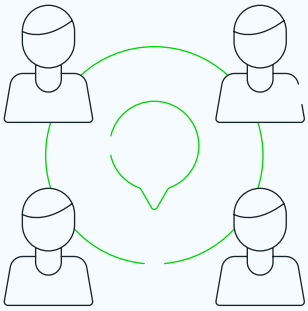
UNITED EUROPEAN GASTROENTEROLOGY

ueg

Integrating Patient Voices into Digestive Health Strategy:

A Manifesto from the UEG Week 2025 Digestive Health Roundtable



At the Digestive Health Roundtable 2025, held during UEG Week, experts from clinical, research, policy, and patient communities united to tackle Europe's rising burden of digestive diseases. Conditions such as chronic liver disease, liver cancer, inflammatory bowel disease (IBD), eosinophilic oesophagitis, and other gastrointestinal cancers remain major public health challenges, calling for stronger prevention, earlier diagnosis, and fairer access to care.[1]

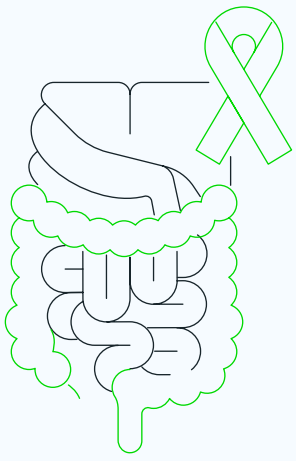
To support meaningful improvement, this co-developed manifesto outlines the key priorities and actions identified across three focus areas: digestive cancer care, patient-reported outcome measures (PROMs) across digestive diseases, and patient involvement in clinical trials related to digestive diseases.

Digestive Cancer Care

In 2019, digestive cancers accounted for over 700,000 deaths across UEG member nations, representing more than one-third of all cancer-related deaths in Europe, making them a leading cause of cancer mortality.[1] The number of incident cases of common digestive cancers increased by 26% between 2000 and 2019 across 44 European countries, with a notable rise among adults under 50, particularly in colorectal cancer cases seen in those aged 25-39 years.[1] Despite advances in diagnosis and treatment, disparities persist in systematic surveillance, awareness, and access to care.

Key recommendations:

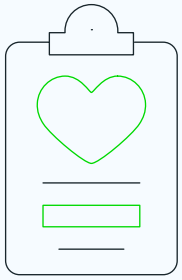
- **Strengthen prevention and screening:** Coordinate population-tailored awareness campaigns to promote early detection and healthier lifestyles, drawing on best practice examples.
- **Empower patients and communities:** Expand specialised cancer nurse roles and structured peer support networks with clear training and responsibilities.
- **Unify voices:** Build on the work of existing umbrella organisations to create a unified voice of patients, clinicians, and scientists to drive advocacy and policy change.
- **Integrate primary care:** Equip GPs to recognise warning signs, provide preventive guidance, and ensure timely referrals.
- **Support implementation and innovation:** Resource screening and surveillance programmes, pilot projects, and evidence-based early detection initiatives.



PROMs in Digestive Diseases

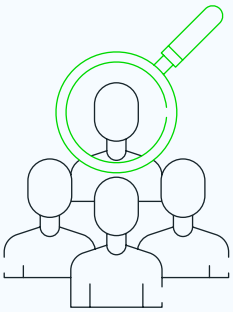
Patient-reported outcome measures (PROMs) capture dimensions often overlooked by traditional clinical metrics, such as how diseases and treatments affect quality of life. Their wider use is limited by misaligned priorities, lack of standardisation, language barriers, and limited recognition by payers and regulators.[2]

Key recommendations:



- **Standardise and co-design PROMs**: Partner with patient groups to ensure measures reflect real-world emotional, social, and functional priorities, and use patient surveys to guide terminology.
- **Promote health literacy and inclusivity:** Adapt PROMs for different ages, cultures, and literacy levels using clear language, visuals, and validated translations.
- **Integrate PROMs into policy and regulation:** Advocate for inclusion in drug evaluation, reimbursement, and healthcare quality frameworks.
- **Develop a UEG PROMs framework:** Create standardised measures across digestive diseases to support comparison and benchmarking across Europe.

Patient Involvement in Clinical Trials

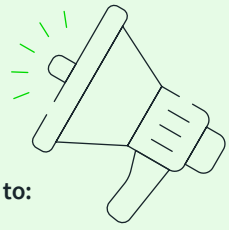


Digestive disease research often overlooks patients' real-world experiences, with barriers such as low awareness, travel demands, and restrictive eligibility criteria.[3] Meaningful patient involvement improves trial design, ethics, participation, implementation in real-world settings, and overall research impact.

Key recommendations:

- **Consider establishment of a UEG Patient Working Group:** Explore the possibility of forming a UEG Patient Working Group to support the UEG PAG by incorporating patient perspectives and priorities.
- **Call for a "Patient-Inclusive Trial" label:** Highlight studies demonstrating exemplary patient engagement, transparency, and feedback mechanisms.
- **Promote equitable access:** Expand decentralised and hybrid trials to reduce travel and improve participation.
- **Strengthen patient-centred research practices:** Consider workshops and training sessions for researchers to strengthen their ability to incorporate the patient voice, lived experience, and partnership into study design, communication, and ethics.
- **Ensure shared benefit:** Adopt transparent, ethical systems for sharing data and samples between researchers and participants.

Call to Action



Patients must be co-creators, not just beneficiaries, of digestive health policy, research, and care. Achieving this requires institutional commitment, dedicated resources, and sustained dialogue between clinicians, researchers, policymakers, and the public.

UEG and its partners call on European institutions, national authorities, and research organisations to:

1. **Recognise patient collaboration as a central part of digestive health policy.**
2. **Adopt shared European frameworks for PROMs, clinical trial engagement, and cancer prevention.**
3. **Support dissemination and implementation of the *Digestive Health Roundtable Manifesto 2025* through coordinated advocacy and resourcing.**

Embedding the patient experience at every level of the digestive health ecosystem can transform care from a medical challenge into a shared societal commitment, ensuring that prevention, treatment, and innovation genuinely serve those they aim to heal.

Developed with the Following Patient Associations

AOECS · Digestive Cancers Europe · IFCCA · ELPA European Liver Patients' Association · ECPO European Coalition for People living with Obesity · EOSNETWORK Eosinophilic Diseases Charity · ILCM International Liver Cancer Movement · Pancreatic Cancer Europe

References

1. Rose TC, Pennington A, Kypridemos C et al. (2022). *Analysis of the burden and economic impact of digestive diseases and investigation of research gaps and priorities in the field of digestive health in the European Region - White Book 2: Executive summary.* United European Gastroenterology Journal.
2. Amil-Dias J. (2025). *PROMs & patient involvement.* Presentation at Digestive Health Roundtable.
3. Maravic Z. (2025). *Clinical trial challenges from patient perspectives.* Presentation at Digestive Health Roundtable.