

National Children's Study Advisory Committee Meeting April 19, 2011

Introductory Remarks
Carol J. Henry, Ph.D., D.A.B.T.
Chair

Highlights from January 2011 Meeting

- ▶ Summary of meeting and presentations posted to Study Web site
- ▶ National Children's Study Update
- ▶ Compensating Providers for Facilitating Recruitment Efforts
 - Prenatal Care Provider Recruitment in Montgomery and Schuylkill Counties, Pennsylvania

Highlights from January 2011 Meeting—cont'd

- Explanation of Health Insurance Portability and Accountability Act (HIPAA) Waivers
- Compensating Providers in Wayne County, Michigan
- ▶ Provision of Educational Materials to Potential Study Participants
- ▶ Vanguard Study Recruitment Data Update and Presentation Plans for Legacy Vanguard Data

From Dr. Tassinari's Summary of January 2011 Meeting

- Issues of and data from provider compensation should be further explored.
- The identification of potential participants not identified through household enumeration and screening should be further investigated.
- Further discussions are needed on challenges and potential hurdles of HIPAA with regulations.
- Provider compensation is an essential element of provider-based recruitment, but compensation is not necessarily monetary. Study Centers will have to find ways to work with providers and ensure that their engagement is fulfilling.

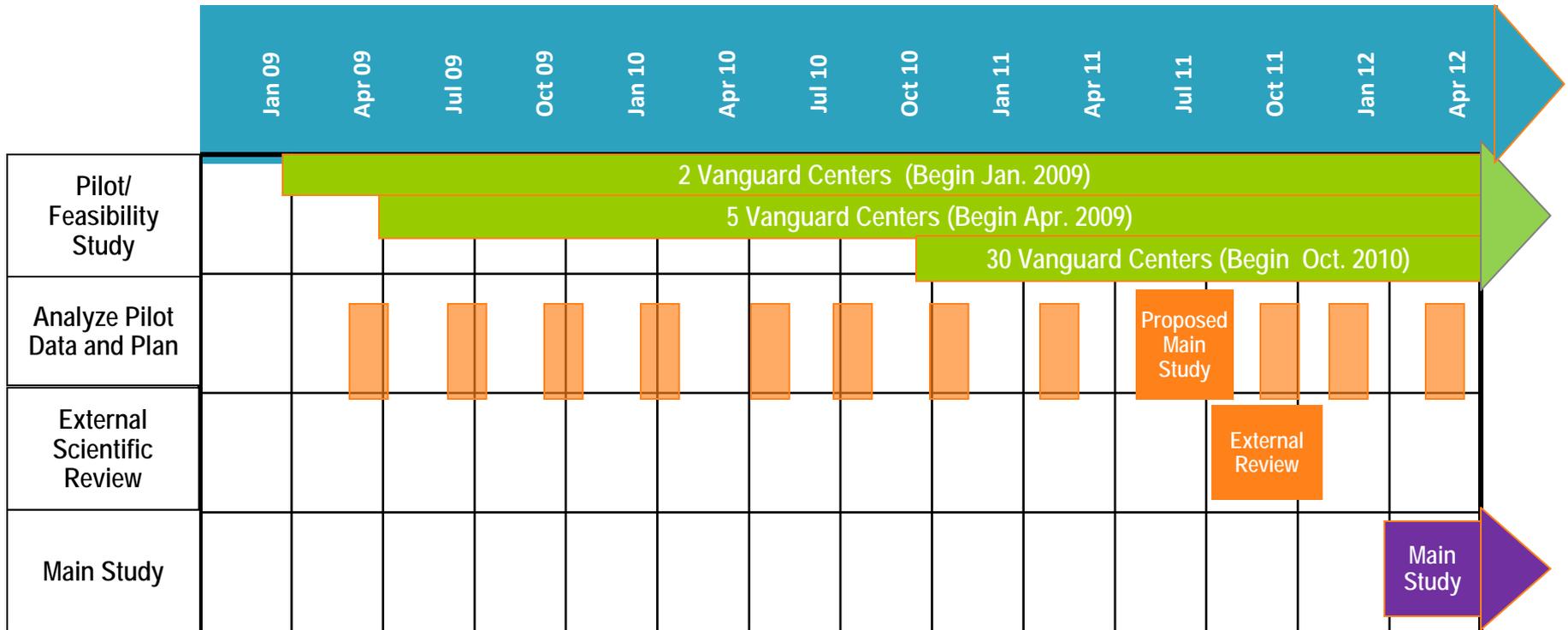
From Dr. Tassinari's Summary of January 2011 Meeting-con'td

- With regard to the provision of educational materials, the Study needs to balance education against confounding or biasing data and maintain the rigors such that the data are interpretable
- The NCSAC agreed that the new formats for presenting data are much improved and informative about past activities.
- The NCSAC agreed that the reasons for participants' refusals, withdrawals, and loss of eligibility due to change in pregnancy status and moving should be further explored.

Next Steps from Jan 2011 Meeting

- Alternate Recruitment Substudy enrollment and data analysis
- Continued analysis of data from initial 7 Vanguard locations including biospecimens and environmental samples*
- Gap analysis for formative research opportunities*
- New models for visit schedule*
- New models for visit assessments*
- Introduction of specimen and sample collection across the Vanguard Study locations
- Begin construction of framework and architecture for Main Study protocol and infrastructure

NCS Projected Timeline



Agenda for April 19, 2011 NCSAC Meeting

- ▶ Welcome & Introductions
- ▶ National Children's Study Update
- ▶ Principal Investigator Experiences in the Alternate Recruitment Substudy of the Vanguard Study
 - Champion: Ana Diez-Roux
- ▶ National Children's Study Sampling Strategy: Discussion of Alternate Models for Secondary Sampling Units
 - Champion: Benjamin Wilfond
- ▶ Meeting Summary by NCSAC Member
 - Rapporteur: Joan Reede