Cancer Clinical Trials in Ireland – Enhancing and Facilitating Patient Participation, Engagement and Involvement

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A key target of the National Cancer Strategy is to achieve a substantial increase in the percentage of eligible patients enrolled to cancer clinical trials, from 3% to 6%. There are benefits to many stakeholders in achieving this, but most importantly there will be clear and measurable benefits to patients living with cancer.

The advantages to patients of clinical trial involvement include the obvious - access to innovative, more effective, and less toxic cancer treatments or preventative strategies that are otherwise unavailable. It is clear however that the benefit to patients extends beyond this, including to clinical care with more intensive monitoring of their condition and provision of patient care by highly experienced staff with specialised understanding of their cancer and treatment.

Clinical trial participation empowers patients to take an active role in management of their cancer and facilitates improved understanding of their condition and new developments in therapeutic strategies. Patients also appreciate the opportunity to contribute to the scientific understanding of their cancer and are motivated by the ability to help others with the same diagnosis, even if in the future. From an institutional perspective, it is essential to develop an innovative, sustainable cancer clinical trial program as part of maintaining quality improvement and international best standards in provision of cancer care.

Increasing cancer clinical trial availability and participation introduces state-of-the-art activities and technology, motivates clinicians to pursue better models of care, and provides additional monitoring of adherence to guidelines for clinical care. It provides a clear focus for international benchmarking of institutional excellence and facilitates research collaboration with academic centres and industry.

These advantages translate into tangible national benefits including improvement in healthcare outcomes, and measurable economic benefits including cost saving in care provision, creation of highly skilled jobs, and attraction of international investment from industry for research and development.

There is a need to prioritise cancer clinical research and achieve these benefits for patients with cancer in Ireland. Most importantly, we need to partner with our patients to facilitate rapid translation of scientific discoveries in academic medical centres in Ireland to innovative, well designed cancer clinical trials. This requires us to put the patient at the centre of clinical and translational cancer research, embedding active public and patient involvement at each stage of development. Only by co-developing the research question with the most important stakeholder – the patient- can we identify and address the key areas of need in cancer care that will have real world impact on cancer outcomes. This principle is well established and acknowledged within the academic and clinical community, however successfully achieving this in practice is more complicated.

Many patients with cancer and their families do not have sufficient time, level of wellbeing or healthcare literacy to participate actively and ensure that their voice is heard, leading to an under-representation of patient with hard-to-treat cancers, or lower socio-economic groups in patient representative groups. We can address this disparity as clinical and translational researchers by partnering with cancer charities, patient advocacy groups and with Cancer Trials Ireland and the Health Research Board to co-develop the appropriate support, environment and educational resources needed to achieve patient representation from all groups and ensure informed patient participation across the research spectrum.

The next decade will bring huge changes in cancer clinical trial design, as the cancer drug development paradigm shifts towards small, biomarker selected studies and with the emergence of next generation cell-based therapies for cancer treatment. Advances in cancer genetics and genomics offer new opportunities not only for precision cancer medicine but also progress in key areas of cancer prevention and survivorship. We have a unique opportunity to co-develop our cancer clinical trial network nationally to embed patient and public involvement in the design of the next generation of studies, and ensure translational researchers are working in tandem with clinical researchers to address key unmet needs and clinical challenges in oncology. Achieving and hopefully exceeding the patient enrolment targets for cancer clinical trials set by the National Cancer Strategy is an essential goal, but we will achieve the greatest impact on cancer outcomes nationally and internationally through combining this with a similar increase in patient engagement and patient involvement through all stages of the cancer research cycle.

Bio:

Maeve Lowery is Professor of Translational Cancer Medicine at Trinity College Dublin and Consultant Medical Oncologist at St James Hospital. She was recently appointed Academic Director of the Trinity St James Cancer Institute (TSJCI) and is chairperson of the Cancer Molecular Diagnostics Advisory Group of the National Cancer Control Program (NCCP). Her clinical and translational research involves design and conduction of clinical trials in patients with gastrointestinal malignancies, incorporating translational study endpoints to validate predictive and prognostic biomarkers, identify mechanisms of resistance and guide the development of rational therapeutic strategies. Her translational research interests use of real time genomic profiling to identify novel therapeutic strategies for gastrointestinal cancers, identification of non-coding alterations as modifiers of the DNA damage response pathway and generation of organoid models of cancer as a tool for precision oncology as a member of the PRECODE consortium. Her work is supported by the Pancreatic Cancer Research Fund (https://www.pcrf.org.uk), Science Foundation Ireland, through the Precision Oncology Ireland Consortium, the EU Horizon 2020 Marie Sklodowska-Curie Programme and the Health Research Board (HRB).