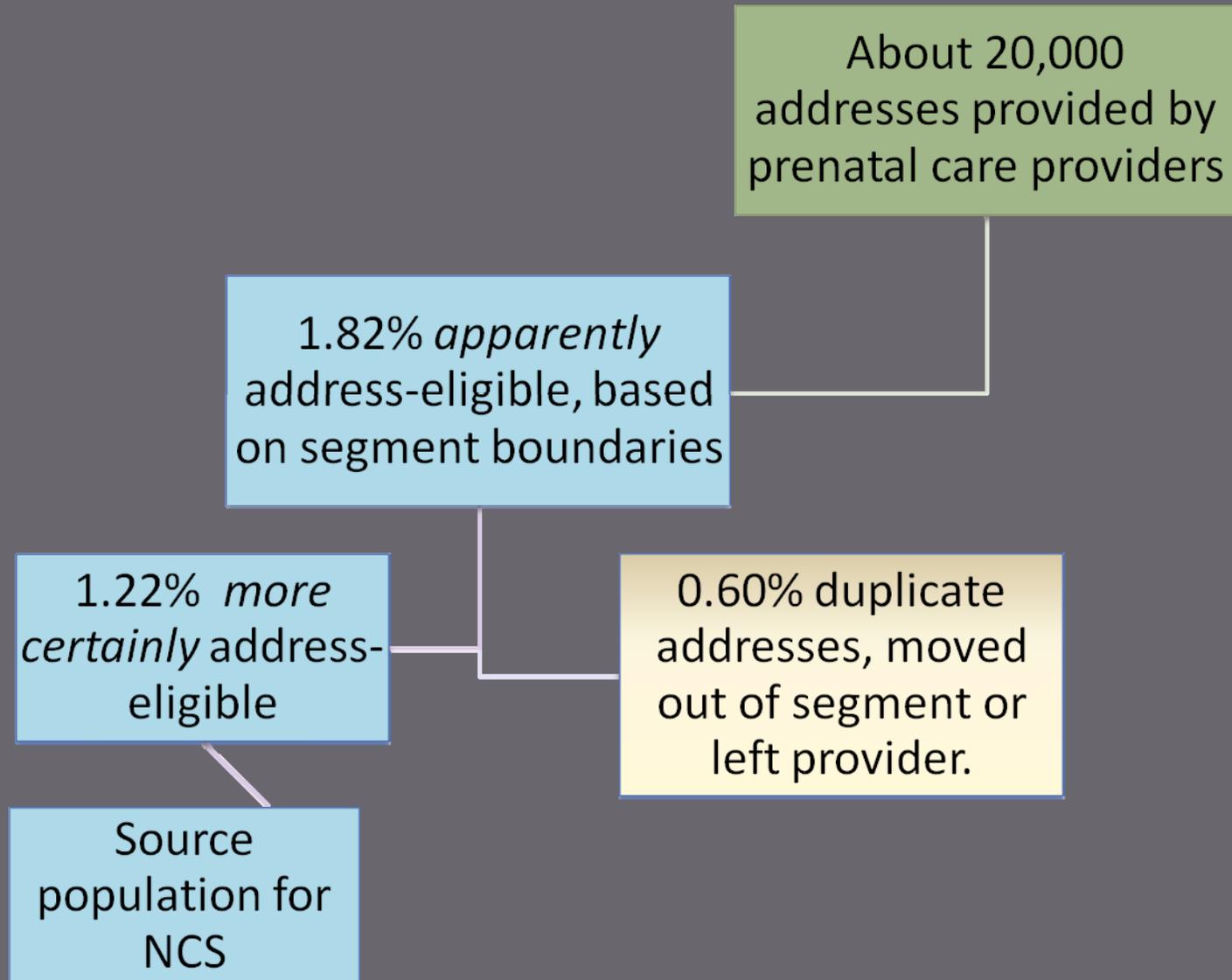
# THREE RECRUITMENT STEPS

1. **PROVIDER OFFICE RESPONSIBILITY:** Getting permission from eligible woman to have our OB staff talk to her about the study
2. **OB CORE RESPONSIBILITY:** Make first study contact with the woman, provide an overview of study, obtain contact information, and obtain permission for the SEM core to call and arrange a home visit.
3. **SEM CORE RESPONSIBILITY:** To schedule and conduct the home visit, including Screening and Consent.

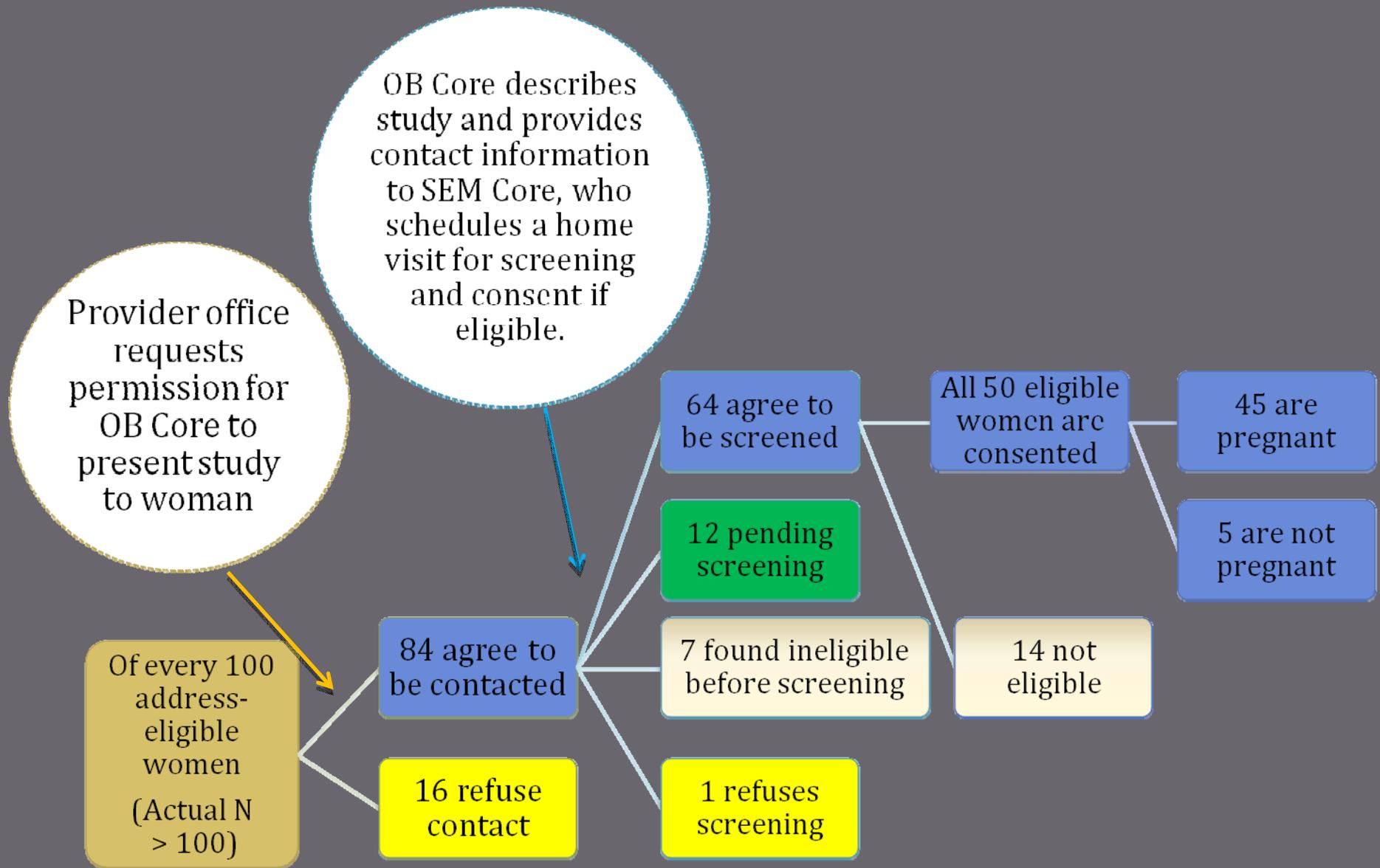
# RESULTS

PERIOD OF REPORTING  
FEBRUARY 14 – JULY 12, 2011  
(21 WEEKS)

# ADDRESS MATCHING IN WAYNE COUNTY



# FROM ADDRESS-ELIGIBLE WOMAN TO STUDY PARTICIPANT



# MAJOR PROBLEMS ENCOUNTERED

- ▣ **Low yield of eligible women per practice.** None of the 90 or so remaining practices see more than 2 segment women per year.
- ▣ Difficulty in **first trimester enrollment because of address-matching** from existing records before approaching women. (mean gestational age at consent – 27 weeks)
- ▣ Some women **do not show up for prenatal appointments**, making for fruitless trips to practices.

# KEY STRENGTHS

- ▣ **Community engagement operations** that support the study
- ▣ A **three-step recruitment procedure**, which allows the potential participant woman to gradually consider joining the study.
- ▣ **Division of responsibilities** of study tasks, with expertise applied to each task.

# PROVIDER-BASED RECRUITMENT IN THIS DESIGN IS EXPENSIVE

- ▣ We must work with **all practices and hospitals in a region.**
  - We invest major resources to **negotiating with and developing strong partnerships** with providers and hospitals.
- ▣ Community engagement must span segments **distributed widely across a large county**

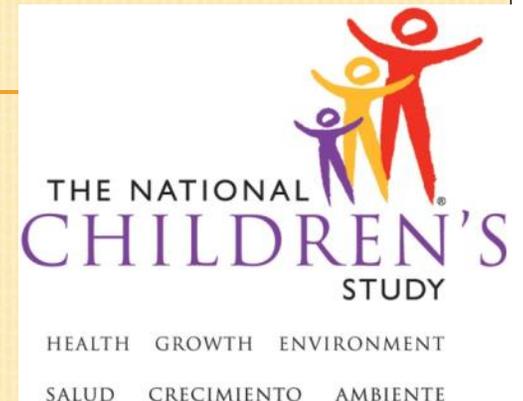
# IMPLEMENTING PROVIDER-BASED SAMPLING FOR THE NATIONAL CHILDREN'S STUDY: OPPORTUNITIES AND CHALLENGES

## SUMMARY OF A CONCEPT PAPER

Prepared by: K. Belanger, S. Buka, D. Cherry, D. Dudley, D. Hale, I. Hertz-Picciotto, N. Paneth, J. Robbins, E. Triche  
On behalf of the NCS Provider-Based Study Sites

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**Stephen Buka, Sc.D.**  
**Brown University**  
**Providence RI Study Center**



## PROVIDER-BASED SAMPLING FRAME

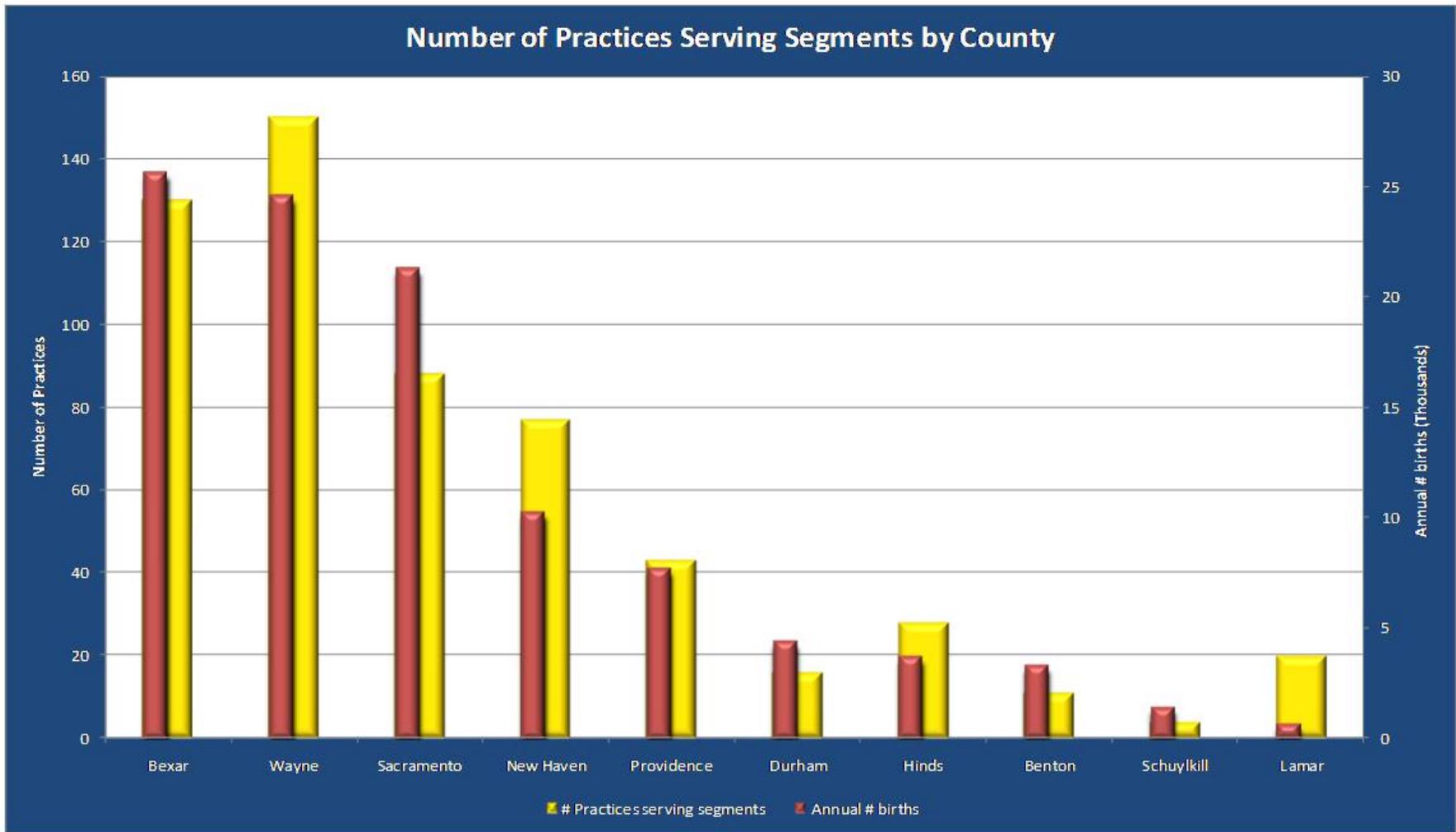
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- ✦ Background, rationale, and study design issues (e.g., identification of appropriate sampling frame, selection and recruitment of unbiased sample of provider locations, etc.) presented and discussed at prior NSCAC – so this presentation is abbreviated

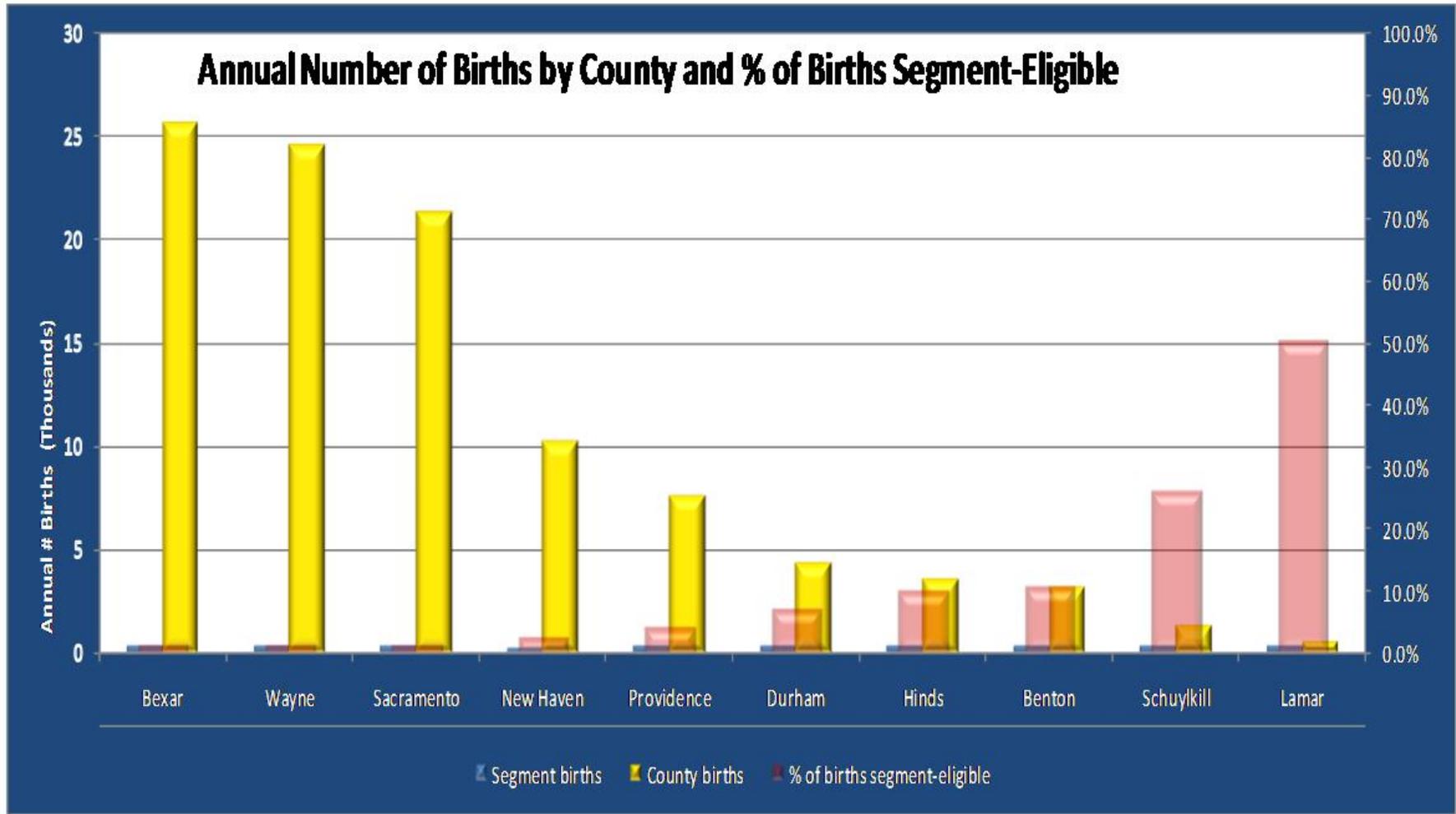
## CENTRAL CHALLENGES WITH PROVIDER-BASED RECRUITMENT APPROACH

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- Considerable variability by study center in numbers of practices and proportion of births that are segment-eligible
- **Large counties** – up to 150 prenatal care practices and 20-30 hospitals provide care to geographically dispersed, segment-eligible women. Only 1-2% of patients may be eligible.
- **Small counties** – small number of providers to recruit large proportion of segment-eligible women. But small counties have considerable proportion of women receiving prenatal care outside of county.



**NUMBER OF PRACTICES SERVING SEGMENTS AND  
NUMBER OF BIRTHS BY COUNTY**



**NUMBER OF BIRTHS AND % OF SEGMENT ELIGIBLE BIRTHS BY COUNTY**

# OVERVIEW OF PROVIDER-BASED SAMPLING APPROACH

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## × **Primary sampling**

1. Select sample of (prenatal) provider groups
2. Sample women within selected provider groups

## × **Supplementary sampling** (non-probability)

- + Enroll women through community engagement

## × **Enrolling women with late or no prenatal care**

- + Enroll in hospitals at time of delivery

## × **Enrolling preconception cohort**

- + Would need additional recruiting sites (e.g., primary care clinics; household screening)

# QUESTIONS AND CHALLENGES OF APPROACH

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- × **Type of providers to include in sampling frame**
- × **Optimization of key parameters of sampling design**
  - + # provider groups; # and % patients sampled within provider group; need to minimize # hospitals
- × **Operational challenges to sampling provider groups**
  - + Having accurate sampling frame
  - + Linking individual providers to practice groups
  - + Finding accurate sources of practice volume
- × **Stratification factors for sampling providers**
  - + Sampling based on provider vs. patient characteristics

# QUESTIONS AND CHALLENGES OF APPROACH

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- ✘ **Sampling pregnant women within provider groups**
  - + Trade-offs between ease of operations, sampling efficiency and cost
- ✘ **Potential bias from enrolling women from provider practices: late or no prenatal care**
- ✘ **Challenges in obtaining a pre-conception cohort**
  - + Provider-based sampling is biased (seekers of gynecological care)
  - + Supplement strategies will be needed to identify sexually active women for follow-up

# **National Children's Study: Recruitment Experiences in Orange County, CA**

## **Where are the Babies? Factors Affecting Recruitment Yield**

Dean Baker, Joan Ignosci, Michael Cox, Kimberley Lakes, James Swanson

with Annamarie Stehli and Haiou Yang

*University of California, Irvine*



# Background - Recruitment Yield in Original Vanguard Pilot Study

- NCS is a nationwide population-based birth cohort study of children who will be followed from gestation until 21 years.
- Orange County, CA was selected as one of seven “Vanguard” locations to pilot test a draft NCS protocol, including community household-based recruitment.
  - Vanguard pilot field work launched in 2009.
  - Initial recruitment yield was significantly smaller than had been estimated based on birth certificate records.
- Need to identify factors that have contributed to the low yield



# Possible Factors Affecting Low Enrollment and Birth Yield in Two Year Pilot Study

- **Low actual births in segments**
  - Methods to geocode past births and estimate future births
  - Lower birth rates associated with recession
- **Deficits in enrollment and births during first year due to study protocol**
  - Protocol to release segments in phases
  - Initial eligibility criteria limited enrollment to women in their first trimester of pregnancy
- **Low participation rates**
- **Low follow-up of non-pregnant eligible women**



# Orange County Sampling Frame

- **Orange County features**

- Fifth most populous county with 3.2 million residents
- 25,900 census blocks with 45,000 births/year
- NCS annual births target is only 0.5% of county births.
- Highly diverse in race/ethnicity, cultures, languages, and socio-economic status.

- **Orange County sample**

- Annual births target =  $250/0.68^* = 368/\text{year}$
- Aggregated contiguous census blocks to form 18,500 segments with ~25 births/year
- Segments were grouped into 15 geographical strata with equal numbers of estimated births and one segment was sampled per stratum

\* *NCS assigned recruitment & retention target*



# Community Outreach and Engagement

- Multi-prong outreach strategy
- Multi-level media outreach
- Neighborhood Advisory Committees (NAC)
- Networking, presentations and materials for property managers & homeowner's associations (HOAs)



# Initial “EPSC” Recruitment and Enrollment

- **Household-based enumeration & pregnancy screening**
  - 15 segments with 10,500 dwelling units (DU)
  - Recruitment launched in four waves of segments from 04/09 to 08/09
  - Study staff attempted in-person contact with residents of each DU to obtain a household roster (“enumeration”) and conduct pregnancy screening interview
- **Eligibility assessment & enrollment**
  - First trimester of pregnancy – invited to enroll in study
  - Not pregnant and not surgically sterile
    - Asked questions to score probability of future pregnancy
    - Obtained information for follow-up telephone contact

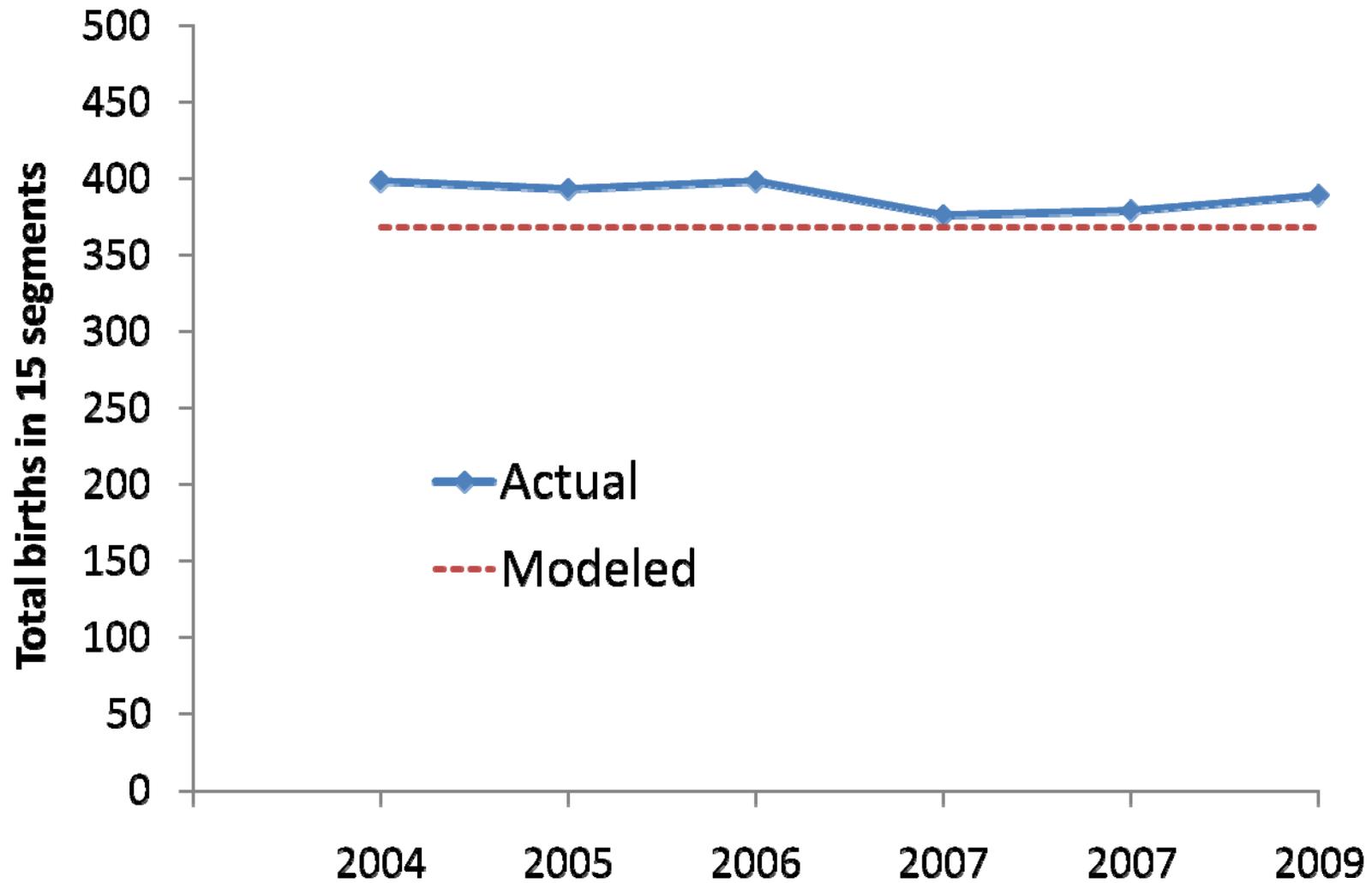


# On-going Recruitment and Enrollment

- **Follow-up of non-pregnant eligible women**
  - Local call center called high PPG women every month
  - National call center called the moderate PPG women every three months and low PPG women every six months
  - Call center follow-up was stopped in March 2011
- **Contact attempts and contacts were recorded in Study Management System (SMS)**
  - Developed by WESTAT; transition to local study center in June 2011
  - Data from SMS were used for this analysis



# Births in Sampled Segments – Orange County, CA, 2004-2009



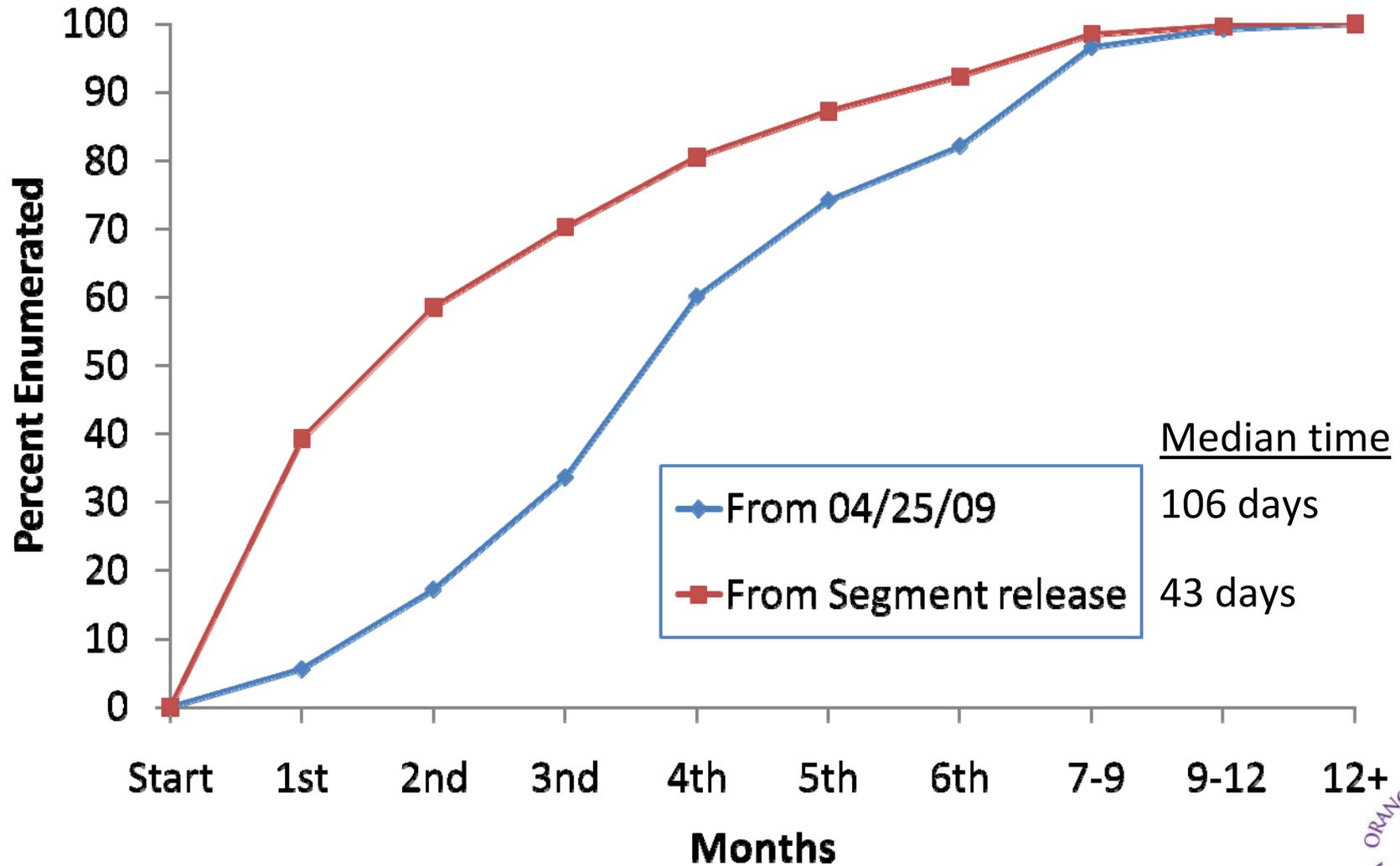
# Births in Orange County Segments during First Year of Recruitment (Launch on 04/25/09)

Birth Calculation Assumption	Number	Percent
Births in segments <sup>1</sup> (04/25/09 to 03/31/10)	362	100%
Births in segments (Segment release date to 03/31/10)	313	86.5%
Eligible Births in segments (6 months after segment release date to 03/31/10)	118	32.5%

<sup>1</sup> [Number of days \* Average daily births per dwelling unit (DU) in segments], where average daily births were calculated based on average number of birth certificate identified segment births for 2004-2009



# Completed Household Enumerations by Month – from April 2009 versus from Segment Release



# Recruitment Results

## *Launch (April 2009) to June 2011*

Recruitment Stage	Total <sup>1</sup>	Rate
<b>Total listed households (DU)</b>	10,500	
<b>Household enumeration completed (DU)</b>	9,550	93%
Age-eligible women identified	5,850	
<b>Pregnancy screening completed</b>	5,400	93%
Eligible pregnant women identified <sup>2</sup>	250	
<b>Consented pregnant women</b>	150	73%
Not pregnant, eligible for follow-up	3,850	
Not eligible for follow-up (e.g., sterile)	1,100	

<sup>1</sup> Numbers rounded according to NCS rounding rules.

<sup>2</sup> Does not include initially identified pregnant women who were ineligible because they moved out of the segment, were not actually pregnant, or lost the pregnancy before study consent.



# Outcome of Enrollment Consent Attempts

Status	Pregnant Eligible	
	All Consent attempts	Consent of eligible women
<b>Complete consent</b>	59%	<b>73%</b>
<b>Refusal</b>	9%	<b>10%</b>
<b>Maximum attempts &amp; other non-complete</b>	14%	<b>17%</b>
<b>Moved</b>	<b>11%</b>	
<b>Participant ineligible</b>	<b>3%</b>	
<b>Not pregnant</b>	<b>2%</b>	
<b>Pregnancy loss</b>	<b>2%</b>	
<b>TOTAL *</b>	<b>300</b>	<b>250</b>

\* Numbers rounded according to NCS rounding rules



# Follow-up Status of Never Pregnant Age-Eligible Women

FU group	Follow-up Status through March 2011			TOTAL *
	Active	Some FU, but lost	No successful FU	
High PPG	22%	48%	30%	200
Moderate PPG	26%	36%	38%	800
Low PPG	26%	30%	44%	2,550
Other	56%	5%	39%	300
<b>TOTAL</b>	<b>1,050 (28%)</b>	<b>1,150 (30%)</b>	<b>1,650 (42%)</b>	<b>3,850</b>

\* Numbers rounded according to NCS rounding rules



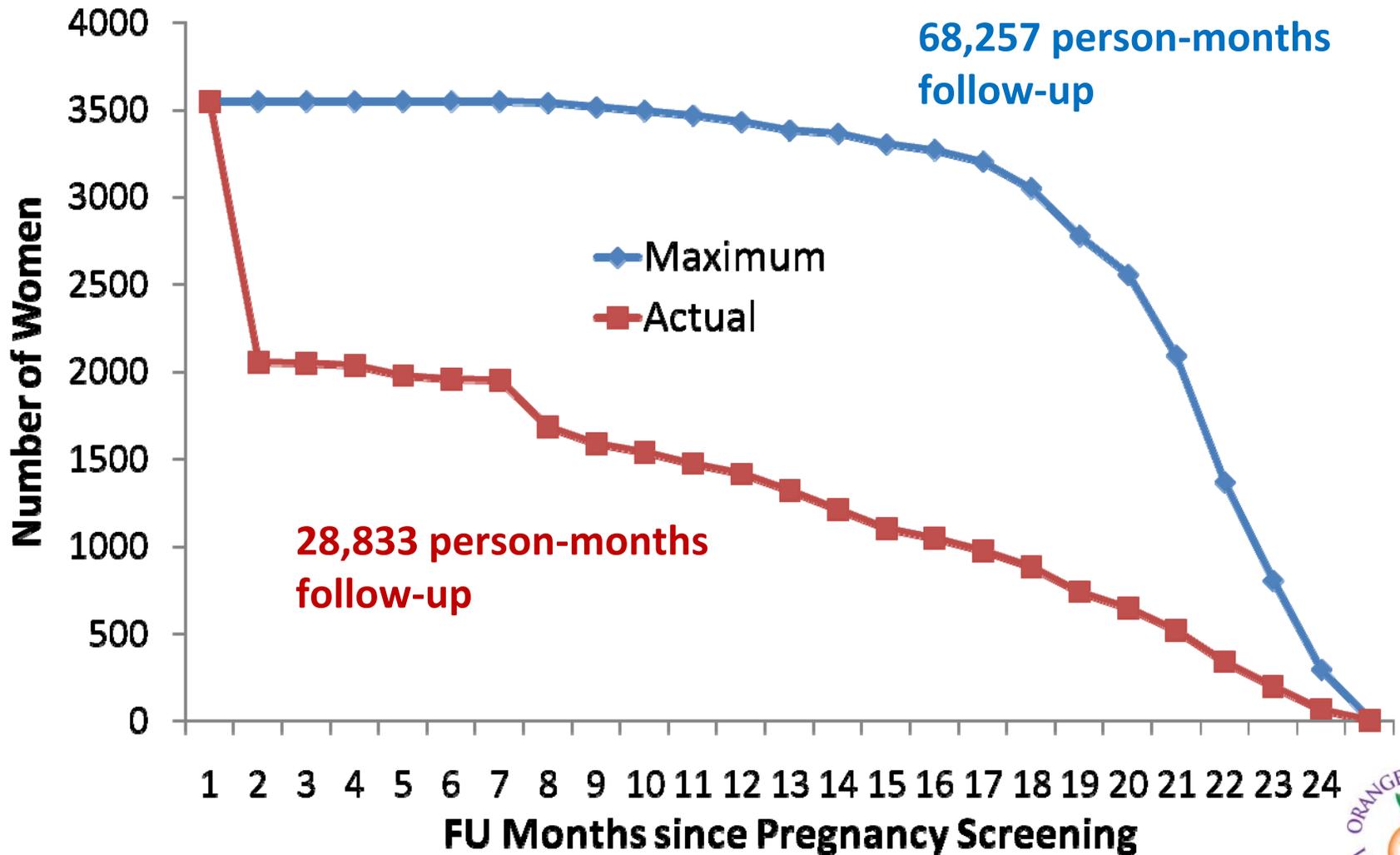
# Call Center Follow-up

## - Reasons for No Successful Follow-up

Reason for No Successful Follow-up	Percent of 1,650
No phone number provided	36%
Not locatable (wrong or disconnected number)	22%
No answer, maximum phone calls, other	42%



# Follow-up of Non-Pregnant Age-eligible Females – Maximum versus Actual Months



# Factors Affecting Low Enrollment and Birth Yield in NCS Pilot Study

- ~~• Low actual births in segments → not a factor~~
- Deficits in enrollment and births during first year
  - ~~– Protocol to release segments in phases~~
    - artifact; catch-up by 9 months after location launch**
  - ~~– Initial eligibility criteria limited enrollment to women in their first trimester of pregnancy~~
    - artifact; catch-up using 6 months enrollment at end**
- Lower than anticipated participation rates → **no**
  - High (93%) enumeration & pregnancy screening rates
  - Enrollment rate (73%) could be improved, but was comparable to similar long-term cohort studies
- **Low follow-up of non-pregnant eligible women**



# Improved Follow-up of Non-Pregnant Eligible Women

- Improved messaging about prospective enrollment component of study design
- Formal enrollment of all age-eligible women
- Obtain more information for follow-up contact
- More intense and multi-methods follow-up
  - Texting, e-mail, social media, web
- Continuous segment tracking to monitor dwelling unit turnover





# Comparison of Completion Rates between Post-Natal Telephone and In-Person Data Collection Events Salt Lake County, UT

**Palmer LE, Tharp DS, Edwards SL, Gilliland MJ, Burke L, Williams L, Sweeney C, Firth SD, Clark EB**

**Salt Lake County Vanguard Center**

# Background



- Various data collection modes
  - telephone administered questionnaires
  - hospital/clinic data collection
  - in-person home visits
- Legacy vs. Light Touch protocols
  - Legacy (4/2009 - 9/2010)
    - longer interviews, anthropometric measures
    - biological and environmental sample collections
  - Light Touch (10/2010 – 7/2011)
    - shorter interviews, no sample collections



# Background, continued



- Operational differences between telephone and in-person events (Table 1)
- Protocols changed, data collection methods remained consistent
- To inform main study, important to assess methods resulting in higher completion rates
- Reviewed differences in mode and completion outcomes at 4 post-natal time points
  - telephone 3 and 9 month (PN3, PN9)
  - in-person 6 and 12 month (PN6, PN12)



# Operational Differences



Table 1	Telephone Collection Events	In-Person Collection Events
<b>Contact Window Length</b>	<b>PN3:</b> 60 days (age 61-120 days) <b>PN9:</b> 90 days (age 211-300 days)	<b>PN6:</b> 90 days (age 5–8 mo.) <b>PN12:</b> 120 days (age 11–15 mo.)
<b>Length of Data Collection Event</b>	<b>PN3 and PN9:</b> Legacy: ~30–45 min Light Touch: ~10–20 min	<b>PN6 and PN12:</b> Legacy: ~3 hours Light Touch: ~1 hour
<b>Incentive</b>	None	<b>PN6 and PN12:</b> Legacy: \$100.00 Light Touch: \$25.00
<b>Scheduling/ Contact Procedures</b>	Up to 10 attempts Variable Modes: Telephone, E-mail (1 only)	No proscribed limit Variable Modes: Telephone, E-mail, Letter, In-person



# Methods



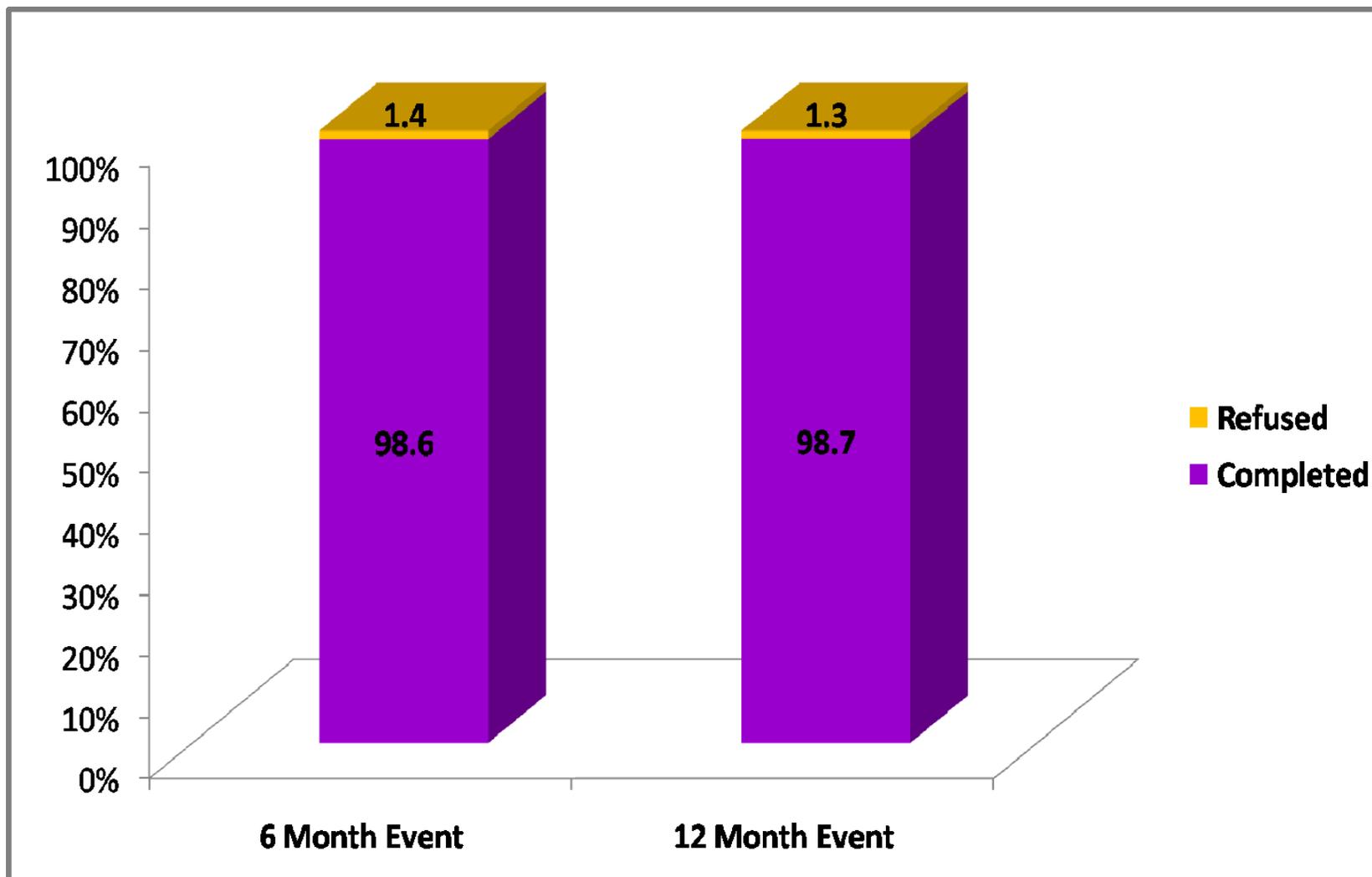
- Post-natal data collection events
  - Data from 4/2009-07/2011 included in analysis
    - Telephone Post-natal 3 mo (PN3) and 9 mo (PN9)
      - ~ 200 events
    - In-person Post-natal 6 mo (PN6) and 12 mo (PN12)
      - ~ 200 events
  - Completion Rates = Completed/Eligible Events
    - Completed = completed & partially completed
    - Eligible Events = system generated in appropriate window
  - Few study withdrawals, none in post-natal windows



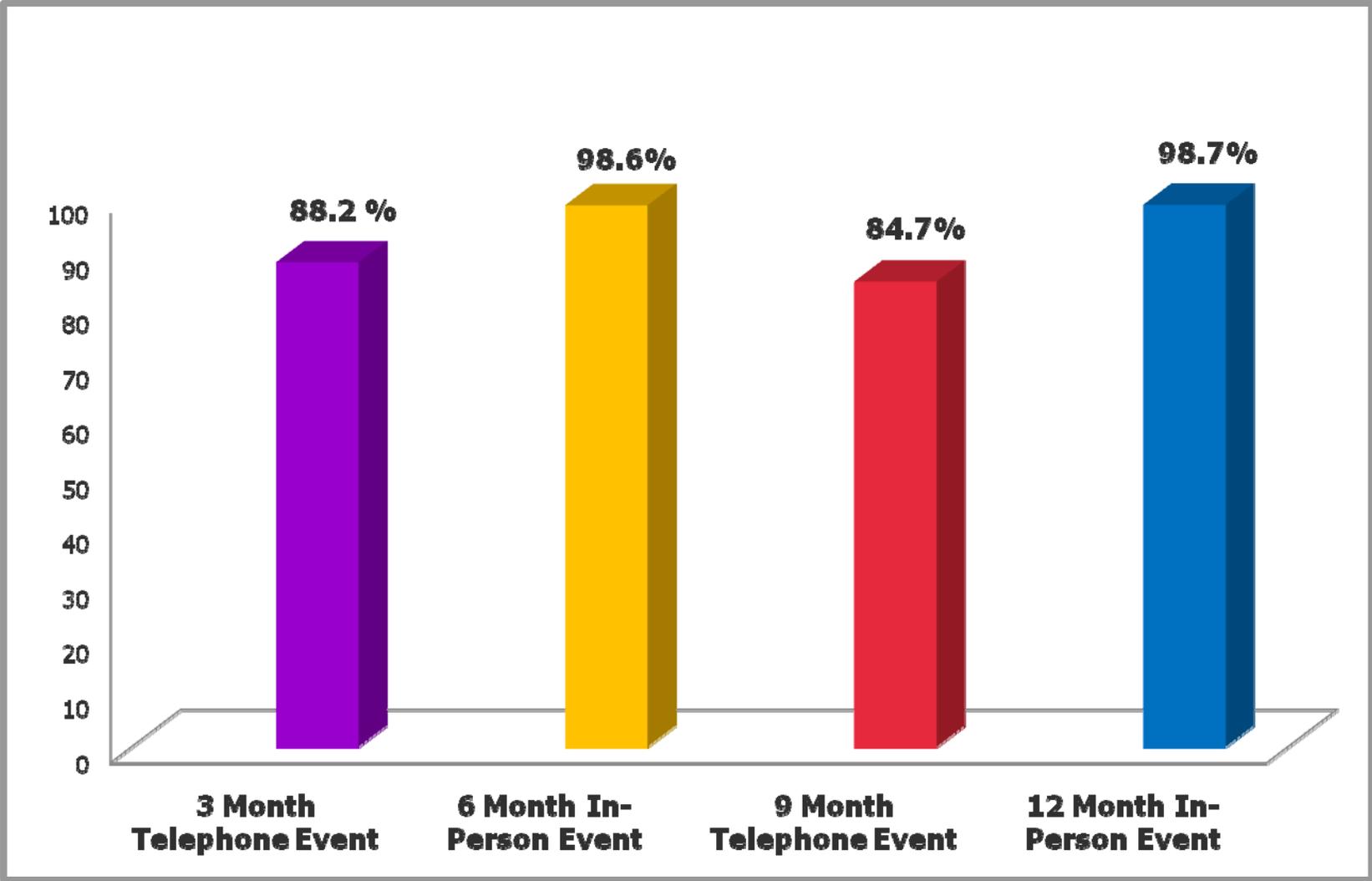
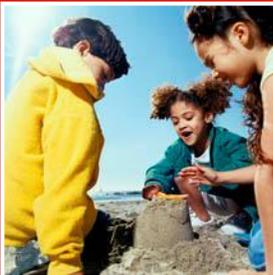
# Results - Telephone Events



# Results - In-Person Events



# Results - Completion Rates



# Conclusions



- Despite greater respondent burden, in-person visits had higher completion rates
- Face-to-face contact may enhance Study bonding and influence retention
- Important to monitor factors influencing completion rates
- Vital to identify operational elements that promote successful data collection & participant retention
  - Phase II introduces incentives and pre-notification letters for telephone events; research literature suggests these strategies enhance response rates



# Sample of Poster Presentations - Recruitment Pilots



- Provider-based Recruitment for the National Children's Study in Schuylkill County - CHOP
- A GIS-based Address Lookup Tool for Provider-Based Recruitment – Univ. of Mississippi
- Direct Mail Recruitment Strategies in the NCS – CHOP
- Direct to consumer recruitment approaches - the experience of the High-Low National Children's Study Vanguard Centers - Univ. of Colorado
- Testing Mail versus Telephone Recruitment in the Hi-Lo Alternative Recruitment Strategy in Cache County, UT – Univ. of Utah
- Using Media and Marketing to Support Hi/Lo Dynamic Enrollment Model – UC Los Angeles



# Sample of Poster Presentations - Fathers and Ethnic Minorities



- Successful Lessons Learned for Ensuring Ethnic Representation in the NCS Sample – Univ. of Washington
- Father Recruitment and Retention in Longitudinal Research: A Quantitative and Qualitative Analysis – Westat
- Successful Recruitment and Retention of Men and Foreign born Women as Participants in Longitudinal Research: Learning from Community Based Organization Staff – Baylor
- Developing Best Practices to Encourage Non-Residential Father's Participation in the National Children's Study: Perspectives of Non-Residential Fathers - CHOP



# Sample of Poster Presentations - Retention & Response Rates



- Community Retention in Duplin County, NC – Univ. North Carolina
- Evaluating Continuous Tracking of Households for the National Children's Study in Wisconsin – Wisconsin
- Feasibility of Text Messaging to Improve Continuous Tracking and Subject Retention for the National Children's Study (NCS): Planning and Development – UC Irvine
- NCS Response Rates Over Time: Ways to Look Strategically at Segment Level Data to Increase Response Rates - Univ. of Utah

