ARGO Accelerating Research in Genomic Oncology
International Cancer Genome Consortium

E7: Patient and Public Involvement and Engagement

Overview

To achieve the aims of the ICGC ARGO project, we need to harness the invaluable lived experience of cancer patients, their families and carers to inform activities, and bolster the involvement of patients to form a closer connection between researchers and patients. We aspire to see patients involved as much and as meaningfully as possible in governance, priority setting, oversight and knowledge translation of ICGC research. Patients ought to take place deservedly as proactive partners who help shape ICGC research and, as a result, enhance the relevance of the research and improve its translation into policy and practice. This will in turn contribute to improving the quality of life for cancer patients and ultimately strengthen health systems.

The healthcare system has dramatically changed in the past two decades, and patient and public involvement in research is not only happening widely across the world, but we are starting to see patients partner with researchers to design studies from the ground up. Not only do patients and the public have a right to be involved in decisions that impact upon them, but involving patients in research has been shown to lead to better research and better outcomes such as enhanced research design, delivery, and dissemination—and over time, the wider impacts of an enriched research culture and agenda.

The Patient and Public Involvement and Engagement working group (PPIE WG) has been formed to focus on engaging with patients, health professionals and the greater public so as to increase the visibility and accessibility of ICGC-ARGO research. The aim is to foster an environment in which researchers, health care providers and policy-makers understand the value of patient involvement, and patients see the value of these interactions.

The meaningful involvement of patients may include the following roles as demonstrated by the Ladder of Participation[1]:

The Ladder of participation

Degree	Participants Role	Illustrative Mode
High	Initiates the research	The community identifies the research needed and sets the appropriate research agenda.
	Has Full control	Researchers asks community to identify the problem and to make all the key decisions on goals and means. Willing to help the community at each step to accomplish goals.
	Have defined level of control	Organisation identifies and presents a problem to the community, defines the limits and asks the community to make a series of decisions, which can be embodied in a plan it can accept.
	Plan jointly	Researchers present tentative plan subject to change and open to change from those affected. Expects to change plan at least slightly and perhaps more subsequently.

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[1] Adopted from “Consumer and Community Participation in Health and Medical research, a practical guide for health and medical research organisations” www.sph.uwa.edu.au.

	Are consulted	Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary
Low		
	Receive information	Organisation makes a plan and announces it. Community is convened for informational purposes. Compliance is expected.
	None	Community not involved

Guiding Principles for Patient and Public Involvement and Engagement

Underpinning the involvement of patients and the public in research are guiding principles to which ICGC ARGO projects can aspire to in pursuing the goal of integrating patient engagement into their research:

- **Inclusiveness:** integrating a diversity of patient perspectives and research is reflective of their contribution.
- **Support:** for potential patient participants to ensure that they can contribute fully to discussions and decisions, creating safe environments that promote honest interactions, cultural competence and training.
- **Mutual Respect:** A shared understanding of individual roles and expectations and ensuring people have the right skills, on both sides.
- **Shared focus- agreed outcomes**; work together from the beginning to identify problems and gaps, set priorities for research and produce and implement solutions. Seek feedback from the public and patients that are involved and act on that feedback.

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