INTERNATIONAL CANCER GENOME CONSORTIUM

UPDATES TO GOALS, STRUCTURE, POLICIES & GUIDELINES

SECTION D – STRUCTURE OF THE CONSORTIUM

MARCH 2010

WWW.ICGC.ORG/POLICY_UPDATE_CONSORTIUM
D. Structure of the Consortium

The ICGC is a confederation of members that share the common goals and principles described in this document and have agreed to work in a coordinated and collaborative manner within a defined structure.

Members consist of Funding Members and Research Members, each of which is an individual or allied group that will provide a level of funding or scientific expertise sufficient to undertake a Cancer Genome Project involving characterization of a minimum of 500 unique cases for each cancer type or subtype. More than 500 samples may be required for tumors that demonstrate considerable heterogeneity. There are circumstances when 500 samples of a tumor type or subtype may be impractical (such as a rare cancer) or unnecessary (such as a tumor subtype that is known to be relatively homogeneous, based on pre-existing molecular studies). ICGC Research Members proposing to tackle such projects should provide the rationale for the choice of sample size. Each Member will have responsibility for financially or scientifically supporting a minimum of one Cancer Genome Project. Members wishing to support Cancer Genome Projects with fewer than 500 samples per tumor type should do so by clustering projects together. Research Members will need to have existing or committed funds from an ICGC Funding Member.

It is recognized that, at the outset, potential Funding Members may not yet have designated funds available to support a Cancer Genome Project and thus may be unable to immediately commit the requisite funds. Funding agencies with a prior record of funding large-scale cancer and/or genome projects will be provided an opportunity to join the ICGC in the absence of a qualifying research project for the first year to allow sufficient time for them to follow their normal policies and procedures to secure funds, to plan initiatives of this magnitude, and to make a firm funding commitment.

Categories of membership are defined as follows.

ICGC Funding Members

1) Single funding agency; or
2) Alliance of organizations, with a representative from a single organization within the coalition appointed to the EXEC. (See Structure, below)

To support the characterization of 500 unique cases of one cancer type or subtype to the degree of comprehensiveness described in this document, ICGC Funding Members will be required to provide the equivalent of a minimum of $20 million US in total on such a project, distributed over 5 years, for operations (salaries, consumables, etc.), excluding overhead/indirect costs and equipment. It is recognized that some countries may have lower research costs, or may be able to provide material contributions (such as specimens) that may offset the level of commitment. Guidelines will be developed to evaluate the value of “in-kind” or lower contributions, with a general principle that the responsibility will rest with the funding organization to ensure that the level of support will be sufficient to mount a cancer genome project that will meet the guidelines of the ICGC.
Funding organizations, bodies or groups that want to join the ICGC as a Funding Member, can self-nominate to the ICGC Executive Committee (described below) which has the responsibility for review and approval of nominations. To become an initial ICGC Funding Member (or ICGC Founder), nominations must be received before September 1, 2008. Additional funding agencies are encouraged to become Funding Members in the future, as they become ready to contribute to the ICGC and adopt the Consortium’s policies and guidelines.

ICGC Research Members

To join the ICGC as a Research Member, nominations must originate from an ICGC Funding Member that will provide support to the research organization. Research Members will have the demonstrated capability and capacity to support a Cancer Genome Project and will perform ICGC-affiliated cancer genome research according to the set of commonly agreed-upon policies and guidelines described in this document. Nominations are reviewed and approved by the Executive Committee. Such organizations will need to have existing or committed funds from an ICGC Funding Member.

Research Members can be:

a) A research center or network of national or international research groups organized to acquire and analyze samples for one or more cancer genome projects;

b) A genome, cancer, clinical, ethics, bioinformatics (or other) center which contributes significantly to the operations of several cancer genome projects.

Given that these organizations will likely have different structures, and include many investigators, clinicians, scientific managers, as well as clinical and technical staff, each organization will be asked to nominate representatives to participate in ICGC coordination activities, such as the International Scientific Steering Committee, working groups, workshops, and ICGC meetings.

Structure

A distributed model for the organization of the ICGC has been selected as most appropriate for the success of this project. This model has been successfully used in other international genome projects, where high standards and policies have been determined at the outset, and acceptance and adherence were prerequisite for joining. The model, illustrated in Figure 1, relies on the interaction among funders (providing oversight), an international scientific steering committee (setting guidelines) and scientific groups and centers (sample providers and data production centers involved in data production, quality assessment and data management). The strength of the Consortium’s structure rests not only with its component parts but also in the bi-directional flow of information between the groups.
Given the diversity of organizations that will be involved in the ICGC and the fact that most are independently governed, it is understood that in addition to their participation in the Consortium most of the organizations will conduct activities in cancer and genome research that are outside the scope of the ICGC.

**Governance**

Oversight of the ICGC will be provided by an EXEC, constituted of individuals nominated by ICGC Funding Members. The EXEC will:

- review and accept nominations of new Members;
- work closely with the International Scientific Steering Committee;
- revise or adopt new recommendations related to ICGC policies;
- monitor progress, data quality, and data accessibility across projects;
- periodically report progress to funding agencies;
- provide a forum to discuss potential overlaps that may arise between projects and negotiate solutions;
- provide a forum to resolve issues that may arise;
- decide about recruitment of consultants or establish expert committees on issues related to science, law, intellectual property, ethics, funding, communications, etc.;
- develop a communications strategy, designate communication leader(s), and assure active consultation of all ICGC stakeholders. The importance of ICGC activities will not be overstated, given that the practical benefits to the public will take time to be realized.

The EXEC that was constituted after the October 2007 meeting in Toronto will act as the Interim EXEC of the ICGC, until a permanent team of committed Funding Members is identified.
**INTERIM ICGC EXECUTIVE**
Warwick Anderson, National Health and Medical Research Council, Australia (Observer Status)
Cindy Bell and Karen Kennedy, Genome Canada, Canada (Observer Status)
Tom Hudson, Ontario Institute for Cancer Research, Canada
Henry Yang, Chinese Cancer Genome Consortium, China
Jacques Remacle, Patrik Kolar and Iiro Eerola, European Commission (Observer Status)
M.K. Bhan and T.S. Rao, Ministry of Science & Technology, Department of Biotechnology, India
Edison Liu, Genome Institute of Singapore, Singapore
Alan Schafer and Michael Stratton, The Wellcome Trust; Wellcome Trust Sanger Institute, United Kingdom
Anna Barker and Daniela Gerhard, National Cancer Institute, United States
Francis Collins, Jane Peterson, Mark Guyer and Brad Ozenberger, National Human Genome Research Institute, United States

**Coordination**

An International Scientific Steering Committee (ISSC) will be constituted with the principal investigators of cancer genome projects in the ICGC, the Data Coordination Center, expert pathologists, oncologists and ethicists, and representatives of funding agencies. This group will interact frequently, through phone conferences, e-mail and regular meetings, to:

- act as a science coordinating body;
- evaluate progress;
- address arising issues of a scientific nature, including those related to samples, consent, ethics, quality standards, evolving technologies;
- exchange protocols, standard operating procedures;
- establish temporary or permanent subcommittees that would be assigned focused tasks;
- establish QC standards.

A Data Coordination Center (DCC) will manage data flow from projects and centers to the central ICGC database, public repositories, quality assessment, curation and data releases (see details in section E.9 Data Management). The DCC will provide regular progress reports to the EXEC and ISSC.

**Quality Assessment Centers**
Quality assessment of the samples used in cancer genome projects is critical to the success of the project. To that end, the Consortium may consider establishing quality assessment centers. The issue of ‘round robin’ style versus 3rd party quality assessment will require further discussion, as well as mechanisms for funding such activities.

**Coordination Support**
Staffing will be committed to help manage the operations of the ICGC committees.