

# Digestive Health Roundtable

## Advancing Digestive Health: Collaborating for Better Outcomes

### Summary report

Leading experts in digestive health, together with dedicated patient advocates, convened at UEG Week 2023 on Sunday, 15 October to launch the Digestive Health Roundtable. This initiative marks the first in a series of multidisciplinary meetings, all driven by a shared purpose – to address challenges, identify opportunities and reach consensus on joint actions aimed at improving digestive health across Europe.

The meeting brought together leading UEG experts representing different UEG Specialist Member Societies: Patrizia Burra (Chair of UEG PAG, EASL), Michael Bretthauer (ESGE), Ana Dugic (EPC), Jorge Amil Dias (ESPGHAN), Joana Torres (ECCO), Pierluigi Fracasso (ECPCG), Tamara Matysiak-Budnik (ESDO), Pilar Acedo (UEG YTG) and Monique van Leerdam. The patient perspective was represented by: Salvatore Leone (European Federation of Crohn's & Ulcerative Colitis Associations), Lena Fels (Danish Celiac Association), Tunde Koltai (Association of European Coeliac Societies), Milan Mishkovikj (European Liver Patient Association), Lone McColaugh (Danish Liver Association), Natasha Münch (Digestive Cancers Europe), Benthe Bertelsen (Danish Colitis-Crohn Association).

### Setting the scene

The two co-Chairs of the meeting, Patrizia Burra and Ana Dugic, opened the event by introducing UEG, providing an overview of the event and setting its objectives. It was explained that the main focus of the meeting was to learn from patient advocates about patients' experiences with digestive diseases.

### Keynote address from WHO Europe

The meeting was joined (remotely) by Dr Kremlin Wickramasinghe – Regional Adviser for Nutrition, Physical Activity and Obesity at WHO/Europe. He reported that, according to WHO data, the burden of noncommunicable diseases (NCDs) has increased continuously over recent years worldwide, and in 2021 they caused 90% of deaths and 85% of years lived with disability (YLDs) in the WHO European Region. Digestive diseases were reported as the 4<sup>th</sup> highest cause of deaths caused by NCDs in 2019. Moreover, Dr Wickramasinghe reported alarming data on obesity and overweight, notably in children, where the findings show that 29% of children in Europe, aged 7-9 years old, are overweight or obese. Please [refer to the presentation](#) for further information.

### White Book 2 findings

Following this year's launch of UEG's latest publication, the [key findings from the White Book 2 study](#), experts from UEG's Public Affairs Group have presented the main findings for the disease areas that were represented at the roundtable: coeliac disease, inflammatory bowel disease (IBD), liver disease, and digestive cancers. The full presentation can be accessed [here](#).

### Button Battery and Magnet Ingestion in children

UEG together with ESPGHAN have taken the opportunity to raise awareness of the scale and consequences of the button battery and magnet ingestion in children, a public health issue which is often unknown but presents a medical emergency. Video is available [here](#).

## Group discussion: Main takeaways

The groups were all asked to:

- 1) Identify the main issues faced by their communities
- 2) Share existing best practice examples
- 3) Explore ways of working together

### Group 1: Prevention (Milan, Natasha, Patrizia, Tamara, Monique)

The group has identified the following issues among their communities:

- Low health literacy at societal level/inadequate knowledge among primary care professionals.
- Lack of incentives for change when addressing addictions.
- Lower trust in medical information and in healthcare professionals following the pandemic.
- Measures which target risk factors are focused too much on the individuals, rather than on systemic changes.

It was agreed that the following measures can lead to positive changes:

- Investing more in education at all societal levels to increase health literacy and community awareness of early signs of diseases, but also about healthy habits and the importance of nutrition.
- Improving the training healthcare professionals receive (e.g. on nutrition).
- Addressing physical inactivity at work: implementing exercise time and supporting employees with on-site facilities.
- Governments and international bodies (e.g. WHO, EU) should invest more in tackling misinformation and producing credible and well-targeted information to rebuild the trust in scientific evidence.

It was also agreed that the best way forward is to engage in coordinated efforts. Moreover, the group has identified the following stakeholders as important collaborators:

- Actors of change: parents and educators
- Actors of power: local policymakers, WHO and the EU institutions

Regarding industry, it was agreed that it is important to work together and advise the food & agri industry on topics of mutual interest (particularly important for coeliac patients). However, it was also noted that it is against our mission to work together with industries that contribute to health harms (e.g. alcohol, tobacco).

### Group 2: Delayed diagnosis (Ana, Benthe, Lena, Jorge, Pilar, and Tunde)

The group has identified the following issues among their communities:

- Barriers to primary care: lack of specific knowledge, repeated examinations.
- Access to diagnosis is very difficult across many countries.
- Wrong diagnosis leads to reduced quality of life and mental health-related burden.
- Risk of overdiagnosis: a diagnosis can also lead to reduced quality of life (e.g. in the case of some cancer diagnoses where treatment has a negative impact on the quality of life of patients).

The group agreed on the following best practice examples:

- Prevention is the most cost-effective investment.
- Increased awareness of common early signs of diseases (e.g. fatigue) in healthcare settings.

- Patients should be regarded as experts in the illness experience and involved accordingly.
- Anti-stigma training for healthcare providers should be the norm.
- Setting up transitional care services should be prioritized.

As a way forward, it was agreed that it is very important that healthcare professionals and patient representatives work together for the development of evidence-based guidelines. Such guidelines should be translated at national levels and summaries made available for non-specialists. It is equally important that joint projects in advocacy always involve the key players: patient representatives, healthcare professionals and policy makers. Additionally, it is important to collaborate with schools and representatives from the educational systems.

### **Group 3: Quality of life** (Salvo, Lone Joana, Michael, and Pierluigi)

The most common issues identified by the group were the following:

- Stigma has a huge toll on patients and is particularly high in liver disease patients.
- Lack of knowledge often leads to guilt and shame in patients.
- Overwhelmed healthcare systems have a significant impact on the quality of life of doctors and of family members who care for patients.

The group came up with a set of recommendations for tackling the identified challenges:

- Self-management education should be prioritised for patients.
- Effective communication between healthcare professionals and patients (including their carers).
- When standards of care are set up, patients should also be involved in the process.
- Implementation of holistic care.
- Reduction of logistical and bureaucratic barriers in healthcare.
- Identification and implementation of transitions of care interventions to improve quality of life among patients.

### **Next steps**

- **Q1 2024:** Produce and publish an article in the UEG Journal based on these findings and recommendations. The drafting group should include PAG members and representatives of European patient organisations.
- **Q1-Q2 2024:** Develop a publication on transitional care involving key specialist Member Societies of UEG and European Patient organisations.
- **Q4 2024:** Organise the second Digestive Health Roundtable in Vienna during UEG Week 2024.