

**NHLBI Workshop on
Using Existing Health Data Collection Systems for Cardiovascular Disease Surveillance**
Rockledge II Building, Room 7111, 6701 Rockledge Drive, Bethesda,
June 21, 2013

Agenda

- 8:00 am WelcomeDr. Lauer
- 8:05 am Call to Order, Review of Agenda..... Dr. Sidney (Chair)
- 8:15 am Focus of this Workshop and Charge.....Dr. Sorlie
- 8:30 am Overview of Selected Existing Health Data Collection Systems
(The purpose of these overviews is to briefly describe 1) how surveillance is done internal to these systems and 2) how lessons learned from these systems could be applied to a larger national system.)
- Cardiovascular surveillance system in CVRN (Dr. Sidney)
 - CMS EHR incentive programs and Multi-payer Claims database (Dr. Wright)
 - Rochester Epidemiology Project Medical Records Linkage System (Dr. Roger)
 - CDC National Hospital/Ambulatory Care Survey (Dr. Brown)
 - National Cardiovascular Data Registry and VA Healthcare Systems (Dr. Rumsfeld)
 - NIH Distributed Research Network (Dr. Platt)
- 9:30 am Usability of Electronic Health Records (EHR)
- Catching a ride on ONC meaningful use clinical data exchange standards and lessons from public health (Dr. McDonald)
 - EHR Interoperability: Structured Data Capture Initiative (Dr. Fridsma)
 - Explorys Explore Application (Dr. Jain)
- 10:00 am Break
- 10:15 am Discussion
- Topic 1:** What should we aim for in using the existing health data collection systems for surveillance of incidence and prevalence of CHD, heart failure, and stroke? (Dr. Roger, Dr. Sacco)
- What study questions can be addressed using the E-surveillance system?
 - What should we aim for in short term and long term?
 - What coverage and representativeness can be achieved by using existing health data collection systems?
 - What is the most cost effective to develop and sustain this system to monitor the trends?
- 11:15 am **Topic 2:** How do we develop this e-surveillance system? (Mr. Merritt, Dr. Platt)
- What criteria should be used to select the data systems for surveillance?
 - What are barriers and challenges in development of this system?
 - What specific considerations are there for MI, heart failure, and stroke?
 - What is the role of validation of e-surveillance data?
 - What resources, partnerships, and technologies are needed for this development?

12:15 pm	Working Lunch
12:35 pm	<p>Topic 3: What are challenges in data collection and sharing? (Dr. Curtis, Dr. Rumsfeld)</p> <ul style="list-style-type: none"> • What key and types of information should be collected? What denominators can be used to define rates? • How comparable are different systems and how do we integrate them? • How should we incorporate e-records from hospitalizations and outpatient visits? • What are the challenges in data management and linkage and how should we address them? • What are the challenges in data analysis and how should we address them? • How should we handle issues in human subject protection such as confidentiality, privacy, security, and informed consent in data sharing and data linkage?
1:35 pm	<p>Topic 4: Are any feasibility studies needed to be done? If so, how to design them? (Dr. Go, Dr. Rosamond)</p> <ul style="list-style-type: none"> • How do we assess the feasibility? • How to assess and monitor data quality, reliability, and validity? • What can be done to speed up the process of developing a national E-surveillance system for cardiovascular disease?
2:35 pm	Recommendations and Prioritizations.....All
3:50 pm	Wrap up, Summary of recommendations.....Dr. Sidney
4:00 pm	Adjourn