

Principles of Successful Patient Involvement in Cancer Research

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REPUBLIC OF SLOVENIA
MINISTRY OF EDUCATION,
SCIENCE AND SPORT



REPÚBLICA
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MINISTRO DA CIÊNCIA,
TECNOLOGIA E ENSINO SUPERIOR



Federal Ministry
of Education
and Research

Introductory Statement of the Trio Presidency of the European Council of Slovenia, Portugal and Germany

Principles of Successful Patient Involvement in Cancer Research

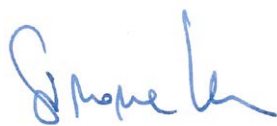
Successful patient involvement requires cancer research to focus on the actual needs of those afflicted with the disease. It thus improves the value of the research and enhances the acceptance and transfer of its results into health care. Much is already known about the benefits of patient involvement and the factors for its success, but noticeable inequalities in their acknowledgement and implementation still exist between and within European countries. Coordinated action of patients, scientists, health care, industry and the policy level is still largely missing.

On 13 October 2020, we adopted the “Europe: Unite Against Cancer” declaration. This declaration defines joint approaches to strengthening cancer research in Europe. It highlights fostering of patient involvement in cancer research as one of the primary objectives of the Trio Presidency. It thus supports similar goals formulated in the Horizon Europe Mission on Cancer and Europe’s Beating Cancer Plan as well as many ongoing national policy-level activities.

In order to ensure that patient participation becomes more standard throughout Europe, we subsequently launched a bottom-up initiative. From September 2020 to June 2021, over 130 contributors from 16 countries across Europe came together in a series of events to collect and discuss basic principles and prerequisites for successful patient involvement in cancer research. Participants came from patient organizations, cancer research, participatory research, medical and healthcare professions, industry, research management, funding organizations and the policy-making level.

We can now present the final version of a document outlining the results of this process. The collected principles reflect the findings of many national, European and international initiatives promoting patient involvement. They provide valuable insights into the state of affairs and the major fields where action is required. Although input was generated with a focus on cancer research, the principles will also hold true for other disease areas and may easily be transferred to other fields of health-oriented research. This paper is not meant to be exhaustive or reflect all existing knowledge on how to facilitate meaningful patient involvement in cancer research. Rather, the contributors intend it to serve as an initial point of reference for further information.

The collected principles may now serve as a catalyst for further developing active patient involvement both on the European level and within countries across Europe. We will continue to provide incentives and networking opportunities to support this process. However, only a combined bottom-up and top-down initiative, which brings together patients, researchers, scientific organizations, healthcare organizations and industry as well as political decision-makers, will lead to comprehensive implementation. Therefore, the Trio Presidency calls on European, national and regional stakeholders to take up this initiative and actively support the transfer of these principles into concrete action.



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