



caBIG™ Community Outreach Summit Executive Summary

January 2008

U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES

National Institutes
of Health



I. Summary of Summit Objectives, Recommendations, and Next Steps

Summit Objectives

The National Cancer Institute's Center for Biomedical Informatics and Information Technology (NCICBIIT) conducted a Community Outreach Summit on November 8–9, 2007, with the following objectives:

- Initiate a dialogue with decision-makers and strategic thinkers from key sectors, about what they need in order to adopt, adapt, buy, sell, and further develop caBIG™ tools and services, and/or participate in the caBIG™ enterprise
- Identify key opportunities, issues, and challenges
- Gather ideas about how caBIG™ should be organizationally structured and governed in the future

Summit Recommendations

Summit participants, following a day and a half of deliberations in three simultaneous subject tracks, achieved consensus on the following eight priorities for the caBIG™ initiative:

1. **Sustain its work in data standards and infrastructure.** caBIG™ data standards and infrastructure are the most important and successful component of the caBIG™ initiative. caBIG™ should continue to expand this work, since it is essential to the goal of connectivity within and beyond the cancer research community.
2. **Spearhead an awareness campaign.** caBIG™ communication programs should be targeted to a larger and wider audience—encompassing all the core constituencies in the cancer research enterprise and potential stakeholders in the broader biomedical environment—in order to alert them to its capabilities and benefits.
3. **Conduct a scientific demonstration project.** caBIG™ can and should become an informatics “nucleating” component in a new clinical research project, to demonstrate its value in facilitating translational medicine. Several specific projects were proposed, including new multi-site clinical projects in prostate and brain cancer.
4. **Maximize engagement with the commercial sector.** caBIG™—to achieve its end goal of connecting the entire cancer research community—needs the active participation of the commercial sector, and efforts should be made to attract and engage both small and large biopharmaceutical and information technology companies. Collaboration with organizations such as BIO, PhRMA, and HIMSS may be helpful in this regard.
5. **Establish more extensive and visible partnerships with other government agencies.** caBIG™ should partner with other government agencies that require data standardization and interoperation, including the Centers for Medicare and Medicaid Services, the Food and Drug Administration, the Centers for Disease Control and Prevention, and the Office of the National Coordinator for Health Information Technology.



6. **Get “inside” Electronic Health Records.** caBIG™ should become a key internal component (comparable to “Intel inside”) of electronic health records (EHRs) for two reasons: first, to provide a data standard and communication infrastructure for highly structured molecular and phenotype data to support personalized medicine; and second, to ensure that the data systems linking research and clinical care become seamless.
7. **Expand beyond cancer.** caBIG™ standards, infrastructure and tools can easily be extended beyond cancer. Such expansion could be beneficial in attracting more constituencies, as well as in leveraging caBIG™ capabilities to other therapeutic areas.
8. **Expand internationally.** caBIG™ already has strong relationships with other countries, as reflected by its collaboration with the UK’s National Cancer Research Institute. By sharing caBIG™ technology, the cancer research community could reap rewards via a globally interconnected research enterprise.

Next Steps

NCI has already launched a formal Cancer Center deployment program, led by NCICBIIT, to enable NCI-designated Cancer Centers and Community Cancer Centers to adopt or adapt to caBIG™ tools and infrastructure. In support of that program and of wider caBIG™ deployment, NCICBIIT is establishing an Enterprise Support Network comprised of Knowledge Centers, Service Providers, and Program Offices to expedite and increase the integration of caBIG™ technology into scientific and clinical research workflows.

Specifically, Knowledge Centers will provide domain specific expertise within the caBIG™ community and serve as points of contact for education, outreach, training, and deployment needs to the rest of the community. As third-party organizations, the Service Providers in the ESN will deliver software application and infrastructure technical support to end-users and IT professionals. Finally, Program Offices will be established within an individual institution to help facilitate and expedite the adoption of caBIG™ technology in that institution.

NCICBIIT is also developing—based on the input of the Summit and other sources—a long-term strategic plan for the future of the caBIG™ initiative that will channel resources into priority areas of focus to fulfill the promise of caBIG™-enabled connectivity throughout the cancer research community, as well as facilitating such connectivity more broadly—beyond cancer—throughout the biomedical environment. As part of these strategic plans, NCICBIIT will explore additional models of governance for caBIG™ for future years.



II. Background

Summit Planning Process

The National Cancer Institute Center for Biomedical Informatics and Information Technology (NCICBIIT) has undertaken a three-step process to catalyze the development of an “ecosystem” to achieve the goal of a truly connected cancer research community:

1. NCICBIIT published the “caBIG™ Pilot Phase Report 2003–2007” to evaluate the accomplishments of, and lessons learned from, the first three years of the initiative. (<http://cabig.cancer.gov/resources/report.asp>) Key findings of the report were that caBIG™ had largely accomplished its initial goals to develop a solid foundation of tools and infrastructure, form a large and dedicated community with common interests, and launch a data transmission network that could support collaborative research.
2. The NCICBIIT organized the Community Outreach Summit, held November 11–12, 2007 in Bethesda, Maryland, designed to bring together approximately 100 strategic decision-makers from across the cancer biomedical community. The Summit was designed as an interactive working meeting, to engage in a dialog with senior leadership from all relevant sectors.
3. NCICBIIT is currently developing a strategic plan for the future of the caBIG™ initiative.

NCICBIIT undertook the following preparatory steps leading up to the Summit:

1. Appointed a Summit advisory group comprised of four multi-disciplinary senior leaders from the caBIG™ community (a CARRA patient advocate, a cancer center clinical investigator and CIO, a computer scientist and bioinformatics center director, and a clinical imaging and informatics department chair) as well as members of the NCICB senior leadership team.
2. Selected a dedicated project coordinator, via an RFP process, with deep roots in the life sciences research community.
3. Identified and invited leaders from all key sectors of the cancer research community.
4. Conducted “focus groups” of registrants prior to the Summit to elicit their opinions about caBIG™ opportunities and challenges, and reflected that input in the agenda of the Summit.
5. Conducted a “caBIG™ Tutorial” by teleconference to inform attendees who were unfamiliar with the program about the basics of caBIG™.
6. Conducted planning phone calls with moderators and panelists to develop working group structure and content.
7. Disseminated caBIG™ background and preparatory materials to all registrants.
8. Appointed leading members of the academic, government, and commercial communities to serve as speakers and moderators to guide the Summit discussion.



Summit Participants

Participants comprised government, academe, large IT companies, small software companies, biotech companies, and patient advocates (see Attendee Demographics chart below). The participants included those who were familiar with caBIG™ programs and technology; those who had been funded to develop and/or adopt the technology; those who are familiar with caBIG™ but have remained on the sidelines; and those largely unfamiliar with caBIG™.

A balance of representation from each constituency was pro-actively sought; in some cases, such as with the pharmaceutical industry, repeated efforts to drive attendance resulted in limited success.

Attendee Demographics

Community	Number of Participants
Cancer Center Directors and their designees	12
Pharmaceutical companies	3
Life science informatics and IT companies	17
Life science tools companies	4
Academic / clinical researchers	26
SPORE Investigators	4
Cooperative groups representatives	3
Patient advocates	4
Entrepreneurial thinkers	8
HHS/NIH/NCI	12
NCICBIIT and caBIG™ project staff	21



Summit Agenda

Major components of the 1.5 day Summit Agenda were:

1. Presentation by Ken Buetow, Ph.D., NCI Associate Director for Bioinformatics and Information Technology, covering the principles and current core capabilities of caBIG™. This presentation included:
 - Videotaped remarks by Dr. Richard Carmona (former Surgeon General) and by Dr. David Brailer (former National Coordinator for Health Information Technology and founder of Health Evolution Partners)
 - Live commentary by Dr. Laura Esserman of UCSF and Greg Simon, President of *FasterCures*.
2. A keynote address by Dr. John Niederhuber, Director of the NCI, describing the importance of the caBIG™ initiative to the achievement of molecular medicine and the development of new products to diagnose, treat, and prevent cancer.
3. An opening panel discussion among Dr. Peter Traber of Baylor College of Medicine, Dr. Steve Lincoln of Affymetrix, and Dr. Iya Khalil of Gene Network Sciences, moderated by Dr. Kim Lyerly, Director of the Duke Comprehensive Cancer Center. Key themes of this panel included the need for caBIG™ to go beyond cancer in its impact on the biomedical research community, and to engage with international research efforts.
4. Three simultaneous Working Session tracks on *Research, Market Development, and Governance*.
5. Two “report out” plenary sessions in which core themes from the Working Sessions were shared with all attendees.



Summit Working Groups

Summit participants were organized into the following three working groups:

Research Track

With the advent of data intensive genomic and clinical profiling technologies, coupled with better informatics networks and tools, the opportunity to implement visionary translational research projects has greatly expanded. This group was charged with identifying such “blue sky” research models and cataloging the informatics implications of their vision. That catalog of informatics implications was used to identify biomedical informatics needs over the next ten years.

Market Track

One of the hallmarks of a technology’s successful transition from a government funded research project is the development of an independent marketplace sufficient in size to attract companies to develop and sustainably provide products and services. This group was asked what would expand the market opportunity for companies and how to grow that marketplace to become self-sustaining.

Governance Track

The caBIG™ initiative model is based upon government funding and governance through a contractual structure organized under a government entity. This group was asked to consider whether this governance model can or should be modified, in the context of broadening the caBIG™ technology user base.