

January 10, 2012

To: National Children's Study Federal Advisory Committee (NCSAC)
From: Acting Director, National Children's Study
Subject: Agenda for January 24, 2012 Meeting

The National Children's Study (NCS) Program Office is continually striving to improve process and communication. Scheduled advisory and oversight interactions as well as ongoing receptivity to questions, comments, and conferences are an important part of this effort. We schedule quarterly meetings with the Committee to convey the status of the complex operations of the Study and solicit informed and thoughtful advice.

Throughout the past two years, the NCS Program Office has solicited input from the NCSAC in a structured fashion using two mechanisms. The first is the use of questions to the Committee to guide discussion for each agenda topic. These questions have been distributed prior to NCSAC meetings and each question has been addressed by the Chair and the Committee. The second mechanism, introduced at the October 2010 meeting, is the use of NCSAC members as Champions for each topic to facilitate discussion and ensure that members' input is heard. In addition, another Committee member designated as a Rapporteur provides an overall summary at the conclusion of each meeting. We also have consistently invited Study Center Principal Investigators to the NCSAC meetings to allow the Committee to interact directly with the people in the field.

From the perspective of the Program Office, the meetings provide valuable input and insight and we plan to continue quarterly meetings for the coming year. The following are the major actions the National Children's Study has taken:

- Separation of the Vanguard Study with distinct operational goals from the Main Study with exposure-response goals
- Reframing the NCS development process as one that is data driven, evidence-based, and community and participant informed
- Initiation of the Alternate Recruitment Substudy
- Transition of Informatics Management Systems from proprietary custom systems to non-proprietary open architecture modular interoperable standards compliant systems
- Analysis of attrition.

These have all been discussed and vetted with the NCSAC prior to taking any action and the NCS is better off for following that business model.

The National Children's Study is a dynamic and complex system and we are dedicated to continual reassessment and improvement. For the January 24 meeting, we plan to discuss four topics:

- The report from the Working Group on enhancing NCSAC input
- A general update on the status of the National Children's Study, followed by a summary of some recent Vanguard Study data that raises questions about potential bias based on recruitment method
- A discussion on the definition of health and a National Children's Study initiative, called the NCS Health Measurement Network, that is charged with vetting, and if need be developing, positive quantitative objective measures of health for all ages and stages
- A brief update on some revisions to our instrument development process to leverage multiple types of expertise.

Part of the Briefing Book for the January 24 meeting is a summary of the topics the NCSAC has so capably addressed over the past two years and a compilation of the questions the Committee discussed. A Working Group of the Committee met last month to provide suggestions on how to further enhance the advice the Committee provides and we will hear a report and recommendations from that discussion during the January 24 meeting.

Preliminary analysis of the Vanguard Study recruiting experience shows that while the demographics of the various Study locations were quite similar when viewed in aggregate based on recruitment strategy, the people that were enrolled into the NCS Vanguard Study from those demographically similar areas differed based on the recruitment strategy used. The NCS Program Office would like to share some of the preliminary findings and solicit input on potential implications for next steps in the evolution of the NCS design.

A topic that the National Children's Study is grappling with is how to assess health in a positive, quantitative, and objective manner across all ages and stages of childhood. Most operational definitions of health use either general categories such as Excellent, Good, Fair, and Poor or assess function in the context of disabilities or define health as the absence of diseases and symptoms. Because the charge of the NCS is to examine the impact of various factors on health and development, we need assessments that allow us to meet this objective in a longitudinal fashion, integrated with other assessments. The NCS has formed a Health Measurements Network as part of its formative research portfolio to address this objective. The Committee will receive a briefing on the topic from the co-leaders of the initiative and will be requested to provide input. The Executive Summary of the *Children's Health, the Nation's Wealth* from the National Academy of Sciences is included as background and a section of the report may be viewed at http://www.nap.edu/openbook.php?record_id=10886&page=28.

The National Children's Study uses a complex process to develop items and instruments for scheduled Study visits. The NCS Program Office will provide a brief update on the instrument development process to keep the Committee current and to solicit any comments on how to improve the process.

We intend to have sufficient time for the Committee to discuss and convey input and perspective. We remain receptive to continue to adjust the Committee meetings to allow all points of view to be heard and receive the maximal benefit from the expertise and enthusiasm the Committee brings to the National Children's Study.

Thank you.

Respectfully,



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