

Research Mission

Our Research Mission Statement

To ensure that the patient's and respective carer's voice is heard and acted upon in research decision making processes and throughout the cycle of digestive cancer-related research projects, and that research knowledge and outcomes are shared to interested stakeholders to make a positive difference to people's lives.

The Burning Platform: The Need for Continued Research in Digestive Cancers

Despite progress in understanding digestive cancer biology, digestive cancers are still under-investigated and under-funded in Europe in relation to their high burden of disease.^{1,2,3} As deeper insights into cancer biology, related causes, prevention, diagnosis, treatment, and care are needed for all digestive cancers, the demand for prioritising research activity and funding is high.⁴ Moreover, research should expand and encompass the, so far limited, studies on the effectiveness of the healthcare systems in improving health outcomes and survival for patients with digestive cancers.

The overall survival and quality of life (QoL) of hundreds of thousands of patients with digestive cancers could improve if all aspects of the patient journey were investigated in a more systematic and better prioritised manner. With this in mind, more studies on digestive cancers need to be undertaken across Europe and within different regions of the same country on a variety of topics, including the following:

Prevention

- Primary prevention including the role of education and that of the family doctor in promoting healthy lifestyles
- Secondary prevention (screening) including cultural and other factors that can contribute to maximum screening uptake

Diagnostics

- Timely vs delayed diagnoses
- The availability and quality of diagnostic tools and procedures of quality standards certified by independent bodies

Access and Decision-Making

- Available treatments and access to innovative drugs and personalized medicine
- Information for patients and patient literacy/understanding
- Shared decision-making
- Views on and current state of patient decision-making tools

Patient Quality of Life for Better Outcomes – Support and Care

- The effect of digestive cancers on patients' QoL
- The importance of diet, exercise, and of a healthy lifestyle
- The role and impact of local patient organisations in supporting patients
- Psychosocial, holistic health care, and occupational health support offered to patients
- Recovery and rehabilitation including management of physical and social constraints and stoma management
- Palliative care offered to patients
- Cultural differences in concepts related to diagnosis, screening, and patient support
- Support for carers
- End of life and family counselling

Disease Awareness – Knowledge and Understanding

- Training and emotional support for health professionals
- Patients', carers', and the general public's awareness, fears, and misconceptions around digestive cancers

Patient Insights Lead to Better Research Outcomes

Research conducted with deep and representative patient insights is more likely to lead to patient-oriented outcomes and have a greater societal impact than studies disconnected from patients' needs.

As the representative umbrella organisation of all patients with digestive cancers in Europe, our priorities are to:

Focus On, Support and Promote Patient-Centric Research

- Identify the gaps and best practices in the patient journey
- Get the patient voice into research - act as the bridge between patients and all relevant research (clinical, translational, social, health economics)
- Understand and communicate outcome differences in digestive cancer care across different centres and countries
- Help develop quality indicators for treatment outcomes of patients with digestive cancers
- Raise public awareness on the need for digestive cancer research
- Communicate and disseminate research outcomes to the European patient community



DIGESTIVE CANCERS EUROPE

- Disseminate our research findings to the wide research community through conference presentations and scientific publications

Use Research to Fuel Positive Change in Public Health Across Europe

- Influence the research agenda at European level based on patients' needs
- Lead research prioritisation discussions ensuring that scarce public funding is allocated to the most needed research topics
- Support and facilitate collaborative research on digestive cancers among European nations
- Translate research findings into policy and action plans
- Train and educate advocates for effective involvement
- Highlight opportunities for maximum benefit with minimum resources at all stages and share with members, partners, collaborators and interested stakeholders

Our Value: What We Bring to the Research Table

We are the representative voice of patients with digestive cancers in Europe supporting more than 30 European country-based organisations, with strong representation in the EU and the World Health Organisation (WHO) in the European Region.

As patients' and carers' representatives, we have a sense of purpose, energy, and urgency to make things happen and reverse the odds for incidence, deterioration in QoL and mortality.

Our value statement: With patient well-being at the centre of our efforts, we offer first-hand insights into patient needs to identify healthcare and societal research gaps; we then help fill these gaps in a spirit of collaboration towards better health outcomes for European citizens.

Specifically, here is what we have to offer to research groups and consortia:

Diverse and Reliable Patient-Centric Approach and Input

- An inclusive, unbiased, non-commercial, fully patient-centric approach
- Insights from a diverse patient population from the EU and the WHO European Region through strong links with patient experts and advocates from many local groups
- Trusted and reliable partner for projects that require direct patient engagement with proven success in patient engagement and communication
- Multilingual team to facilitate European wide communication (at our EU HQ, we speak Croatian, Dutch, English, French, German, Greek, Italian, Polish, Serbian, and Spanish)

Scientific Rigor

- Guidance from our expert Medical Advisory Committee and Patients and Carers Network



- DiCE team includes scientific experts with high academic merit
- We understand every step of the research process, ensuring that the patient perspective can be fully considered

Funding and Project Management Experience

- Colleagues with track record of successful acquisition of research funds
- Experience in research project participation and management

European Level Representation and Recognition in and by the EU Commission Research Registration Body

- We maintain a European network of top-level research centres, the cancer community, EU politicians, and policy experts from political and institutional worlds (e.g. the EU parliament and the WHO)
- We stay abreast of European institutional insights, as we are fully informed
- We are registered at European level for research participation (EU Commission Participant Identification Code: PIC 895.346.570)

Research: How We Can Work Together

We believe that high-quality outcomes are the fruit of productive collaborations. We support full engagement in a project from conception or from the earliest stages possible. That way, we can contribute fully to all patient-related issues, designing or advising on the necessary methodology and incorporating the patient perspective throughout the development of a project. As a neutral entity, we have full capacity of participating as equal partners in multi-stakeholder research proposals. Our experience and expertise places us in an ideal position to lead or coordinate different segments of a project, during both its preparation and execution phases.

We invite our partners and collaborators to reach out to us, so that together we can achieve the highest value that first-hand patient experience can bring to any digestive cancer-related project.

References

1. Begum M et al. Mapping cancer research across Central and Eastern Europe, the Russian Federation and Central Asia: Implications for future national cancer control planning. *Eur J Cancer*. 2018 Nov;104:127-136. doi:10.1016/j.ejca.2018.08.024.
2. Begum M et al. Mapping the European cancer research landscape: An evidence base for national and Pan-European research and funding. *Eur J Cancer*. 2018 Sep;100:75-84. doi: 10.1016/j.ejca.2018.04.017.
3. Maruthappu M et al. Investments in cancer research awarded to UK institutions and the global burden of cancer 2000-2013: a systematic analysis. *BMJ Open*. 2017 Apr 20;7(4):e013936. doi: 10.1136/bmjopen-2016-013936.
4. Lawler M et al. Critical research gaps and recommendations to inform research prioritisation for more effective prevention and improved outcomes in colorectal cancer. *Gut*. 2018 Jan;67(1):179-193. doi: 10.1136/gutjnl-2017-315333.