

Involvement of patients in RWE studies in cancer: Learnings from a colorectal cancer study

Taking part in real-world evidence (RWE) studies can benefit your treatment journey and may help other patients



Clinical trials are used to explore how a new treatment affects patients in a specific environment. However, the findings may not be reflective of the patient experience in the real world¹



RWE studies look at what is experienced by patients in **clinical practice**, providing essential information to help improve treatment¹



By **contributing to RWE studies**, you can assist in making the study **relevant to patients**, helping future patients through your personal experience¹

How are RWE cancer studies carried out?

RWE studies share the following features:



Include a **wider range of patients than clinical trials**, with fewer restrictions on type of treatments received, reflecting a **diverse and more typical patient population**²



Data are collected on patients' **own opinions and priorities** regarding their mental and physical health, as well as quality of life. This includes levels of **pain and fatigue, side effects, anxiety and depression, treatment satisfaction**, and their ability to do normal daily tasks²

How will you benefit from taking part in RWE studies?



When you take part in a RWE study, you play a more active role in your treatment decisions, thus improving³⁻⁸

- > Your symptom monitoring, which will aid your doctor in understanding how well your treatment is working
- > Your quality of life and delivery of cancer care, as you will be contributing to your own treatment decisions
- > The outcomes of your treatment
- > Your discussions with your doctors as you will feel more able to ask questions

How do you help other patients by taking part in RWE studies?



RWE studies collect data from real patients. Patients and carers can refer to the findings, benefiting future patients in the following ways³⁻⁸

- > Increased evidence directly relevant to patients' needs, including survival and quality of life
- > Increased understanding of the impact of the disease and treatment on patient wellbeing
- > Improved communication between doctors and patients
- > Increased capacity for patients to make treatment decisions with their doctor
- > Increased understanding of the impact of lifestyle changes

What are the possible barriers to participation in RWE studies?

What barriers may you encounter?



Not knowing about the importance of RWE studies and available opportunities for participation^{9,10}



Necessary time commitment to fill out the questionnaires^{9,10}



Your doctor may not have the time to engage with the study⁷

How can these barriers be overcome?



Information for patients and doctors to increase understanding of the benefits of RWE studies and relevant opportunities¹



Flexible appointments for patients, giving an idea of the amount of time needed to take part¹



Adequate training of clinicians to highlight the importance of RWE studies¹

Why do RWE studies need you?¹

1 You can contribute to the design and delivery of RWE studies, highlighting what is important for patients to make the study more relevant for them

2 You can help improve patient knowledge and understanding of RWE studies – through sharing your own experience, patients, carers, and their doctors can have a better understanding of the disease through working more closely together

How can you take part in the design and delivery of RWE studies?³⁻⁸

Before the study

- > You can help decide the aims of the study to make sure they fit patient priorities
- > You can advise on the study processes and procedures, e.g. what information patients and carers might need to know
- > You can help develop additional patient information about the study, e.g. website design and patient information leaflets

During the study

- > You can let other patients and carers know about the study and help them understand the importance of RWE studies
- > You can check that the questions asked to patients during the study are relevant to patients like you
- > You can help to adapt the design of the study. Your experience will help to ensure that the outcomes will be useful for other patients

After the study

- > You can discuss and help identify the results that are most relevant for patients
- > You can inform other patients and carers about the results of the study
- > You can help doctors understand how they can use the results to help their patients

PROMETCO: Collecting real-world data on the management of metastatic colorectal cancer (mCRC)

The PROMETCO study is the first international RWE study investigating care of patients with mCRC¹²

738

patients enrolled



The study enrolled adults with mCRC whose disease had worsened twice since the first diagnosis of metastatic disease and are subsequent to receive treatment¹²

18

participating countries



By collecting real-world data on overall survival, treatment patterns, effectiveness and safety, and impact on patients, the study will provide vital information for current and future patients with mCRC¹²

This study involved patients in its design, using real-world patient experiences to collect data relevant to a wide range of patients, improving each patient's ability to make shared decisions with their doctor and empowering them to take an active role in their treatment

- By taking part in RWE studies, patients experience improvements in quality of life and treatment
- Patients take part in the design and delivery of RWE studies to help determine what is measured during the study to ensure the data are relevant to other patients in a similar position

For more information on the PROMETCO study, please visit the [PROMETCO website](#).

For more information and support about digestive cancers, please visit [Digestive Cancers Europe](#)