Europe strengthens patient involvement in cancer research

Current Trio Council Presidency partners Slovenia, Portugal and Germany adopt joint Principles of Successful Patient Involvement in Cancer Research

Cancer continues to be one of the major challenges in modern medicine. In Europe, more than 2.7 million people are diagnosed with cancer every year. Patient-centred cancer research is to become the standard in Europe in the long term, becoming even more closely aligned to the needs of patients. For this reason, the research ministers of Germany, Portugal and Slovenia have today adopted the Principles of Successful Patient Involvement in Cancer Research. These new general principles were drawn up in a multi-stage process by patient organisations, researchers, medical and care professionals, representatives from industry and funding organisations as well as other stakeholders from across Europe. Germany’s Federal Research Minister Anja Karliczek explained:

“We are providing important impetus as the Trio Presidency with the new Principles of Successful Patient Involvement in Cancer Research. Science must open up across Europe. We need a change of culture in research towards greater participation. These new principles call for the systematic involvement of patients in cancer research. For example, this means that there will be an even greater focus on quality of life, which is so important to cancer patients. The principles are an important aid for practitioners and offer specific proposals for action. In this way, they provide an important basis for new links between patients and scientists in cancer research.

“However, the principles also have significance beyond the field of oncology. They can also be applied to health-oriented research as a whole. The clear signal is that patient involvement must become more standard throughout Europe. This is an important message for all patients in the whole of Europe.”

Quote Slovenia
Simona Kustec, the Slovenian Minister of Education, Science and Sport added:

“We are expanding and transforming the boundaries of this research field by emphasising the successful engagement of cancer patients, survivors and their families into cancer research. Our aim is to provide them with the opportunity to become active agents in the research and enable them to be at the core of
shared decision-making. We are focusing on the entire cancer research/care/prevention continuum for better results and healthier community.

“Therefore, today we pledge our dedication to aligning national and European research efforts and call upon all European countries to join in. Improving the life and care of cancer patients and survivors should be our top priority, as indeed it has been one of Slovenia’s health priorities already since the EU Council Presidency in 2008 and a defined objective of our current National Cancer Control Programme.”

**Background**

Under Germany’s leadership, the current Trio Council Presidency adopted the “Europe: Unite Against Cancer” declaration in October 2020, which emphasizes the importance of patient-centred cancer research. In adopting the declaration, the three countries triggered a process which has culminated in the joint principles of patient involvement in cancer research.

Over the past few months, more than 130 stakeholders from 16 countries across Europe were involved in drawing up the “Principles of Successful Patient Involvement in Cancer Research”. The contributors came from patient organisations, cancer research, participatory research, the medical and care professions, industry, research management, funding organisations and the political decision-making level. It is now up to local, regional and national partners in research and the patient community to implement the principles on the ground.

Patient-centred cancer research is to become the standard in Europe in the long term so that it becomes even more closely aligned to the needs of patients. By involving both those giving and receiving cancer treatment, research projects can be better designed to address the real demands of patients. This in turn improves project implementation. Including patients already in the design of the research process also leads to greater acceptance of research results and generates greater support for projects.

The National Decade against Cancer initiated by the Federal Ministry of Education and Research (BMBF) in 2019 not only sets new standards in bringing together all the stakeholders, it also builds new bridges between patients and cancer research in one of its seven fields of action, which is devoted to strengthening involvement.

**Further information**