

E. ICGC-ARGO Policies and Guidelines

E1. Ethics and Informed Consent

E.1.1 Core Bioethical Elements for Participation in ICGC-ARGO

ICGC-ARGO follows the Global Alliance for Genomics and Health's (GA4GH) *Framework for Responsible Sharing of Genomic and Health-Related Data*^[1] which is founded on the belief that everyone should benefit from scientific advances and that data producers should receive proper attribution. ICGC-ARGO is also mindful that local cultural and regulatory practices, including ethical review, will differ across its member projects and their individual research studies. In order to support the aims of ICGC-ARGO while respecting differences between members, core bioethical principles will be adopted to help enable the gathering and translating of cancer genomics data into more effective prevention strategies and therapies, to provide better outcomes for patients and their families.

E.1.2 Informed Consent

Because of the differing regulatory requirements and cultural norms held by differing countries, harmonisation of consent across ICGC-ARGO is not possible. However, for the science to move forward, a core set of elements is needed to ensure the ethical use of patient and participant data. ICGC ARGO Programmes are asked if their data is consented for:

- Any approved future biomedical research?
- Deposit of open access fields/datasets in open access databases?
- Deposit of controlled fields/datasets in controlled access databases?
- Linkage with other research datasets?
- International data sharing?
- Sharing for widespread use without specific restrictions?

The ICGC-ARGO can assist programmes to decide if their existing consent materials meet these, and if not, what measures they can take, such as re-consent or ethics waivers.

E.1.3 Return of Results

Decisions regarding returning individual results will be the responsibility of the member projects. All member projects should notify ICGC-ARGO if they will be returning individual results to participants and confirm that this decision has received approval from a responsible body, according to applicable regulations and policies. This policy will be kept under review.

^[1] Knoppers B. Framework for responsible sharing of genomic and health-related data. *The HUGO Journal*. 2014;8(1):3.