What matters most to people affected by oesophagogastric cancer?

Outcomes of workshop and discussion, February 15, 2024

Summary

- This workshop brought together people with experience of oesophagogastric cancer and health professionals to talk about the challenges that matter most to patients.
- Patients and families prioritise work to **improve early diagnosis**. They would like better **awareness** of the condition in primary care settings. They would like better, more consistent guidance on the challenges of **eating and nutrition** in the years after surgery. They would like less invasive surgery and improved efficacy of treatment. The discussion also included issues around **communications**, **information** about what to expect of surgery, **peer to peer support** for carers and frustrations with NHS standards of care.
- The workshop raised awareness of oesophagogastric cancer research in Oxford and ways in which patients can get involved with it.

Background

Oxford Cancer is a group that supports and facilitates cancer research in Oxford, bringing together people from different disciplines and different approaches to cancer science. One way it does this is to establish Centres of Excellence for specific cancers, to allow researchers who share an interest in that area to pool experience, resources and data. Oxford Cancer supports these Centres with services including data management, project management and PPI (patient and public involvement). As part of its PPI strategy, Oxford Cancer wants to ensure that the research we support proceeds from a good understanding of what matters most to people affected by cancer.

The Oxfordshire Oesophageal and Stomach Organisation (OOSO) is a large and well-established support group for people with experience of oesophageal cancer, their families and friends. OOSO was established with the support of health professionals with an interest in upper gastrointestinal medicine, and enjoys sustained relationships with committed professionals who actively support its efforts to improve the lives of those affected by these conditions.

OOSO invited the Oxford Cancer PPI Team, including a professional facilitator, to attend an annual meeting and dinner. It was agreed that we would run a workshop session for two hours before dinner to get the room to talk about their priorities and to see if patient and carer priorities matched those of the health professionals in the room.

Method

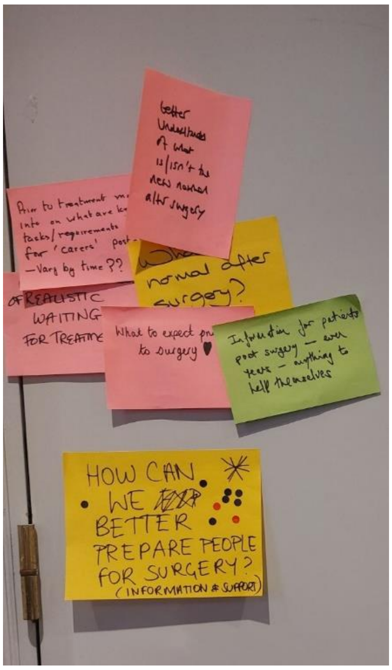
Attendees were seated at tables organised around the room, with families and carers separate from health professionals. People were invited to write on post it notes anything that they felt needed further attention: it might have been something that they struggled with personally, something they felt their clinical teams couldn't answer, or something they had observed among their peers. It didn't have to be a question – it could just simply be one word.

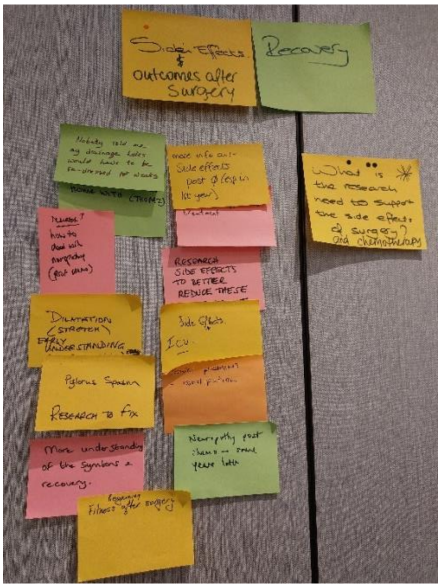
The post it notes were put on the wall around the room, and organised into themes. The facilitators then synthesised the post it notes into questions that represented the collective comments and observations. There were separate walls for health professionals' questions.

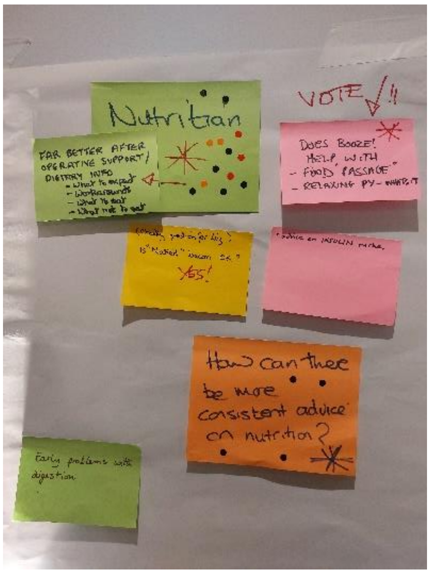
At this point the delegates were invited to mingle, chat with the health professionals and observe and discuss the suggestions on display.

The questions were then put to a vote: if you had £50 million pounds to answer some of these questions, which questions would you focus on? Each delegate had 5 coloured sticker dots, each dot representing £10 million.

The coloured dots for each question were counted, and the final results were as listed in figures 1 and 2.







Themes and observations

The responses were numerous and diverse, but delegates' comments and questions were organised under the following headings:

- Prevention
- Early diagnosis
- Primary care
- Communications and information
- Support groups and carer experience
- Side effects
- Preparation for surgery
- Nutrition
- Emotional support
- Improving treatments
- NHS service delivery issues.

One of the challenges when reporting this sort of work is to adequately represent the content of what takes place in the room: the many thoughts and issues raised and the experiences that people share. It is tempting to focus on the questions that attract most of the final votes, but to do so is to overlook a great deal. In the end, people often choose to vote on an issue that they feel might be fixable, and not on the issue that really matters most but that might feel too intractable to solve.

It is therefore important to emphasise how much of the discussion centred on information and communications: communications skills of health professionals; the isolation experienced by people with this diagnosis; the difficulty knowing what is or is not “normal”; the difficulty fully grasping what to expect of surgery and of treatment side effects; the challenges of getting access to good quality information. Similarly, delegates expressed the importance of getting peer support and the ways in which conversations with other people like you can mean a great deal more than the best information leaflet.

The challenges facing the NHS are a perennial topic of conversation in workshops such as this. Many people, when asked what could be improved, will first point to issues related to lack of resources and other logistical difficulties: delays in waiting for investigations, test results or treatment; the shortage of adequately experienced staff on the wards; the inequity in standards of care and the postcode lottery. It should be pointed out that the people in this room appeared to be happy with the care they received and the expertise of the teams caring for them, but aware that other patients do not have the same good fortune. The lack of adequate emotional support is another issue for people, especially support for those who have completed treatment and are learning to live life afterwards.

So it is never easy to extract patient priorities for research from the wider ecosystem of patient experience, which is embedded in a complex network of moving parts, many of them creaking, many that don’t appear to work together. The challenges presented by the bigger picture will continue to complicate and compromise patients’ experience of oesophageal cancer and the extent to which people feel adequately looked after and supported.

The top 5

What matters most

to people with

Oesophageal Cancer?

1
How do we improve early diagnosis of oesophagogastric cancer?

2
How do we improve awareness of oesophagogastric cancer in primary care settings?

3
How do we ensure more consistent, good quality information on diet and nutrition?

4
How can we ensure greater efficacy of treatments for oesophagogastric cancer?

= 5
Can we develop treatments that are less invasive?

= 5
How can we ensure that all people are fully prepared for surgery?

Figure 1 Patient and Carer Top 5

What matters most

to health professionals treating

Oesophageal Cancer?

1. How do we give more long-term advice and support regarding nutrition after surgery?
2. How do we support personalised treatment plans and greater treatment stratification?
3. How do we lessen the long-term effects of treatment?
4. How do we give more rehabilitation support for patients after treatment?
5. How do we improve GP awareness?

Figure 2: Health Professional Top 5

Discussion

The patients' first two priorities speak to the experience of getting adequate attention and support in the world outside the secondary care setting, with its expertise and specialist intervention. People experience delays in diagnosis and are concerned that more should be done to ensure that people are diagnosed much sooner in future without the need for repeated visits to the GP. Likewise, people are discharged from specialist care to a system that lacks any familiarity with oesophageal cancer and the consequences of its management, leading to frustration and anxiety for patients and families.

What is notable from the two lists is the extent to which they concur, especially on the subjects of nutrition and primary care awareness. Other studies that compare patient and professional research priorities suggest a greater degree of disagreement than what we observed on this occasion. This is arguably testament to the great work done by OOSO, which works in partnership with health professionals, and the calibre of those health professionals who clearly care very deeply about what matters to patients.

It should also be noted that the participants in this workshop are in the category of people who have survived; their concerns are about maximising quality of life. As this is a condition associated with a poor prognosis and short overall survival, this group are not typical, and a group of people who are not going to survive might have very different emphases.

It might be argued that 'cancer research' is too narrowly defined in academic circles, or perhaps it is more accurate to suggest that prestige and resources accrue around questions of cure, new medicines and prevention; research relating to supportive care attracts far less attention than it needs. The nutritional challenges associated with oesophageal cancer treatment, and the inconsistencies in information and support for patients, point to a particular need for more work on this subject.

Next steps

The patient priorities and the discussion we had will be shared with the wider membership of OOSO, who are warmly invited to get involved with oesophageal cancer researchers. They will also be shared with research and clinical colleagues in the Oxford Cancer network.

Oxford Cancer has already invited one of the delegates to share her idea for research into improving blood sugar regulation after oesophageal surgery. Steps are being taken with a dietician and a surgeon to explore the feasibility of such research, potentially with pump priming support from Oxford Cancer to get a study up and running. This illustrates our commitment to ensuring patients have the opportunity to influence and lead research design and delivery.

Appendix i – priorities with votes cast

Rank	Votes	What issues matter most to patients and their families?
1	22	How do we improve early diagnosis of oesophagogastric cancer?
2	15	How do we improve awareness of oesophagogastric cancer in primary care settings?
=2	15	How do we ensure more consistent, good quality information on diet and nutrition?
3	13	How can we ensure greater efficacy of treatments for oesophagogastric cancer?
4	10	Can we develop treatments that are less invasive?
5	9	How can we ensure that all people are fully prepared for surgery?

Rank	Votes	What issues matter most to upper GI health professionals?
1	13	How do we give more long-term advice and support regarding nutrition after surgery?
2	11	How do we support personalised treatment plans and greater treatment stratification?
3	10	How do we lessen the long-term effects of treatment?
4	8	How do we give more rehabilitation support for patients after treatment?
5	7	How do we improve GP awareness?