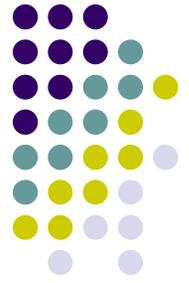
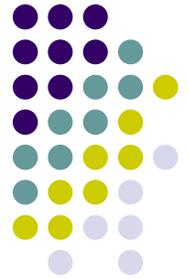


**Health Informatics,  
caBIG, and  
Population Sciences and Cancer  
Control**



**Deborah Winn, Ph.D.  
Epidemiology and Genetics Research  
Program,  
Division of Cancer Control and Population  
Sciences, NCI**

## Mission of the DCCPS Health Informatics Steering Committee



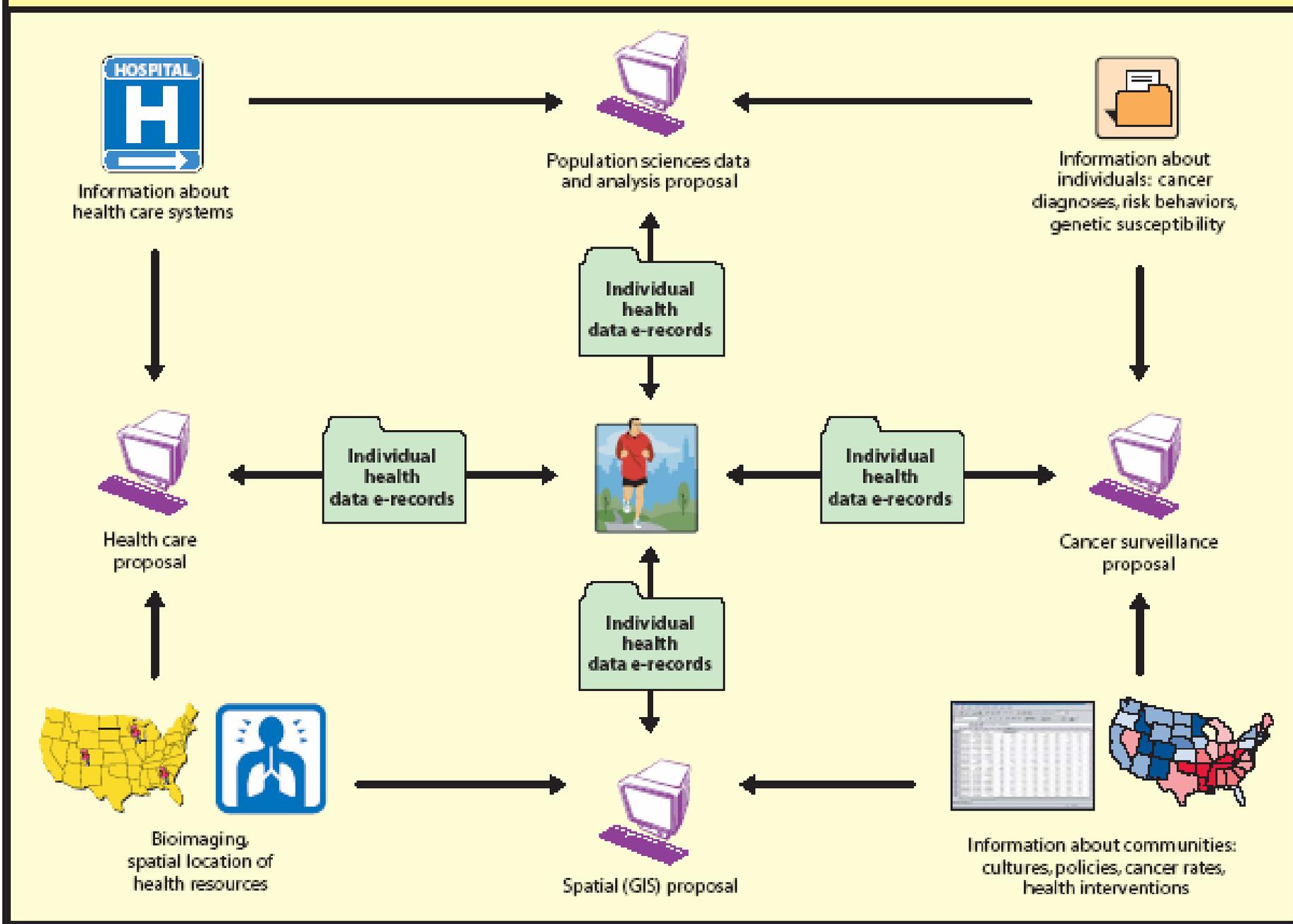
The mission of the DCCPS Healthcare Informatics Steering Committee is to apply health informatics tools across the spectrum of DCCPS research and activities to optimize the use of existing data and the collection of new data. The committee also hopes to promote the application and sharing of data and research advances with individuals and their communities.

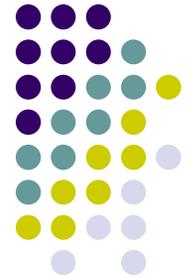


# Key areas of focus

- Cancer care
- Cancer surveillance
- Data collection and analysis strategies in population science and behavioral and cancer survivorship research
- Application of geographic information system methods to address complex confidential cancer data and bioimaging

Figure: Transforming Population Sciences and Cancer Control Through Information Technology





## What is caBIG?

- The **cancer Biomedical Informatics Grid**, or **caBIG**, is a voluntary network or grid connecting individuals and institutions to enable the sharing of data and tools, creating a World Wide Web of cancer research.
- Activities undertaken according to:
  - Open source
  - Open access
  - Open development principles
  - Based on common standards

# caBIG Workspaces and Working Groups



- Pilot Domain Workspaces
  - Clinical Trials Management Systems
  - Integrative Cancer Research Workspace
  - Tissue Banks and Pathology Tools Workspace
- Pilot Cross Cutting Workspaces
  - Architecture
  - Vocabularies and Common Data Elements
- Strategic Level Working Groups
  - Strategic Planning
  - Data Sharing and Intellectual Capital
  - Training

# caBIG Special Interest Groups



- Integrative Cancer Research
  - Population Sciences and Cancer Control
  - Microarray Repositories
  - Data Analysis and Statistical Methods
  - Gene Annotation and Computational Genomics
  - Pathway Tools
  - Translational Tools
  - Informatics for Proteomics

# Common Data Elements for Population Sciences and Cancer Control



- Division of Cancer Etiology and Genetics and of Cancer Control and Population Sciences embarked on a joint project to develop CDEs for population sciences and cancer control applications - July, 2004
- In the pilot phase CDEs have been developed for:
  - Demographics
  - Tobacco History
  - BMI
  - Mammography Screening (in progress)

# Cancer Data Standards Repository (caDSR)



- Registry for Common Data Elements and vocabularies
- Developed by NCI to provide unambiguous semantics for data collected for cancer studies, trials and scientific research
- Contains tools used to translate CDEs and vocabularies into forms



# “Modeling questionnaires”

- Identify and describe all of the characteristics of questionnaires
- Describe the relationship of a questionnaire to other entities
  - A person
  - A biospecimen
- Develop standardize language to describe these characteristics and entities
- Develop the tool(s) to create a questionnaire builder
- Extend this concept to model population studies

## Benefits of using questionnaires and forms derived from the caDSR repository



- Well-defined terminology that can be rapidly re-used for new studies
- Consistent data collection
  - Within studies, as protocols are updated
  - Among multiple studies that may share common elements  
example: questionnaire modules
- Consistent analysis and meta-analysis
- Error reduction
- Vastly enhanced data sharing and data pooling capabilities
- Facilitate development of analytic and data management software applications that maximize portability and cost effectiveness

# Partner Organizations

Division of Cancer Control and Population  
Sciences, NCI

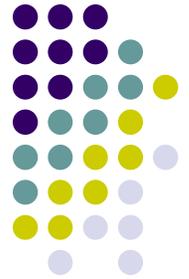
Division of Cancer Epidemiology and Genetics,  
NCI

Center for Bioinformatics

Comprehensive Cancer Centers through caBIG  
activities

Booz/Allen/Hamilton

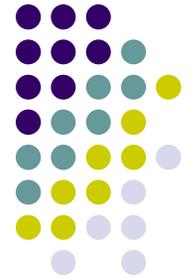
SAIC





## Want more information?

- Epidemiology and Genetics Research Program
  - Debbie Winn ([winnde@mail.nih.gov](mailto:winnde@mail.nih.gov))
  - Mukesh Verma ([Vermam@mail.nih.gov](mailto:Vermam@mail.nih.gov))
  - Fernando Arena ([Arenaj@mail.nih.gov](mailto:Arenaj@mail.nih.gov))
- To join the Population Sciences and Cancer Control Interest Group within caBIG, contact Joseph Hanauer at [hanauer\\_joseph@bah.com](mailto:hanauer_joseph@bah.com)



# Forms/Questionnaires

- Form Builder  
This tool allows users to pull data elements from the caDSR into the form builder. Questions can be sequenced and annotated for use as questionnaires.
- These standardized forms can be added to a dictionary of questionnaires that can be used by the wider research community

# Mission of the Division of Cancer Control and Population Sciences, National Cancer Institute



DCCPS aims to reduce risk, incidence, and deaths from cancer as well as enhance the quality of life for cancer survivors. The division conducts and supports an integrated program of the highest quality genetic, epidemiologic, behavioral, social, applied, and surveillance cancer research. DCCPS-funded research aims to understand the causes and distribution of cancer in populations, support the development and implementation of effective interventions, and monitor and explain cancer trends in all segments of the population. Central to these activities is the process of synthesis and decision-making that aids in evaluating what has been learned, identifying new priorities and strategies, and effectively applying research discoveries to reduce the cancer burden.