



Your bowel cancer follow-up

This leaflet is for patients who have had treatment for bowel cancer, and their relatives and carers. It explains how the Open Access Follow Up (OAFU) works to help you and your clinical nurse specialist (CNS) decide which type of follow up will work best for you.

What is Open Access Follow-Up?

OAFU is a type of follow up and aftercare for people who have received treatment for bowel cancer. Routine follow-up appointments are replaced with an arrangement that allows you to contact us at any time if you have concerns about your bowel function, have any new symptoms you would like to report, or have questions about your treatment or other related issues.

OAFU also gives you access to a dedicated helpline for reporting symptoms, worries or concerns. You will receive a response within 24 working hours (Monday-Friday) if no one is available to answer immediately. Depending on your symptoms, we may give telephone advice, suggest you see your GP or ask you to be seen in one of our rapid access clinics.

In the case of a medical emergency, contact NHS 111 or 999.

Why have we introduced OAFU?

We have introduced OAFU as this arrangement has been trialled in other hospitals and patients have found it a better way of following-up on their care. It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well. Patients often find traditional clinical appointments are a source of anxiety and can lead to them being tempted to put off reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it has been proven that new problems are unlikely to be picked up by clinical examination alone. Most problems are identified by surveillance investigations, which you will continue to have as part of this programme.

OAFU gives you the freedom to get on with your life with the reassurance of fast advice and a prompt clinic appointment should you need one.

How does OAFU work?

Three months after completing your treatment, you will have a consultation with a colorectal clinical nurse specialist (CNS), who will explain the service to you. They will discuss your diagnosis, treatment and any possible side effects, and provide advice on related health, lifestyle and wellbeing issues. The nurse will also tell you about further sources of help and support and explain:

- The signs and symptoms to look out for that might indicate a return or spread of the disease.

- The helpline you can contact if you have any symptoms, concerns or queries.
- The arrangements for any investigations, such as CT scans, blood tests and colonoscopies, why these are important, and the process for getting the results.
- What happens if your results are abnormal.
- What information and ongoing support is available to you and your family.
- We will also send your GP full details of your treatment and follow-up programme.

Is OAFU for everyone?

The programme is not suitable for everyone and this is why your CNS will discuss the programme with you. You may have physical, psychological or social issues, which make OAFU inappropriate, and in this situation, we will either see you in our face-to-face clinics or refer you back to your GP for ongoing support. The decision to have OAFU is a decision made jointly by you and your clinical nurse specialist.

What routine follow-up tests will I need?

As part of your bowel cancer follow-up, you will have investigations for at least five years after completing your treatment. This varies from person to person, depending on the type of cancer, and your CNS will give you a plan specific to you. This may involve blood tests, scans, colonoscopy or other tests, as required.

What blood tests will I have?

We check your CEA (carcino-embryonic antigen), which is a tumour marker for bowel cancer. The normal range for this is between 0 and 5 and if this value is raised, this may indicate recurrence of disease. However, this value can also be raised due to other factors, so it is important that we get a full picture, with a comprehensive blood check that will include kidney and liver function and haemoglobin levels.

What scans will I need?

You will be offered a CT scan of your chest, abdomen and pelvis at points during your follow-up. You may have other scans, such as MRIs, depending on your cancer type.

Endoscopic surveillance

Depending on the location of your bowel cancer and type of surgery you had, you may be offered a colonoscopy or flexible sigmoidoscopy (camera up your back passage or via your stoma) as part of your follow-up. The aim of this is to locate and remove any new polyps and reduce the risk of further cancers developing. These procedures are not always suitable for everyone and your CNS will discuss the plan with you.

Holistic Needs Assessment

You will be given a link to complete a Holistic Needs Assessment, either on paper or online before your next appointment in three months. This can help identify ways we can continue to

support you. You should already have received a booklet explaining this, but please contact us if you need any more information or assistance with completing it.

What happens next?

You will be given an appointment to see the colorectal specialist nursing team in approximately three months from today. At this appointment:

- We will discuss how you are recovering from your surgery and give any advice you may need to help you continue with your recovery.
- We will agree the right type of follow-up with you and give you appropriate information on what symptoms to look out for and what investigations you may require.
- If you have completed your HNA prior to this, we will discuss this with you and again give any advice or support needed.
- We will make sure you have relevant contact details to ensure you are able to contact us with any concerns.

In the meantime, please do not hesitate to contact us if you have any questions or concerns on 0118 322 7182.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Berkshire Cancer Centre, December 2023.

Next review due: December 2025