

INTERNATIONAL CANCER GENOME CONSORTIUM

UPDATES TO
GOALS, STRUCTURE,
POLICIES & GUIDELINES

SECTION D –
STRUCTURE OF THE
CONSORTIUM

May 2012



ICGC

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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 are individual or allied groups that provide a level of funding or scientific expertise sufficient to undertake at least one **Cancer Genome Project**. Most projects involve the characterization of a minimum of 500 unique cases of a 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). In March 2012, the ICGC formalized the status of smaller projects to encourage the launching of studies of rare forms of cancer: Affiliate Status will be granted to projects that are funded to study a minimum of 100 tumors (see below). ICGC Research Members proposing to tackle smaller projects should provide the rationale for the choice of sample size. Each member will have the responsibility for financially or scientifically supporting a minimum of one Cancer Genome Project. 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 as Observers in the absence of a qualifying research project for a period of approximately a year to allow them sufficient time 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 Launching Large-Scale Projects (more than 500 samples)

- 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 \$10 million USD 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 agencies supporting large-scale projects can self-nominate to the ICGC Executive Committee (described below) which has the responsibility for review and approval of nominations. Funding agencies are encouraged to apply for Funding Member status as they become ready to contribute to the ICGC and adopt the Consortium's policies and guidelines.

ICGC Members Funding Affiliate Status Projects (fewer than 500 samples)

In early 2012, ICGC approved establishing Affiliate status for projects with less than \$10 million USD in funding and fewer than 500 cases available for analysis. This decision was taken to promote the study of rare tumors within the Consortium. Affiliate projects must commit to the analysis of at least 100 tumors. (For very rare tumors, 100 or more cases may be obtained using an aggregate of smaller collections.) The expected level of funding of a project that will study 100 tumors is \$3M USD distributed over five years.

Funding agencies that are supporting Affiliate projects with total funding less than \$10 million USD and are not supporting any full Cancer Genome Projects will not qualify for membership on the Executive Committee. Existing ICGC member organizations launching Affiliate Status projects retain membership on the Executive Committee.

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.

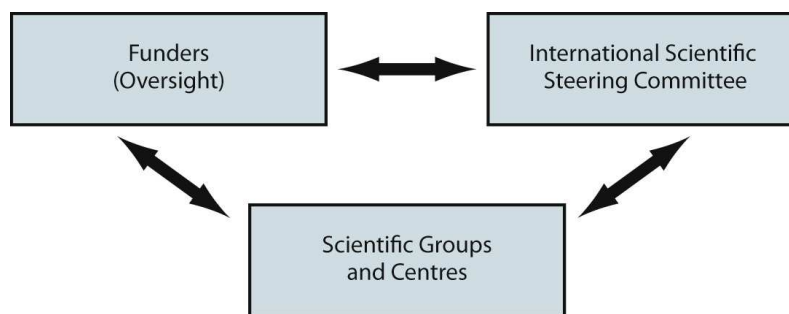
Given that these organizations will likely have different structures, and include many investigators, clinicians, scientific managers, as well as clinical and technical staff, each organization will be asked to nominate representatives to participate in ICGC coordination activities, such as the International Scientific Steering Committee, working groups, workshops, and ICGC meetings. At least one member for each Affiliate project will be invited to join the ICGC scientific workshops. One scientist from each Affiliate project will be invited to join the International Scientific Steering Committee teleconferences.

Researchers wishing to apply for funding to support an ICGC project (large-scale or Affiliate status) can contact the ICGC Secretariat for a letter of support. When funding is obtained, ICGC will request a letter from the funding organization to confirm the funding commitment.

Structure

A distributed model for the organization of the ICGC was 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.

Figure 1: Structure of Consortium



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 is provided by an EXEC, constituted of individuals nominated by ICGC Funding Members. The EXEC:

- reviews and accepts nominations of new Members;
- works closely with the International Scientific Steering Committee;
- revises or adopts new recommendations related to ICGC policies;
- monitors progress, data quality, and data accessibility across projects;
- periodically reports progress to funding agencies;
- provides a forum to discuss potential overlaps that may arise between projects and negotiate solutions;
- provides a forum to resolve issues that may arise;
- decides about recruitment of consultants or establish expert committees on issues related to science, law, intellectual property, ethics, funding, communications, etc.;

- develops a communications strategy, designates 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.

Coordination

An **International Scientific Steering Committee (ISSC)** includes 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 interacts 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)** manages 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 provides 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.