

# What matters most to people with colorectal cancer?

## Results of a 2-part online workshop

March 2024

### Background

The What Matters Most method was designed as a way of bringing people together to talk about shared experience of illness and agree a list of priorities for research and service / resource development. It represents an opportunity for clinical teams to hear from and engage with the concerns of their patients and respond to the challenges they suggest. The method has been used by Oxford BRC and Oxford University Hospitals Foundation NHS Trust to engage with haematology patients since 2019.

Oxford Cancer supports cancer research across the University of Oxford and Oxford University Hospitals. It is keen to promote involvement in research, and to ensure that researchers have a good understanding of what matters most to people affected by cancer. In February of 2024, a group of colorectal cancer patients came together to talk about their experiences of this condition and talk about their priorities. The workshops were funded by a grant from [Occtopus](#), a local colorectal cancer research charity.

### Method

People with colorectal cancer and close family members were recruited via Occtopus, the Oxford Cancer PPI group, the [Bowel Cancer Intelligence Group](#) and wider networks. 12 people attended the workshops. The people who took part were of mixed ethnicity, and were from geographically diverse locations across the UK. Three people were close family or carers of people who had experienced colorectal cancer. Those who had experienced it themselves had been through a range of treatments, and included people living with advanced disease. The workshop included people diagnosed at a relatively young age.

The workshop was divided into two sessions each of two and a half hours duration. Workshops were conducted using Zoom. The process invites participants to spend time discussing and sharing ideas about the issues they struggle with, and challenges that they feel need more attention. All of this input was based on their own experience or the experiences of people they knew. The issues were itemised and then put into themes. We used break-out rooms to allow more focused discussion in smaller groups before reconvening to agree themes as a whole. We used the online platform Miro to replicate a white board, with virtual 'Post-it' notes and sticky dots for voting.

By the end of the first workshop, the participants had come up with 79 individual issues that fell under the themes of:

- Communication
- Side effects
- Improving diagnosis and detection
- Prevention
- Recovery and relapse
- Improving current treatment
- Training and education
- Support needs
- Other questions for research

Between the two workshops, Catriona synthesised the 79 issues to come up with 43 questions that captured the issues raised under each theme. This process involved combining similar questions to avoid repetition. The shortlist of 43 questions was shared with participants in advance of the 2<sup>nd</sup> workshop, and individuals were invited to contact Catriona with any comments or additions should the questions not represent what they had wanted to contribute. They were invited to consider how they might prioritise these questions in preparation for workshop 2.

The second meeting began with discussion and agreement of the final questions, before we voted. Working in break-out rooms again, the participants were given 10 coloured dots or stars, each representing a hypothetical £10 million in funding. They had to decide which of the final 43 questions would attract their support if it was in their gift to allocate funding. This was tallied up to produce a final top 10 list of research questions of importance to people living with colorectal cancer. There were some questions attracting equal numbers of votes, as indicated in the list below.

One of the outcomes of workshops of this nature is a reminder to researchers that, while patients recognise the importance of prevention and cure for future patients, they also want research to attend to the difficulties of people who are living with the illness now or living with the side effects of existing treatments.

### The Top 10

- 1 How can we better understand the natural history of colorectal cancer so that we can reduce recurrence, better predict who will get secondaries and how soon, and ensure appropriate, timely treatment? How can new technologies and innovation prevent the spread of the disease?
- 2 How can we ensure best practice in oral and written communications: sensitivity at diagnosis, enabling shared decision making, ensuring clarity and understanding, ensuring accuracy in order to maintain trust?
- =3 What can be done to improve collaboration between centres of excellence with publicly available, streamlined information about best practice and what patients should expect of their care?
- =3 How can we develop and implement a framework for support beyond the end of treatment and for those living with advanced disease: living well, explanations of follow-up, emotional and psychological support, information about self-care, what to look out for, and who to speak to?
- =3 How do we improve information provision and timing about side effects and efficacy so that people have a much better understanding of what to expect in the short and longer term?
- =3 How can we understand gender/age/ethnicity and their impacts on CRC diagnosis and outcomes?
- 7 Can we offer more personalised treatment plans for individuals: more options, more information, supporting decision-making?
- 8 How can we ensure that all patients are signposted to comprehensive, good quality information: charity websites, talking to children, information about finances, information about lifestyle and nutrition?
- 9 How can we improve awareness of CRC in General Practice?
- =10 Should more screening be offered to younger people and relatives of people with CRC?
- =10 How can we share data to ensure people living with stage 4 CRC are treated with the best long-term combinations of chemotherapy drugs that maximise quality of life?

### Near Misses

- What can be done to improve collaboration and communication between the teams involved in the care of people with Lynch syndrome? We need to avoid the patient having to join all the dots themselves.
- How can we encourage better collaboration between medical teams, nutritionists and holistic therapists?
- How can we better understand and address the factors that prevent early detection and diagnosis of CRC?

## Reflections on findings: Reading between the lines of the top ten

It is impossible for relatively few words to adequately reflect the experiences shared over the course of several hours' work together. The following reflections aim to flesh out these sparse assertions and capture more of the essence of the group's discussion.

### Communication, information, isolation

Much of the top 10 indicates patients' experiences of not feeling that they have enough information: not knowing if the treatment they have had is the best for them; not knowing what gold standard treatment looks like and whether they'd be better off being treated somewhere else; not feeling that their treatment is sufficiently individualised; not feeling prepared for side effects of treatment; not knowing how to live well after treatment or with advanced disease. Participants in work of this nature are typically engaged, literate and relatively empowered compared to colorectal cancer patients in general. It is notable that in spite of these individual attributes, people still yearn for more information and more of a sense of being in control of what's happening to them. This sense of isolation must be amplified in those who are poorly equipped to navigate the complexities of cancer treatment. The workshops bore witness to the onus on individuals: feeling adequately informed can feel like a battle that you have to fight at a point when you don't have the resources to rise to the challenge.

### The struggle to diagnose

Delegates spent a lot of time wondering why there are still so many delays in diagnosis. We heard personal accounts of people who made repeated visits to their GP with well documented symptoms of colorectal cancer. We heard about individuals being overlooked because of their relative youth. We heard stories of parents unwilling to engage with screening, or to seek help, because of stigma and embarrassment, or because of cultural sensitivities. People wondered if more screening is needed, for younger people, and if those at high risk of colorectal cancer have adequate pathways for early detection. People living with the illness or learning to live with the consequences of surgery remain baffled and frustrated that we can't do better to protect people.

### Fear of recurrence

The number one slot, which had a vote from almost everyone who took part, indicates people's fears about metastatic disease. It was not clear from our discussion whether people had been provided with information about the consequences of spread of disease: were people fearful because of what they know or because of what they don't know? This raises a question about how best to anticipate fears, and perhaps manage anxiety with more reassurance – if possible – about what happens if secondaries occur. If there is reason to maintain hope – with successful surgeries, or new treatments, or technologies in the pipeline – might more be done to tell people about this should they wish to know more?

### What the top 10 obscures

When reporting work of this nature, there is a risk that attention on the top 10 will obscure some important issues that came out in group discussions. When people were pressed to spend their hypothetical £100 million on a series of questions, it felt as though the emphasis of the workshops shifted slightly with participants thinking more about the big picture than the challenges of their own experience. People might also vote in favour of what feels fixable, which is not always the same as what matters most. Intractable issues relating to, for instance, the challenges of NHS service delivery might be just as important but might feel insurmountable.

## Nursing expertise, communications, and other NHS frustrations

Several delegates expressed concern about delays in getting important diagnostic tests and delays in getting results. Some reported lack of expertise and insensitivity among nursing staff caring for patients post operatively. Other people talked about the consequences of poor written communications with patients, with letters that were not accurate reflections of a consultation.

It is impossible to overstate the consequences of such experiences. In order for a person to have faith in their care, they must first establish a relationship with the care provider. Lack of care, lack of sensitivity, inexplicable delays, and inaccurate or poor communications – something as apparently ‘inconsequential’ as a poorly written or delayed letter – will fundamentally undermine a person’s trust in the care they so desperately need.

## Support with consequences of treatment

A great deal of time was spent listening to people’s struggles with the consequences of surgery and the difficulties people have with living well post operatively. Problems with sexual function in particular were singled out as a cause of great distress and a compromise in quality of life. The difficulties of living with these complications sometimes come as a shock and people feel ill prepared to deal with them.

People also talked about the value of peer-to-peer support in getting information about stoma equipment and how to find the best suppliers.

## Similarities with international prioritisation initiatives

This work involved a small number of people and a short space of time; it was never intended as an alternative to far more comprehensive attempts to agree patient priorities using methods such as the gold standard James Lind Alliance approach. It is notable, therefore, that our work bears thematic consistencies with the conclusions of the Canadian James Lind Alliance priorities [for early stage colorectal cancer](#), published in 2022, and the German James Lind Alliance priorities for [colorectal cancer](#), also published in 2022. The German top ten is dominated by questions relating to the consequences of existing treatments, especially surgical complications, and the importance of quality of life. Likewise, the Canadian top 10 emphasizes preventing recurrence, individualization of treatment, and improvements in detection. Although prevention and early detection are recognized priorities, none of these lists of concerns mention the word ‘cure’ in particular, nor do they mention new drugs. Reducing the impacts of treatment, ensuring the best treatment for an individual, living well with colorectal cancer, and maintaining a good quality of life, are the things that matter most to the people affected by it and those close to them.

## Next steps

- This work will be shared with the Trustees of Octopus, a consortium of colorectal cancer researchers who commissioned these workshops.
- It will also be shared with Oxford Cancer’s colorectal cancer Centre of Excellence and published as a resource for researchers on the Oxford Cancer website. Colleagues with a particular interest in metastatic disease will be approached for comment about potential information resources for patients.
- Suggestions for resources for patients based on this work will be promoted via the Centre of Excellence. The workshop outcomes will be shared with charity partners supporting people affected by colorectal cancer.
- Many of the conclusions of this work point to things that might be improved in the delivery of support in NHS settings, and will be shared accordingly with colleagues at OUH NHS Foundation Trust.