Statement of Expectations, Purpose and Goals From the caBIG™ Patient Advocates

It is the expectation of the caBIG™ Patient Advocates that caBIG™ will have a direct impact on the cancer patient's journey from diagnosis through treatment and beyond, by providing the tools necessary to lead to:

1. more rapid translation of basic research to the clinic,
2. centralized clinical trial information that is easily accessible to clinicians, and,
3. feedback from the patient to the research community.

Our expectation is that caBIG™ will lead to bringing new treatments to the patient with comprehensive knowledge about effectiveness and possible side effects so as to advance the NCI goal of eliminating the suffering and death due to cancer by 2015.

The purpose of caBIG™ Patient Advocates is to:

help ensure that the caBIG™ end product, The Grid, will ultimately benefit the cancer patient by improving patient care and outcomes in the most effective and timely way possible.

Broad goals of particular interest to the caBIG™ Patient Advocates

While these goals are not exclusive to patient advocates or to caBIG™, it is our expectation that:

- the informatics tools developed through caBIG™ will help the broader scientific community bring the research goals to realization, and,
- our patient experiences will lead to the development of caBIG™ communication and education efforts that will reach and engage the broader patient advocacy community and, ultimately, then patients themselves.

1. Research

a. caBIG™ will ensure the use of common standards that can be applied across the cancer community worldwide, allowing easy collaboration across institutions.

b. caBIG™ will enable and encourage these collaborative efforts which will result in reducing redundancy in research efforts and allow more rapid discoveries in the etiology, prevention, early detection, and treatment of cancer.

c. caBIG™ will enable new technologies such as proteomics, genomics, and targeted therapies to move forward more rapidly through the development of standardized software to process information.

d. caBIG™ will collaborate with current efforts that are translating scientific discoveries into patient results (i.e. SPOREs and cooperative groups) so that their efforts can be multiplied, and can be used as models for additional collaborative efforts.

e. caBIG™ will enable more rapid implementation of basic research discoveries in the clinic, ultimately improving cancer patient care and outcomes.

2. Clinical Applications of Research

a. caBIG™ will provide comprehensive information to physicians treating patients both within and after the completion of clinical trials. This will include contraindications, side effects, and efficacy information which are meaningful for individuals and not just aggregations of statistical information.

b. Standardized software will enable the comparison of clinical trials run in different venues and could help to speed up the accrual of patients and data. Taken together, these could increase the speed of trial completion and result in more rapid development of treatments for patients.

3. Communication/Education

a. The role of the Patient Advocate within caBIG™ is to:

i. Encourage and facilitate communication among different workspaces, between and among groups of software developers and their potential adopters and end users, including patients; and, where possible, help identify domain experts for each workspace and offer suggestions on ways to make it as easy as possible for these experts to work with caBIG™.

ii. Participate in teleconferences and meetings, bring in patient perspectives and concerns as software is developed. This includes information the caBIG™ initiatives may have stimulated in the public or private sectors, outside the caBIG™ structured community, and which may now have direct or indirect impact on developing software within caBIG™.

iii. Continually emphasize the importance of making caBIG™ projects relevant to the patient.

iv. Highlight concerns that are important to patients, e.g., security, privacy, access to clinical trials, seamless collaboration among research institutions, and seamless coordination of individual medical care.

v. Participate in Request for Proposal (RFP) reviews to help bring a full consideration of significance, relevance, and timeliness to the table.

vi. Actively participate in the annual caBIG™ Strategic Planning process.

vii. Be visible and recognized in workspace meetings and annual caBIG™ meetings (presentations/breakout facilitators/posters).

viii. Aid in the creation/production of caBIG™ literature/presentations to the broader advocate and more public communities, ensuring the use of appropriate and understandable language for those communities.

ix. Articulate the patient perspective in caBIG™ documents, especially those identified as having particular importance to patients and the public, such as security, tissues, and consent.

x. Develop a mechanism among the Patient Advocates to address common/special concerns as they arise in the different workspaces.

b. The role of the Patient Advocate in the broader advocate community is to:

i. Gain a broader perspective and audience through the NCI Director's Consumer Liaison Group (DCLG): The Patient Advocates requested a liaison representative from the NCI Director's Consumer Liaison Group. A DCLG liaison has now been identified and has been integrated into the caBIG™ advocate listserv and caBIG™ Patient Advocate teleconferences.

ii. Access and engage the NCI Consumer Advocates in Research and Related Activities (CARRA) community: Several caBIG™ Patient Advocates are members of CARRA, based in the NCI Office of Liaison Activities (OLA).

iii. Participate in the planning and presentation of an NCI OLA teleconference about caBIG™ in 2006, as part of their toll-free teleconference series entitled "Understanding NCI". Each teleconference session is open to advocates and anyone else across the country.

iv. Explore additional mechanisms to communicate caBIG™ achievements, issues, and concerns to the broader patient advocate community.

caBIG™ Patient Advocates

Greg Bielawski, Strategic Planning Workspace
Deborah Collyar, Clinical Trials Management Systems and Data Sharing and Intellectual Capital Workspaces
Don Melancon, Training Workspace
Diane Paul, Architecture Workspace
Mary Lou Smith, Data Sharing and Intellectual Capital Workspace
Patty Spears, Integrative Cancer Research Workspace