DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP MEETING
Bethesda, MD

October 20–22, 2009

Members Present

Ms. Gwen Darien, Chair	Dr. Yvette Colón	Dr. Deborah Morosini
Mr. Everett Dodson, Vice Chair	Ms. Kelly Cotter*	Ms. Phyllis Pettit Nassi*
Dr. Jeff Allen	Ms. Marie Dahlstrom	Ms. Wendy Selig
Ms. Susan Braun	Ms. Joyce Wilcox Graff	Ms. Arlene Wahwasuck
Dr. Grace Butler	Ms. Cheryl Jernigan	Mr. Max Wallace

*Participated by telephone for portions of the meeting.

Speakers

Ms. Shannon K. Bell, Director, Office of Advocacy Relations (OAR), NCI
Dr. John E. Niederhuber, Director, NCI
Dr. Carolyn Compton, Director, Office of Biorepositories and Biospecimen Research, NCI
Dr. James H. Doroshow, Director, Division of Cancer Treatment and Diagnosis, NCI
Dr. Kenneth H. Buetow, Director, NCI Center for Bioinformatics
Mr. James Hadley, Director, National Outreach Network
Dr. Sanya A. Springfield, Director, Center to Reduce Cancer Health Disparities
Dr. Patricia Steeg, Chief, Women's Cancers Section, Laboratory of Molecular Pharmacology, NCI
Ms. Musa Mayer, Breast Cancer Advocate
Dr. Robert Mittman, Facilitator

National Cancer Institute Staff

Ms. Shannon K. Bell, Director, Office of Advocacy Relations
Ms. Amy Bulman, Advocacy Relations Manager
Mr. Benjamin Carollo, Advocacy Relations Manager
Ms. Anne Lubenow, Special Assistant to the NCI Director

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Welcome and Opening Remarks
Rules governing potential conflicts of interest were reviewed, and a quorum was determined to be present. It was also noted that the meeting was open to the public and being webcast.

The goals for the meeting were as follows:

- Create a shared understanding of the NCI therapeutics platform.
- Identify the advocacy and research communities' expectations for the platform.
- Obtain input from the DCLG about how NCI can communicate with the advocacy community about the platform.
- Develop recommendations for how NCI can proactively engage the advocacy community to fulfill the platform's goals.

In round-robin fashion, the participants introduced themselves and gave brief answers to the question, "What is the most important key to engaging the research and advocacy communities?" Communication was a major point of emphasis, but the idea of shared intention came out as well. Additionally, relationships, trust, mutuality, and respect are essential. Communication is more than broadcasting a message; the term encompasses dialogue as a way to build collaboration.

The NCI Therapeutics Platform: Facilitating Patient-Centered Cancer Research
Presenter: Dr. John E. Niederhuber

The focus of the presentation was on the complexities and opportunities of cancer; the power of genomics for dissecting the disease's complexity; the importance of identifying biomarkers; and the ways in which technology is driving progress in the prevention, diagnosis, and treatment of cancer as well as the identification of biomarkers.

Cancer is a disease of altered genes (i.e., mutated, up- or down-regulated, changed copy number, translocations). These genetic changes not only affect the protein product of the affected gene itself but also how it is regulated (epigenetics). Novel, next-generation DNA sequencing technologies will enable full genomes to be sequenced in real time. Technology allows these changes to be catalogued. The next step is to figure out what is important in the catalog and construct treatments to correct the changes—the basis of personalized medicine.

The Cancer Genome Atlas (TCGA) pilot studies have shown that tumor sequencing can be accomplished in high-throughput fashion in academic research settings (selected on a competitive basis). Huge amounts of data are generated by sequencing different tumors, and new technology has slashed the cost of genomic analysis as well as the time necessary to conduct such studies.

The advanced therapeutics platform (see diagram) demonstrates how NCI is attempting to make anticancer drug development more robust. Via the platform, NCI is:

- Using mathematical models for analysis of extremely large datasets.
- Undertaking studies in functional and chemical biology to define causal/"druggable" targets.
- Developing procedure to conduct genomic characterization of each new patient, who then becomes part of a national the national cohort of cancer patients.

- Establishing a new model for patient selection in translational research.
- Facilitating handoffs and filling gaps.

For the development of targeted therapies, it will be necessary to obtain tissues, characterize them, and put the clinical and molecular information into a central database. In this way, every patient will contribute to the knowledge base.

The platform provides numerous places for academic and industry researchers to plug in. Under this paradigm, researchers will be able to go into the database to find the right patients to provide the data for particular drug comparisons.NCI is the facilitator, to make all the pieces work effectively.

Intellectual property issues may have to be tackled with new legislation. In the context of the therapeutics platform, advocates may also be able to facilitate handoffs between the private sector and NCI.

The Therapeutics Platform—A Panel Discussion with NCI Leadership

Presenters: *Dr. Niederhuber*
Dr. Kenneth Buetow
Dr. Carolyn Compton
Dr. James Doroshow

Each panelist responded to Dr. Niederhuber's presentation:

- Dr. Buetow said that the value of the platform lies in its interconnectedness, which will be necessary to bring about 21st century breakthroughs. Progress in information technology has eliminated technological barriers to progress.
- Dr. Compton discussed the importance ensuring the quality of biospecimens, which are patients' representatives in the platform and at the point of care. Biospecimens will be needed for every patient. caHUB is filling a gap in the research enterprise by creating a system for collecting, processing, and storing human samples in a standardized way to create a biobank of reliable samples for researchers. NCI is, in essence, donating the infrastructure for moving the research enterprise forward.
- Dr. Doroshow stressed the importance of communication and interaction. It is challenging to help all parties understand what NCI is doing. It is hard to change views of academic colleagues and community oncologists. NCI started at the end of the clinical trials process to try to make the research enterprise more efficient; now, the focus is on the middle part of the clinical research continuum (i.e., to do early trials more efficiently).

DCLG member comments about the schematic of the therapeutics platform included:

- On the left, indicate that other populations will be included, such as healthy volunteers and people at risk for developing cancer.
- On the right, modify "personalized medicine at the point of care" to show that the outcome could also be risk identification and stratification.
- Instead of "targeted therapies," refer to "targeted interventions" to encompass cancer prevention.

The DCLG members and panelists reacted to the following question: How would the world be different if the platform were implemented?

- Currently, drug development requires 10–15 years, from discovery to clinical trial. If the platform were successful, clinical relevance could be achieved in half the time.
- The platform could reduce the cost of drug development by eliminating redundancies in research.
- For humankind, there will be less suffering, a lower incidence of cancer, and fewer deaths.
- For patients, there will be fewer toxicities, fewer missed diagnoses, and better outcomes.
- Taxpayers will receive direct benefit; fewer tax dollars will be needed for cancer treatment.
- Taxpayers will earn a greater return on their investment in research.
- Every medical act will contribute to medical knowledge.

To implement the platform, the DCLG identified several overarching changes that will have to occur, among them:

- Change how the academic endeavor is funded and recognized, including tenure.
- Establish better and more uniform IT standards.
- Change the way surgery is performed to ensure that biospecimens are collected and handled properly and provide incentives (reimbursement) for surgeons.
- Promulgate standards and accreditation for ensuring biospecimen quality, perhaps through the College of American Pathologists and/or The Joint Commission.
- Develop a new workforce of technical experts to be professional biobankers.
- Stimulate professional behavior change by educating professionals about biospecimen standards and providing data to show why it is important to adhere to the standards.
- Incorporate standards into contracts with institutions and professionals who collect and process biospecimens, and monitor adherence.
- Work with the Centers for Medicare & Medicaid Services (CMS) and the U.S. Food and Drug Administration (FDA) to help engender the comprehensive changes required.
- Change laws governing restraint of trade and intellectual property.
- Identify ways advocates can help improve accrual on clinical trials.
- Adopt electronic health records (EHRs), including genetic information.
- Ensure the effort/platform needs is understood by all funders.
- Set aside "disease balkanization" to help researchers score an early home run and make it easier to apply the new system to other tumors.

This special opportunity, made possible with funds from the American Recovery and Reinvestment Act of 2009(ARRA), must be undertaken wisely. NCI wants to share the story about this exciting transformation, starting with the TCGA effort to sequence 20 or 25 tumors. The goal is to maximally characterize each patient to the extent the technology allows. Dr. Niederhuber asked for advocates' help in communicating this vision and building excitement about it. If new models are shown to work, people will quickly shift to them.

It was clear to the DCLG members that their voices will be needed to articulate this vision as they return to their various constituencies. They asked that NCI equip them with preparation during the nascent stage as they start to engage their groups.

Board's Discussion of the NCI Therapeutics Platform
A discussion ensued about the various constituencies' expectations regarding the therapeutics platform and how best to engage communities to fulfill the promise of this system.

Expectations

- Expectations need to be managed from the beginning. Identifying and focusing on potential early wins could demonstrate that the platform works and help achieve success in increments.
- There is optimism about the promise of the platform. Nevertheless, being prepared and informed about potential downsides will help manage risks.
- The health care delivery system will have to be changed to support this new paradigm. The vision of a national cancer cohort cannot be realized otherwise. Providers have to be part of the conversation.
- Respect, build upon, and improve existing tissue biobanks.
- A plan must be put in place to focus CMS on how the platform can be implemented and underlying activities be reimbursed.

Points of Resistance

- Identify and engage resistors (e.g., those R01s displaced by a directed-research model).
- Limited access to technology in some communities may be a significant factor in determining outcomes.
- Participation on clinical trials has always been very low. Most patients are served outside of research institutions and may not be able to participate in trials.
- Little is known about the effectiveness of treatments in the community. Delivery of care is more about effectiveness than efficacy.
- Austere funding resources ahead may add to apprehension in the research community.
- The easiest groups to convert will be the National Community Cancer Center Programs (NCCCPs) and the Special Programs of Research Excellence. It may be more difficult to get buy-in from community oncologists and local physicians.
- More than 300 American Indian tribes live in the United States, each with a different culture and system of governance.
- A host of tissue banks already exists and may be reluctant to defer to the NCI repository.
- Underserved populations may not trust the government to have their best interests at heart.
- The therapeutics platform may not dovetail with academic incentives.
- A professional work stream is needed to develop biobanking and bioinformatics personnel.
- The pharmaceutical industry targets sales toward chemotherapy "shotgun" therapies that have large markets.
- The pathology community may resist the movement toward molecular biology and a different way of characterizing cancers.
- It is difficult to get research results applied in a highly fragmented clinical care system.

Overcoming Resistance

- Other government agencies (e.g., FDA, CMS) need to get involved early to make the platform a reality. Coordination is needed at the federal level. Align and deploy advocacy

groups to engage these federal agencies. Secretary Kathleen Sibelius may need to provide the leadership to bring all parties to the table and articulate the new vision.

- Professional societies would be a way to engage their members and leaders.
- Incentives are needed to foster team science. Grants can include stipulations to make use of particular resources (e.g., caBIG®).
- Provide incentives to community physicians (e.g., by conferring credentials to show that they are using the most up-to-date technologies).
- Make grants more like contracts by imposing requirements.
- Regarding EHRs, people should have some power about what information will be included, but if there are too many choices, the data will be inconsistent.
- Prevention is very important to many communities, and the risks of some cancers are more amenable to behavior modification than are others.

Possible Early Wins

- EHRs could be a platform for retrospective, longitudinal, and population research.
- The work of TCGA should be built upon, and the resulting information disseminated (e.g., the success of genomic studies of glioblastoma multiforme).
- Prevention, primary and secondary, is a way to engage more communities in the platform.
- Engage underserved populations early.
- Leverage caBIG® connections to NCCCP participants.
- Conduct retrospective analyses independent of biospecimen collection.
- For purposes of the therapeutics platform, it may be possible to create an EHR that is based on an oncology questionnaire.

Providing updates to the DCLG about how the reality is matching the vision would be useful.

Communication Strategy

Because communication is a two-way street, the group was careful to differentiate "delivering information" from "eliciting a dialogue."

Key Content Domains for the Research Community

- Emphasize that the platform will supplement—not replace—good ongoing work.
- Emphasize compliance with standards for use of biospecimens as well as data.
- Set the stage at NCI and show how this platform can make research more relevant.

Key Content Domains for Advocacy Communities

- Use petitions and patient testimony.
- Use 5-minute patient activities to encourage interest.
- Go for the low-hanging fruit to influence legislation.
- Issue a call to action to the general public.
- Develop a list of questions that all organizations should be asking.
- Make the platform understandable to advocacy organizations.
- Assemble a set of tools for a "road show" to help advocates communicate with legislators.

Key Content Domains for Legislators

- Engage cancer centers involved in public policy to communicate with legislators.
- Be opportunistic about finding entry points to educate legislators and their staffers.
- Hold a summit to bring together relevant parties.
- Develop a set of organizing principles to convey that advocates are linking arms to represent the larger community.

Key Content Domains for Clinicians and Professional Organizations

- Target communications to associations of clinicians, especially guideline organizations.
- Communicate the added benefit of protocol-driven care (versus clinical trials).
- Emphasize that this transition is a consumer-driven effort.
- Develop messages that clinicians can deliver to consumers.
- Create public service announcements.

Key Content Domains for Consumers

- Insert messages into television (e.g., soap opera) scripts.

NCI National Outreach Network—Presentation and Discussion

Presenters: *Dr. Sanya Springfield*
Mr. James Hadley

The National Outreach Network partnerships build on minority-serving institutions and NCI to reach minority populations, with the goal of reducing cancer and health disparities.

Dr. Springfield described use of evidence-driven approaches for cancer outreach, especially among rural uninsured populations. Also described were training opportunities intended to increase the size of the talent pool of cancer researchers.

Mr. Hadley, the new director of the National Outreach Network, explained that the Network is linking underserved communities to NCI and cancer information via research, training, and outreach provided by community health educators. The Network has three components: the Community Networks Program, the Minority Institutions/Cancer Center Program, and the Patient Navigation Research Program.

Community health educators work half-time on the program and half-time on a regional or national level to promote adoption of NCI research advances.

The DCLG members sought clarification on the following:

- For FY 2009, at what point can an organization come in with administrative supplements? The Cancer Centers are more complicated because of five-year renewals, so some will be handled as administrative supplements and others as grant renewals.
- Administrative supplements are rolling; there is no deadline, especially for diversity supplements. The application process will reopen in FY 2010 for the community health education program.

A Case Study of Advocate Involvement in the NCI Intramural Program
Presenters: *Dr. Patricia Steeg*
Ms. Musa Mayer

Dr. Steeg is an NCI researcher, and Ms. Mayer is a patient advocate with AdvancedBC.org. Dr. Steeg explained the integral role played by Ms. Mayer in the design and conduct of a trial for a potential new treatment for brain metastases in breast cancer. Ms. Mayer was involved from the beginning and had input in decisions about investigators to collaborate on the project. She helped plan such study aspects and helped keep the study both realistic and relevant. Her outreach to scientists aided in the identification of projects with good translational potential. For public outreach, she used such conduits as BrainmetsBC.org and coordinated or wrote articles for publication in scientific and consumer periodicals, including a Perspectives article for *Clinical Cancer Research.*

The DCLG members emphasized the importance of exporting this model. To this end, an article has been accepted for publication in the *Journal of Participatory Medicine.* The scientific community is still the dominant structure for decision making. Advocates should try to integrate into this community by attending grand rounds and other meetings. Thanks to OAR, most NCI researchers are open to advocates' participation.

Advocates in Research Working Group (ARWG): Final Recommendations
Presenter: *Ms. Shannon K. Bell*

Advocates are engaged in research at NCI in four main capacities: advisory, design, dissemination, and review of proposals.

The goal of the recommendations being developed by the ARWG is to set up a standard way to engage advocates in research to improve care for cancer patients. The ARWG's final report is in progress. Ms. Bell presented the detailed recommendations and sought feedback from the DCLG members.

Top-Level Recommendations of the ARWG

1. *Recruitment:* Develop a proactive, systematic approach to recruit a cadre of diverse, highly qualified research advocates and enhance the extent to which NCI staff effectively engage advocates across the research continuum.
2. *Assess & Match:* Develop a robust assessment and matching process that focuses on identifying NCI's needs and engages the right advocate in the right activity at the right time.
3. *Training:* Provide training, coaching, and resources to advocates and NCI staff to ensure participants have the information and tools they need to be effective.
4. *Facilitate:* The NCI OAR should guide the engagement process, facilitating relationships to enhance and realize desired outcomes.
5. *Evaluate:* Track and evaluate advocacy involvement at NCI to ensure a continuous improvement process and the ability to articulate outcomes.
6. *Retain & Promote:* Retain research advocates and NCI staff and promote successful advocate engagements.

Recommendations of the Board
The objective of the breakout session was to develop recommendations about three categories of potential early wins in which NCI can engage the advocacy community to fulfill the platform's goals. The product for NCI's consideration will be guidance from the perspective of advocates that would allow the platform to be realized.

The group affirmed the value of the advanced therapeutics platform. caHUB and caBIG® are major improvements to infrastructure. The platform should provide better coordination and adhesion of activities to make them more accessible to those outside the system. Research processes will be deployed in a more integrated way under this framework. The platform is action oriented and moves toward a goal—personalized medicine at the point of care. All of these pieces existed before, but now the technology exists to connect them and make them function more efficiently.

The three groups were: (1) TCGA and study of the first 20 tumors; (2) cancer-oriented EHRs and IT; and (3) communication, new opportunities, and prevention. Each group was asked to develop a game plan to include:

- *Objectives:* If we are completely successful in engaging advocates/researchers/patients, what will that look like? The objectives are not just for NCI and the DCLG.
- *Metrics:* How would you know that success has been achieved?
- *Challenges:* What are the challenges that stand in the way?
- *Success factors:* What needs to be put into place to achieve the objectives?
- *Action steps:* This is basically a time continuum, or it could be categorized by constituency (e.g., DCLG, researchers).

After reconvening in plenary session, each group presented its game plan to Dr. Niederhuber.

TCGA—20 Cancer Types
- *Objectives:* Robust and inclusive prospectively collected tissue; development of targeted therapy based on better TCGA disease characterization; development of new research models and cell lines from collected samples; increased continued and sustainable growth to the system to include other tumor types; enhanced understanding across a broad swath of people.
- *Metrics:* Number of TCGA grant applications; extent to which TCGA data are collected in standard fashion; controlled access to data and samples.
- *Challenges:* Widespread participation in prospective sampling; need for a tiered consent document for model/cell line development; funding; growth of enhanced bioinformatics to transform data into information; uptake of the data by care providers; providing incentives for incorporating TCGA in research.
- *Success factors:* Tiered informed consent; targeted community participation; transparency.
- *Action steps for NCI:*
  1. Establish transparent selection criteria (e.g., additional tumor types) and rationale.
  2. Engage the community about which tumors to research next.
  3. Discuss informed consent, and adjust as necessary.
  4. Provide communication tools about downstream goals.

5. Provide directed research funding mechanism.
6. Use carrots and sticks to encourage collection and use of TCGA data and samples.

- *Action steps for the DCLG:*
  1. Disseminate the criteria.
  2. Support collection methods.
  3. Work with NCI to develop message points for communities.
  4. Disseminate results of directed research.
- *Action steps for the research community:*
  1. Help them recognize that there is funding available for directed research.
  2. Adhere to guidelines for tissue collection in standardized form for caHUB.
  3. Provide storage facilities for biospecimens and provide access for other researchers.
  4. Messaging must reach the ground and go beyond scientific presentations and publications.
- *Action steps for the advocacy community:*
  1. Push for more philanthropic funding for platform activities.
  2. Encourage sustained federal support for this research.
  3. Start messaging about the new NCI.

Dr. Niederhuber complimented the group's work and acknowledged the important point about philanthropic support of NCI research. The work of the platform, although task-oriented, is being done in academic centers and through public-private partnerships.

Cancer-Oriented EHRs and IT

Three major components of information are needed in cancer-oriented EHRs: (1) data to include in caBIG® about the cancer, which data can overlay legacy systems or be add-on modules; (2) basic patient information (billing information, demographic data); and (3) ongoing health records. Regarding tumor information, such information is easiest to obtain from the point of diagnosis onward. Data on outcomes are also needed.

- *Objectives:* Standardize information flow, beginning at the point of care; establish a basic EHR for cancer with defined terms and common understanding; ensure data privacy, control, and security.
- *Metrics:* National virtual cohort; integration of the provider and research communities; standardized data collection; NCI-issued progress reports delivered to all stakeholders.
- *Success factors:* Definition of the dataset necessary for the study of tumor initiation; telling of the story of why this information is necessary (e.g., video); answers to questions about data and EHR ownership/control; definition of fields for basic EHR; collaboration of agencies participating in EHRs (e.g., FDA, CMS, Office of the National Coordinator); garnering of input from the consumer perspective about what data are to be collected.
- *Challenges:* Resistance to change; overreaching data collection; granularity of data; missing data points; scarce resources (time and money) at physicians' offices and NCI; fragmented care-delivery system; inequitable access to health care and insurance, which may make people reluctant to give access to their information; unequal participation in this new platform; lack of trust in the government; issues of data ownership/control (collective and individual data).

- *Action steps for researchers and institutions:*
  1. Share success stories.
  2. Collaborate and participate.
  3. Share the larger vision.
  4. Change institutional incentives/tenure/authorship.
- *Action steps for NCI:*
  1. Lead a process to determine the data dictionary.
  2. Identify data that are needed to bring about the new paradigm of cancer research.
  3. Begin at home to require all funded entities to participate.
  4. Create and inspire the vision.
  5. Engage all stakeholders.
  6. Design and implement the process.
- *Action steps for the public and the advocacy community:*
  1. Support this research through taxes; this is a national priority.
  2. Spread the word and tell the story.
  3. Participate by giving access to your data and tissue.
  4. Help with design, education, and other tasks.
  5. Engage in public policy advocacy.
  6. Conduct grassroots advocacy in the community.
  7. Advocate with providers.
- *Action steps for legislators/policy makers:*
  1. Establish billing codes for data and tissue collection to provide incentives for these activities.
  2. Address issues of privacy, security, and access.
  3. Provide funding for the platform.
  4. Deliberate about ownership and control of data.
  5. Establish system of "carrots and sticks" to encourage participation in and support of platform.
  6. Foster collaboration among relevant government agencies for EHRs as well as data privacy/security.
- *Action steps for providers:*
  1. Change incentives.
  2. Share the bigger vision.
  3. Educate patients.
  4. Pilot-test platform activities via the NCCCPs.
  5. Educate themselves and their peers.

Dr. Niederhuber agreed that coordination is the key. EHRs and IT need to be open source, open information. Most of the information has already been compiled, but access is not set up. EHRs can improve quality of care and reduce health care costs. He underscored the fact that DCLG advocacy can be especially fruitful in this area. He asked that the DCLG advocates rally their colleagues around this topic.

Communications and New Opportunities

This group focused not so much on prevention as it did on risk reduction and risk stratification. Stratification entails identification and classification of risk.

- *Objectives:* Fold risk reduction and stratification into the NCI therapeutics platform; change the public/NCI vernacular to encompass risk reduction and stratification; identify or create a mechanism for communicating with identified communities.
- *Metrics:* Published definition of risk reduction.
- *Challenges:* Collecting biospecimens from healthy people; risk reduction is usually low on lists of scientific priorities; risk reduction is often a lower priority among our communities than finding a cure for cancer; the platform, as currently articulated, does not encompass risk reduction/risk stratification; resistance to a shift in emphasis from prevention to risk reduction/stratification.
- *Success factors:* Evolve away from the "body-part focus" that has constrained progress in cancer research, especially with regard to risk reduction; coordinate and collaborate with primary care providers; engage a prominent group of researchers, educators, public health providers, and advocates working on risk reduction.
- *Action steps (mostly for the DCLG):*
  1. Review existing strategies for defining and differentiation prevention and risk reduction.
  2. Participate in all discussions, at the start, for developing a communication plan for the platform.
  3. Clarify that modifiable factors include personal behaviors plus environmental factors (excludes heritable genetics).
  4. Establish a community of advocates focused on risk reduction.
- *Action steps for NCI:*
  1. Put risk reduction at a higher priority in research enterprise, especially at NCI.
  2. Consider adding to the platform a parallel schematic that encompasses risk stratification/risk reduction.

Dr. Niederhuber pointed out that the ideas presented by this group provide an excellent opportunity for the DCLG to work across various oncology communities to understand the relationship between somatic genetic changes and the environment. Risk reduction is a high priority and is integrated into NCI's research agenda, especially with the National Institute on Environmental Health Sciences.

State of NCI
Presenter: Dr. John E. Niederhuber

This is the first year since 2004 that there has been an increase in the appropriated budget for NCI. In response to this one-time infusion of ARRA funds, NCI awarded many two-year grants. Unfortunately, science cannot be accomplished in two-year blocks. There is a real risk, if the baseline stays constant, that the success rate for funding applicants could drop precipitously. NCI would like to guarantee ARRA-funded projects for four years.

The hope is that NCI can convince the rest of the world about the importance of the new platform. NCI also is leading NIH on the five themes advanced by the NIH Director, Dr. Francis Collins.

The DCLG board members raised several questions for Dr. Niederhuber's consideration:

- Because 60 percent of cancer diagnoses occur in people 65 and older, most patients have comorbidities (e.g., elevated blood pressure, obesity). These conditions must be taken into account when planning cancer treatment.
- Could the platform be leveraged to develop targeted therapies for other chronic diseases? The platform can support other drug development efforts, but other NIH Institutes tend to engage pharmaceutical firms more because the markets are larger.
- Where does NCI need the help of advocates? Focusing on TCGA would be an important early focus for advocates' communication efforts. We all need to work together to tell the story in an exciting way without overpromising.

Next Steps
OAR staff will formulate an action plan for moving the DCLG forward with the platform. Digital photos of the meeting charts will be made available, and a process will be put in place to elicit and act upon grounds for action.

Ms. Darien and Mr. Dodson thanked all the board members for their participation, whereupon the meeting was adjourned.

Certification
I hereby certify that the foregoing minutes are accurate and complete.

_____	_____
Date	Chair, Director's Consumer Liaison Group
_____	_____
Date	Executive Secretary Director's Consumer Liaison Group