More than 25 participants from the private sector, existing UICC partners from international NGOs and the World Health Organization (WHO) convened in April in the offices of the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA) in Geneva to discuss the global lack of cancer data.

This meeting was the first UICC Global Roundtable Series in 2012. The leads for the meeting were the International Agency for Research on Cancer (IARC), the global centre for excellence in cancer information, and UICC represented by Dr John Seffrin, CEO of the American Cancer Society.

“Reliable data provides the basis for us to communicate what we do and what we do not know about cancer – helping us to realise the promise of the United Nations Political Declaration on NCDs – the single largest health, disease and disability challenge of this century.”

Dr John Seffrin, CEO, American Cancer Society

Population-based cancer registry data is an essential foundation of national cancer control planning – if you don’t know your cancer burden, how can scarce resources be targeted at the most appropriate solutions for cancer?

Dr Eduardo Cazap, President, UICC

Key messages

All participants recognised the fundamental need for robust cancer data to support their own field of interest – researchers, academics, leaders of NGOs, the private sector and United Nations agencies. In all instances it was agreed that data helps make a compelling case. Evidence-based outcomes from cancer control initiatives (whether these are on prevention, detection, treatment or care) need to be available to show progress in cancer control and to illustrate global and national trends.

It was agreed that accurate and robust cancer data gives credibility to cancer-fighting organisations who “sound the alarm” and it is essential to encourage governments and international bodies to introduce evidence-based policy changes which improve cancer control outcomes. Great cancer data can be utilised to design effective communication strategies about cancer risk and treatments to the general public and also to guide research, drug development and health systems management.
There was recognition that many high-income countries have the high quality cancer data. However, for many parts of the world cancer registries cover less than 10% of a country’s population. Thus, the challenges facing data collection and usage of that data differ in developed countries versus developing countries.

The issue of transparency in cancer data is a critical factor in the fight against cancer. The ability to share data is vital for comparing outcomes – particularly institutional outcomes. For example, it has been demonstrated that openly publishing and sharing statistics on hospital performance can uncover variation which can then bring about a “regression towards the best” and not regression to the average, as many people would assume.

The participants heard that some companies are rising to the challenge of providing and linking disease datasets for improved outcomes. Promising work on systems that are better able to gather and share data are in progress – electronic records, automatic capture, collaborative research platforms, guideline monitoring and benchmarking approaches, systems to provide expert information to physicians and patients alike – all with the common aim of improving data quality, reducing time delays while avoiding duplication, seeking synergies and linkages, but they are not there yet. It is considered that a key success factor is empowering healthcare workers (those that deliver the care) to participate in the data collection.

The gap in population coverage of cancer registration is staggering (in North America, 83% of the population is covered versus less than 1% in Africa). In the developing world, governments and cancer organisations need basic information on the most common cancers in their country, to create a fact-driven national cancer control plan which identifies the key issues to be addressed and how to measure the progress of implementation.

The barriers to obtaining cancer data are numerous and include: institutional, financial, political, legal and technological. We need to learn from information and communication companies and harness new technologies for improved cancer control information. The private and public sectors need to work together to resolve the cancer information dilemma. Cancer registries in the developing world can especially benefit from technology innovations to collect, distribute, analyse and report cancer information more effectively.

“Measuring is not enough – you need to share outcomes widely and transparently.”

Dr Thomas Paulsson, Executive Director
Health Economics and Outcomes Research, BMS

“How do we take the methodologies from high-income countries and apply them to the developing economies? How do we reinforce awareness for the need of data? We lack information but the first issue of oncologists in the field is getting enough resources to treat the patients.”

Martin Bernhardt, Vice President Relations with International Institutions, Sanofi

Global Initiative for Cancer Registries (GICR)

Convened by the International Agency for Research on Cancer (IARC) and in partnership with UICC, GICR aims to develop and create the capacity to produce reliable, high-quality information on the burden of cancer so that effective policies for cancer control can be developed and implemented. One of the main activities resulting from GICR will be to establish ‘centres of excellence’ or ‘knowledge hubs’ which will act as IARC regional resource centres, capable of providing developmental support towards and for population-based cancer registries. Learn more at http://gicr.iarc.fr.

At the event in Geneva, Head of Cancer Information at IARC, David Forman, reported that the first of six planned hubs had been launched and two others would follow shortly.
Information about the burden of cancer and survival rates is much more comprehensive and of higher quality in high-income countries compared with low- and middle-income countries. In partnership with UICC, IARC is developing a fundraising programme The Global Initiative for Cancer Registries to raise $5M over the next five years to address this information disparity.

Dr David Forman, Head, Section of Cancer Information, International Agency for Research on Cancer (IARC)

There is a clear role for information technology in the fight against cancer. Information technology has great potential to transform healthcare and research which ultimately will save lives and reduce costs by a higher degree of efficiency and effectiveness.

Mr Uwe Höhne Consultancy Partner for Business Analytics and Optimization, IBM

Upcoming events in the Global Roundtable Series

This event was the first in UICC’s Global Round Table Series for 2012, which gathers leaders in key cities around the world to discuss the most pressing issues in the cancer community. The attendees were enthused by the discussion, with some becoming aware of the global information problem for the first time. Many attendees expressed interest in following-up on the discussion to see how their organisation could become involved in improving the situation.

- August 2012 - Montréal, Canada
  Leveraging Your Network
  Annual UICC Vanguards Meeting
- November 2012 - Geneva, Switzerland
  Cancer Treatment in 2030

Thanks to our Partners

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