

# Workshop on Long-term Preservation & Management of Electronic Health Record

<http://ddpehr.nist.gov>

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## BACKGROUND

Electronic health-related patient information is vital for clinical care and medical research. However, systems interoperability for preservation, storage, and accessibility of such health data have not yet been defined. Clinical data in digital form represents a “digital library,” and inherits all the same administration and technical issues faced by digital libraries in other fields: what to retain and for how long; how to handle obsolescence of hardware and software; interchange of information; costs; assignment of responsibility; standards. In addition, clinical data involves issues of privacy, legal constraints, economics, and data ownership that complicate preservation even further. If preservation of clinical information is not addressed, valuable and irreplaceable information will become inaccessible, or disappear over time with disastrous consequences for patient care and research value. Replacing lost data even if possible, will entail huge costs for patients, clinicians, administrators, pharmacists, and potentially, the entire country’s economy.

## CHALLENGES

How to preserve and provide access of electronic clinical data as electronic health record (EHR) for a sufficiently long period of time to maximize value to patient, caretaker, and scientist.

## ACTIONS

To ascertain current practices for long-term preservation and lifecycle management of EHR, including an interoperability framework which supports a wide variety of data types, data formats/records, and data delivery mechanisms, while providing technology-independent infrastructure to acquire, store, search, retrieve, migrate, replicate, and distribute EHRs over time. The expected outcomes will be the following:

- ❖ Survey current practices and identify best strategies to be used as models on EHRs
- ❖ Begin to develop requirements, technologies, standards and best practices for long-term preservation and life-cycle management on EHRs
- ❖ Differentiate between requirements for patient care and those for secondary use
- ❖ Catalog current legal requirements for retention of EHRs
- ❖ Identify interested collaborators to form a WG on this area
- ❖ Discuss possible test scenarios and datasets for collaboration and testbed

## SPEAKERS:

- ❖ Keynote: Dr. William Stead, Vanderbilt University Medical Center
- ❖ Dr. Charles Friedman, HHS/Office of the National Coordinator for Health Information Technology (ONC)
- ❖ Dr. Chris Greer, Office of Science and Technology Policy (OSTP), White House
- ❖ Dr. John D. Halamka, Harvard Medical School
- ❖ Mr. John Quinn, Department of Veterans Affairs
- ❖ Dr. Mark Frisse, Vanderbilt Center for Better Health
- ❖ Dr. Clement McDonald, Director of Lister Hill National Center for Biomedical Communication
- ❖ Dr. Lynn H. Vogel, University of Texas M.D. Anderson Cancer Center
- ❖ Dr. Christopher G. Chute, The Mayo Clinic of Medicine
- ❖ Dr. Susie Stephens, W3C Semantic Web Healthcare and Life Science Interest Group
- ❖ Session Chair: Ms. Nancy Orvis, Office of the Assistant Secretary of Defense (Health Affairs)
- ❖ Session Chair: Mr. Larry Johnson, Member of OMG Board of Directors

## PARTICIPANTS

Policy makers, EHR experts, hospitals, laboratories, pharmacies, representatives of CMS & ONC

## GENERAL CO-CHAIRS

Milton Corn	National Institutes of Health /National Library of Medicine
Umesh Thakkar	Department of Veterans Affairs
Robert Chadduck	National Archives and Records Administration
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