Final Agenda NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS Ad Hoc Workgroup for Secondary Uses of Health Data

August 1-3, 2007

Wilbur Cohen Building 300 C. Street, S.W. **Washington, DC 20201**

Wednesday, August 1	Context Setting, Background on Seminal Work	
9:00 – 9:15 a.m.	Introductions and Overview	Simon Cohn, M.D., M.P.H.
9:15 – 10:00 a.m.	Key Opportunities and Challenges in Framing Uses of Health Data	John R. Lumpkin, <i>M.D., M.P.H.</i> Wendy Patterson, <i>caBIG</i>
10:00 – 10:15 a.m.	Break	
	Perspectives on Uses of Health Data	
10:15 – 12:00p.m.	Quality Perspectives	Joel Goldwein, M.D., Oncology Data Alliance/Elekta, Inc. Impac Scott Young, M.D., Archimedes DM Model (by phone)
12:00 – 1:15 p.m.	Lunch	
1:15 – 2:30 p.m.	Secondary/Tertiary Perspectives	Jean Chenoweth, <i>Solucient Top 100 Hospitals</i> ; TBD
2:30 – 2:45 p.m.	Break	
2:45 – 4:00 p.m.	Public Health/Statewide Planning Perspectives	David Carlisle, M.D. California Office of Statewide Health Planning Leslie Lenert, M.D., Centers for Disease Control and Prevention Vickie Hohner, Fox Systems (by phone)
4:00 – 5:30 p.m.	Working session	
Thursday, August 2	Perspectives on Uses of Health Data, Con't.	
8:30 – 10:00 a.m.	Research Perspectives: Quality vs. Research; Data Use Agreements; IRB	Marcelline Harris, <i>R.N., Ph.D., Mayo, ANA</i> Sharon Terry, <i>Genetic Alliance</i> Margaret Gunter, <i>HMO Research Network</i> and Lovelace Clinic Fdn/NM RHIO
10:00 – 10:15 a.m.	Break	
10:15 – 11:45 a.m.	Health Plan Perspectives	Carmella Bocchino, America's Health Insurance Plans Shirley Lady, Blue Cross Blue Shield Association — BHI Deborah Peel, M.D., Patient Privacy Rights Foundation

11:45 – 1:00 p.m. Lunch

1:00 – 2:30 p.m. Data Sharing Perspectives

- Longitudinal Data in NHIN Karen Adams, *M.D., NQF Senior Program*

- New IOM Panel on Privacy Director

- Transparency and Authorization/ Sharyl Nass, *Ph.D., Study Dir. IOM Privacy*

Consent "on the ground" Committee

Barbara Siegel, American Health Information

Management Association

2:30 – 2:45 p.m. Break

2:45-5:30 p.m. Working Session

Friday, August 3

8:30 – 10:00 a.m. Working Session Dr. Cohn

- Framework Draft Discussion

- Taxonomy Draft Discussion

10:00 – 10:55 a.m. Planning and Next Steps Dr. Cohn

11:00 a.m. Adjourn Dr. Cohn

August 8, 2007

Note: Written Testimony submitted by:

Deborah Collyar, President, Patient Advocates in Research (PAIR)