The International Cancer Genome Consortium (ICGC) was launched in 2007 to coordinate large-scale cancer genome studies in tumours from 50 different cancer types and/or subtypes that are of clinical and societal importance across the globe. To date the ICGC has provided more than 20,000 cancer genome data sets to the community across 26 cancer types. These data have enabled the revealing of the repertoire of oncogenic mutations, uncovered traces of mutagenic influences, defined clinically relevant subtypes for prognosis and therapeutic management, and driven the development of new cancer therapies. The ICGC network ultimately involved 86 project teams in 22 jurisdictions on nearly every continent.

Data generated through the ICGC has transformed research strategies in academia and industry alike, with more than 456 landmark articles published directly using ICGC data, in the world's elite scientific journals. No therapeutic is developed today without, in some way, applying the knowledge that ICGC has provided the world.

The ICGC has served two key purposes. First, it served as a centralized communications forum for the international scientific community, to share information about cancer genome research. Secondly, it has provided a resource of genomic, transcriptomic and epigenomic changes to the scientific community in a rapid and responsible way through a data access governance framework encompassing: the Data Access Compliance Office (DACO), handling data access requests, and the International Data Access Committee (IDAC), helping to establish data access guidelines and balance the protection of participants' personal data and sharing data to accelerate cancer research.

The centrality of the use of personal data, and the importance of international data sharing cannot be underestimated in this work. The importance of the work in developing new treatments for patients with cancer is also self-evident. It is equally, self-evident that the environment within which this work is undertaken, and sensitive personal data are shared, must respect the highest standards of personal data protection, privacy and confidentiality outlined in the regulations evolving globally; to achieve the necessary trust and confidence that is essential to ensure participation of patients in both treatment and research, all work must ensure privacy and data protection by design at its very highest standards. As indicated above, this has always been at the forefront of the consortia principles and governance model.

In its second iteration, ICGC ARGO aims to build upon its early efforts and utilize genomic data to address outstanding clinical questions in cancer to directly impact patients. However, global regulations have created difficulties for consortia such as ours. The advent of GDPR has left little margin for continuous international data sharing and amalgamation of health and genomic data on the scale of that envisaged by ICGC ARGO.

The GDPR, as it is often interpreted and enforced, produces a number of difficult barriers to the work undertaken by projects within ICGC ARGO. In particular, this is an issue for international transfers of personal data essential to the continued development of ICGC ARGO and its objective to accelerate research in genomic oncology. There are routes to processing available in the legislation that would make the work possible, and the sector-specific codes of conduct could make these available. Further, the development of such sector-specific codes could be a space for inter-jurisdictional solutions to the current difficulties experienced by researchers in international projects. The ICGC project has already proven the power of working collaboratively across continents to enable comparable studies of different types of cancer and to capture the diversity of cancers worldwide.

The Code of Conduct, a new mechanism has always seemed an ideal solution for health research data transfers. The guidance is a significant step towards an international agreement that will enable the continued progress in research that patients across the world need whilst recognizing the protection that all citizens require for their legitimate interests. The further steps are to realize those codes of conduct, and ICGC ARGO will focus on making the most of this exciting opportunity. We look forward to further guidance on the application of the elements of a code of a conduct and for health research.