

Summary for charities: research priorities for cancers of the oesophagus and stomach: recommendations from a UK and Ireland patient and healthcare professional partnership exercise
Jones et al.; Gut 2025;74(12):1949

Why we did this work

Oesophageal and stomach cancers are difficult to treat. They cause a lot of symptoms, as do the treatments used for them, and sadly many people still die from these cancers. Because of this, there is a real need for more and better research.

However, in the past, decisions about what research should be done have mainly been made by doctors and researchers. This means important priorities for patients and families may have been missed. For example, research into quality of life, recovery, or day-to-day challenges may not have received enough attention.

We wanted to change this by creating a research agenda that truly reflects the needs of patients, alongside the views of healthcare professionals.

Our aims

Our aim was to work with patients, carers, and healthcare professionals across the UK and Republic of Ireland to:

- Identify the most important unanswered questions about oesophageal and gastric cancers
- Agree which research areas should be prioritised
- Create a clear list of priorities that can guide research funders, charities, and policymakers

This helps ensure that future research makes the biggest possible difference to people living with or affected by an oesophageal or gastric cancer.

How we did it

We brought together:

- Patients and people with lived experience of oesophageal and gastric cancer
- Carers and family members of people with an oesophageal or gastric cancer diagnosis
- Healthcare professionals from many backgrounds (community, hospital, specialist teams)

These groups completed two major surveys:

- A first survey asked people to tell us what they felt were the most important research questions.
 - 455 people took part
 - They suggested 4,295 possible research questions
 - These were grouped into 92 clear questions
- A second survey asked people to choose which of the 92 questions were most important.
 - 380 people took part

Answers were “weighted” so that patient views had a strong influence on the final results. This approach made sure the final priorities were shaped by patient experience as well as clinical and scientific opinions.

What we found

1. Patient involvement made a big difference. When patient views were added into the rankings, 22–46% of the priorities established by scientists and healthcare professionals changed position.
2. Across all the results, three key areas stood out:

- a. Treatments should be more personalised and effective (including better combinations of treatments)
 - b. There needs to be more research with a focus on improving nutrition before, during, and after treatment
 - c. Research focussed on improving quality of life and survivorship care is important, especially for people who are not cured and need long-term support
3. We produced:
- a. A top 20 list covering the whole OG cancer journey
 - b. Separate lists that show where research is most urgently needed for:
 - i. Cancer prevention
 - ii. Diagnosis & staging
 - iii. Treatment
 - iv. Survivorship
 - v. Palliative care

Why this matters for future research

1. Patients have shaped the research priorities. The project shows that patient and carer priorities are sometimes very different from those of clinicians. For research to be meaningful, funders need to reflect these patient-centred priorities.
2. This was a large and robust exercise. This is one of the biggest and most detailed exercises of its kind for oesophageal and gastric cancers. It gives funders a high-quality map of where research should go next, from lab research to clinical trials to supportive care.
3. We highlight key areas needing urgent investment. These include nutrition and quality-of-life research, which came out as top priorities but which have received relatively little research funding in the past. These areas represent important opportunities to make a real difference to patients' lives.