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Patient-led home-based follow-up after surgery for colorectal cancer: the protocol of the prospective, multicentre FUTURE-primary implementation study

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ABSTRACT

Introduction Colorectal cancer (CRC) is the third most common type of cancer in the Netherlands. Approximately 90% of patients can be treated with surgery, which is considered potentially curative. Postoperative surveillance during the first 5 years after surgery pursues to detect metastases in an early, asymptomatic and treatable stage. Multiple large randomised controlled trials have failed to show any (cancer-specific) survival benefit of intensive postoperative surveillance compared with a minimalistic approach in patients with CRC. This raises the question whether an (intensive) in-hospital postoperative surveillance strategy is still warranted from both a patient well-being and societal perspective. A more modern, home-based surveillance strategy could be beneficial in terms of patients' quality of life and healthcare costs.

Methods and analysis The multicentre, prospective FUTURE-primary study implements a patient-led home-based surveillance after curative CRC treatment. Here, patients are involved in the choice regarding three fundamental aspects of their postoperative surveillance. First regarding frequency, patients can opt for additional follow-up moments to the minimal requirement as outlined by the current Dutch national guidelines. Second regarding the setting, both in-hospital or predominantly home-based options are available. And third, concerning patient–doctor communication choices ranging from in-person to video chat, and even silent check-ups. The aim of the FUTURE-primary study is to evaluate if such a patient-led home-based follow-up approach is successful in terms of quality of life, satisfaction and anxiety compared with historic data. A successful implementation of the patient-led aspect will be assessed by the degree in which the additional, optional follow-up moments are actually utilised. Secondary objectives are to evaluate quality of life, anxiety, fear of cancer recurrence and cost-effectiveness.

Ethics and dissemination Ethical approval was given by the Medical Ethics Review Committee of Erasmus Medical Centre, The Netherlands (2021-0499). Results will be presented in peer-reviewed journals.

Trial registration number NCT05656326.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Multicentre, prospective design allows for reliable comparison of different follow-up types between patients and make clinically relevant recommendations to improve quality of life and satisfaction in the postoperative trajectory.
⇒ Involvement of patients in the design of this study.
⇒ The possibility to draw blood in the home environment.
⇒ Single arm study, outcome measurements will be compared with historic data and prospective studies.

INTRODUCTION

Colorectal cancer (CRC) is the third most common type of cancer in the Netherlands, resulting in almost 12 000 new patients in 2020.[1] Approximately 95% of patients can be treated with surgery, which is considered potentially curative.[2] Unfortunately, a considerable number of patients develops metastatic disease after resection of CRC. When detected in an early stage, local recurrences and metastases in the liver, lung, and peritoneum can possibly still be treated with curative intent.[3]

Postoperative surveillance pursues the detection of metastases in an early, asymptomatic and treatable stage. The optimal detection of these recurrences has led to growing interest in postoperative surveillance. The current national standard of care consists of an in-hospital multimodality follow-up, using imaging (CT), hospital consultation and blood tumour marker assessment of carcinoembryonic antigen (CEA).

Multiple large randomised controlled trials and a recently published systematic review have failed to show any (cancer-specific) survival benefit of intensive postoperative

surveillance compared with a minimalistic approach.[4 5] In addition to the detection of disease recurrence, follow-up contributes to psychological support and surveillance of postoperative complaints. However, less intensive follow-up has no negative influence on health-related quality of life (HRQoL).[6] Besides the lacking survival and HRQoL benefit, there are other reasons to revisit current follow-up practice in patients with CRC. Frequent hospital visits have significant impact on patients' lives, as follow-up visitations evoke distress around the time of visits.[7–9] Follow-up for CRC is also associated with considerable societal healthcare costs, especially as it is one of the most common types of cancer in the western world.[10] Although value-based healthcare and patient-reported outcomes are getting increasingly important in current healthcare, few groups have attempted to appropriately assess quality of life and cost-effectiveness of follow-up in patients with resected CRC. Two important trials have been performed. Rodríguez-Moranta *et al* demonstrated that the costs associated with follow-up procedures and additional treatments (for recurrent disease) were estimated to be higher with use of 'intensive' follow-up protocols (multimodality, in hospital surveillance), compared with 'simple' surveillance protocols (in hospital CEA-monitoring and physical examinations).[11] Augestad *et al* evaluated the cost-effectiveness of surgeon versus general practitioner (GP)-based follow-up. The authors demonstrated that GP organised follow-up was associated with societal cost savings.[12] Both studies imply that CEA based, out of hospital follow-up could considerably reduce the costs associated with postoperative surveillance.

Patients may need some follow-up for psychosocial counselling and information on their disease status during their postoperative surveillance.[9 13 14] In order to improve HRQoL on a population basis, the variety of patient needs with regard to follow-up should therefore be taken into account. A patient-led surveillance strategy could potentially be able to address the broad spectrum of desired follow-up of patients. Chapman *et al* demonstrated that such a patient-led surveillance strategy improves HRQoL and patient satisfaction, while improving cost-effectiveness.[15]

As intensive follow-up might impact patients' HRQoL and societal healthcare costs, it is questionable whether an (intensive) in-hospital postoperative surveillance strategy is still warranted. A more modern, home-based surveillance strategy could be beneficial from both a patient well-being and societal perspective. This multicentre, prospective study will assess whether a patient-led home-based follow-up approach is successful, without a negative impact on quality of life, satisfaction, and anxiety during the years after surgical treatment of CRC.

METHODS AND ANALYSIS

This protocol was written in accordance with the SPIRIT-PRO guidelines (Standard Protocol Items: Recommendations for Interventional Trials & Patient-Reported Outcome) for inclusion of patient-reported outcomes in clinical trial protocols.[16]

Objectives

The primary objective of this study is to implement a patient-led home-based follow-up approach in patients who underwent curative surgery treated surgically for CRC. A successful implementation of the patient-led aspect is defined as 75% or less of optional follow-up moments (ie, CEA measurements) used. The rationale behind is that if more than 75% of the optional follow-up moments are used, the added value of providing patients with a say in the frequency of their postoperative surveillance is minimal, as most will opt for the maximum frequency anyway. Secondary objectives are to evaluate successful home-based blood withdrawal, HRQoL, anxiety, fear of cancer recurrence and cost-effectiveness.

Study design and setting

The FUTURE-primary study is a multicentre, prospective, regional implementation study of a patient-led home-based follow-up approach after curative treatment for CRC. Follow-up will be carried out for up to 5 years after surgery. The study started recruitment at Erasmus Medical Centre Rotterdam in October 2021. Consequently, Amphia Ziekenhuis Breda and IJsselland Ziekenhuis started recruiting patients at the beginning of 2022. In 2023, University Medical Centre Leiden and Sint Franscisus Gasthuis will also join as participating study centres. The final inclusion of participants is expected to take place in the last quarter of 2023. The end of the study is planned in December 2028.

Patient and public involvement

The 'Stichting voor Patienten met Kanker aan het Spijsverteringskanaal' is a national patient organisation for patients with cancer of the digestive tract. Their committee provided feedback on the protocol, patient information sheet and informed consent form regarding content and readability.

Study participants

In order to be eligible to participate in this study, a subject must meet all of the following criteria:

- Age ≥18 years.
- Histologically confirmed colorectal adenocarcinoma without distant metastasis and treated with curative intent surgical resection less than 6 months ago.
- Scheduled or currently undergoing postoperative surveillance according to national guidelines.
- Written informed consent by the patient.

A potential subject who meets any of the following criteria will be excluded from participation in this study:

- Patients with a severely complicated postoperative course, needing in hospital follow-up longer than 6 months postoperatively.
- Patients enrolled in other studies that require strict adherence to any specific follow-up practice with

regular imaging—yearly or more frequent—of the abdomen and/or thorax.
- Patients with comorbidity or other malignancy that requires imaging of the abdomen and/or thorax every year or more frequent.
- Inability to complete the questionnaires due to illiteracy and/or insufficient proficiency of the Dutch language.

Patient-led follow-up and study procedures

A patient-led home-based follow-up approach will be implemented for up to 5 years after surgery for all eligible patients. The current Dutch national guidelines for postoperative CRC surveillance advocate blood CEA assessments every 3–6 months during the first 2 years, and every 6–12 months during the last 3 years of follow-up, alongside a single thoracoabdominal CT scan (or medical imaging equivalent) performed 12 months after surgery.

In the patient-led home-based approach implemented in this study, the patients will to a certain degree have control over the frequency, setting and communication of their postoperative surveillance. In principal, the frequency of CEA measurements will be identical to the minimal requirement of the current Dutch national guidelines, that is, every 6 months during the first 2 years, and yearly thereafter. In addition, all patients will have one planned in-hospital evaluation with medical imaging 1 year after surgery. Patients can however opt (by email or telephone) for more frequent CEA measurements up to the current maximum advocated by the national guidelines, that is, quarterly in years 1 and 2, and semi-annually thereafter (see figure 1). The successful implementation of the patient-led aspect will be assessed by the degree in which these optional follow-up moments are actually utilised. In addition to the frequency of follow-up, patients can also choose their desired setting. In principle, blood sampling will be performed at home by the patients themselves using a lancet and a blood collection tube by Labonovum B.V. The reliability of CEA using this capillary sampling method has been tested in the CASA-pilot.[17] If, however desired, patients can opt (by email or telephone) to have their blood drawn at either their gp, local health centre or treating hospital. The successful implementation of the home-based aspect will be assessed by the degree in which blood sampling is actually performed at home. Lastly, patients can choose their desired form of communication in case of normal CEA values. They can choose between either a telephone or video call, an in-hospital visit, or a silent check-up (ie, no doctor–patient communication in case of normal CEA levels and absent symptoms). Further clinical and diagnostic evaluation will be performed in accordance with the current national guideline; in case of symptoms or CEA levels above 5 µg/L, a twofold increase in CEA level compared with baseline, or two consecutive increases in CEA level over time (see figure 2).

Questionnaires

Figure 3 summarises the time points at which each questionnaire is being measured. Questionnaires can be completed on paper or digitally.

HRQoL will semiannually and later annually be measured through questionnaires (European Organisation for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) and QLQ-CR29). The EORTC QLQ-C30 comprises 30 items, 28 items scored on a Likert-scale from 1 to 4 and 2 items (the Global Health Status) scored on a Likert-scale from 1 to 7. The questionnaire measures five multi-item functional scales (physical, role, emotional, cognitive and functioning), three multi-item symptom scales (fatigue, nausea, vomiting and pain), six single- items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties) and the global health status scale. All scales and single-item

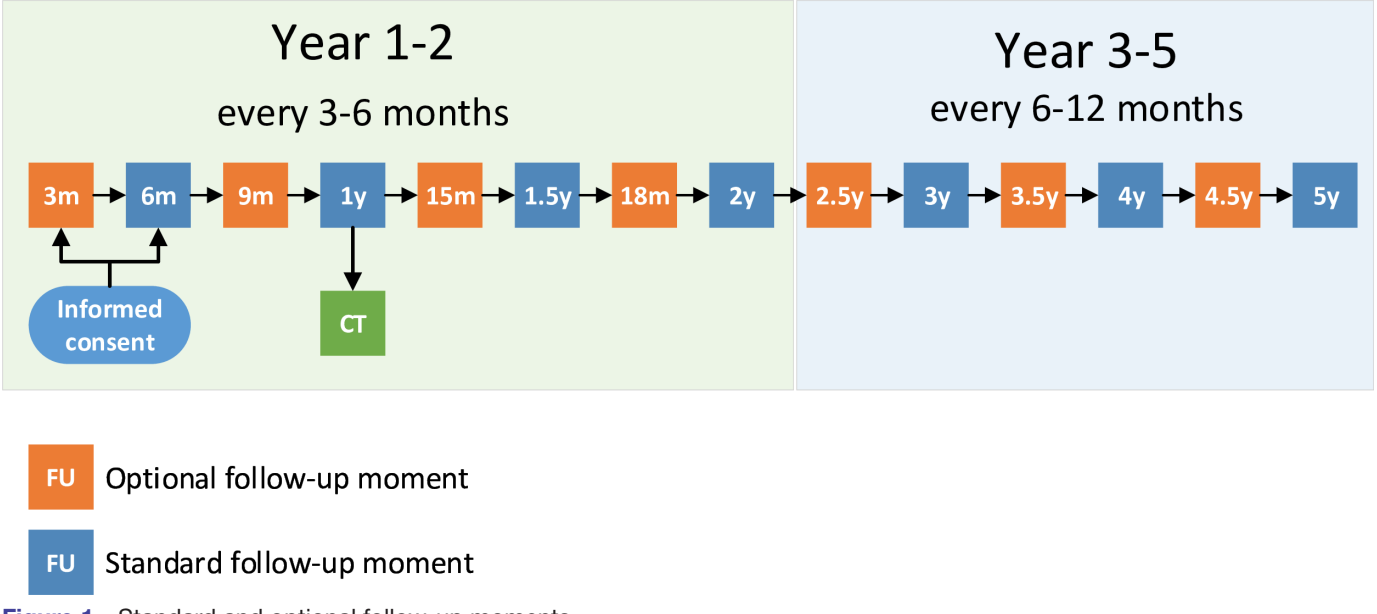

Figure 1 Standard and optional follow-up moments.

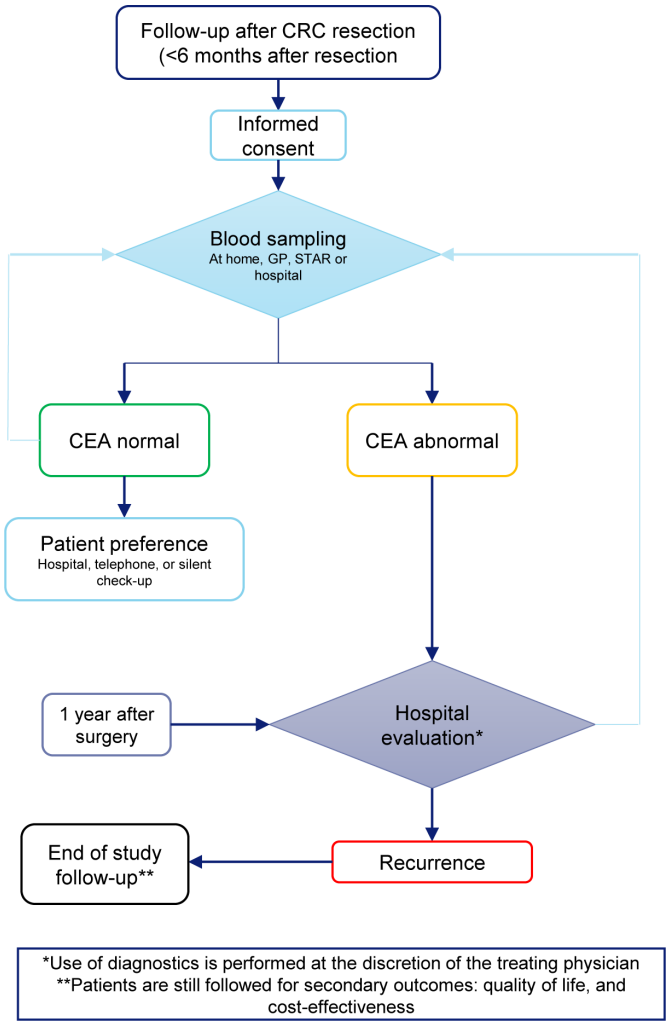

Figure 2 Schematic overview of the study procedures. CEA, carcinoembryonic antigen; CRC, colorectal cancer.

measures range from 0 to 100 and are calculated using their respective formulas. A high scale score expresses a higher response level.[18] The recall period is 1 week.

The EORTC QLQ-CR29 is a tumour-specific HRQoL questionnaire for CRC patients. The questionnaire has 5 functional and 18 symptom scales. Four subscales (urinary frequency, blood and mucus in stool, stool frequency and body image) and 19 single items (urinary incontinence, dysuria, abdominal pain, buttock pain, bloating, dry mouth, hair loss, taste, anxiety, weight, flatulence, faecal incontinence, sore skin, embarrassment, stoma care problems, sexual interest, impotence (men) and dyspareunia (women)) are used. Patients are asked to indicate their symptoms during the past weeks on a score from 1 to 4.[19]

HRQoL will also be measured through ecological momentary assessment every 10 days, to assess short-term changes. The global health status of the EORTC QLQ-C30 was chosen due to its simplicity, limited number of questions and validity. The two items are scored on a Likert-scale from 1 to 7. There is no recall period for this momentary assessment because of the frequent measurement every 10 days. To keep compliance as high as possible patients will receive a text message to their smartphone every 10 days to complete the questionnaire. If desired, the invitations can also be sent via e-mail.

A short and validated questionnaire State-Trait-Anxiety Inventory (STAI) was chosen to assess anxiety, to keep the total number of questions as low as possible. The STAI-6 comprises six items, each scored on a Likert-scale from 1 to 4. The final score ranges from 20 to 80 and is calculated by adding up the score of all single items (positive items are reverse scored) and multiplying by 20/6.[20]

Study subjects will only be asked to complete the Assessment of Survivor Concerns-Cancer Worry subscale (ASC-CW) questionnaire once during the entire duration of the study and only in case of no disease recurrence. The ASC-CW subscale comprises 3 items all scored on a Likert-scale from 1 to 4. The total score is calculated by adding up the individual items and ranges from 3 to 12.[21] As no validated Dutch version of the ASC-CW was readily available, a translated version was generated in accordance with guidelines for cross-cultural adaptation of HRQoL measures.[22]

The utility measure for the cost-effectiveness analysis is the EQ-5D-5L (EuroQol-5 Dimension 5-level version) and was selected due to its validity, widespread use and relatively limited amount of questions. The EQ-5D-5L consists of five levels (mobility, self-care, usual activities, pain/discomfort and anxiety/depression), each scored on a Likert-scale from 1 to 5 and a Visual Analogue Scale scored from 0 to 100. The total score can be converted into an index value to be used in quality-adjusted life-year (QALY) analysis by ways of an index value calculator with regard to country-specific reference values. This calculator can be downloaded from https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/valuation/crosswalk-index-value-calculator/. The EQ-5D-5L has no specific recall period.[23]

For the cost-effectiveness analyses both intramural costs directly related to the follow-up after surgical treatment of CRC and extramural costs will be taken into account. The intramural costs related to the treatment and follow-up of CRC will be collected from review of the medical records. For the assessment of the extramural costs a selection of questions relevant to extramural medical costs from the validated iMTA Medical Consumption Questionnaire will be used. A selection is taken due to the fact that the relevant intramural costs can readily be collected by review of the patient records, therefore, no retrospective questions assessing intramural medical costs are necessitated.[24]

The coping of patients will be measured through the Threatening Medical Situations Inventory (TMSI) at baseline. This questionnaire measures cognitive confrontation (monitoring) and avoidance (blunting) within the domain of medical treatment. The relation between coping styles and patient's preference of their follow-up schedule will be investigated. The TMSI consists of 4 scenarios which are all followed by three monitoring and three blunting alternatives, in random order, to be answered on five point scales. Total monitoring and

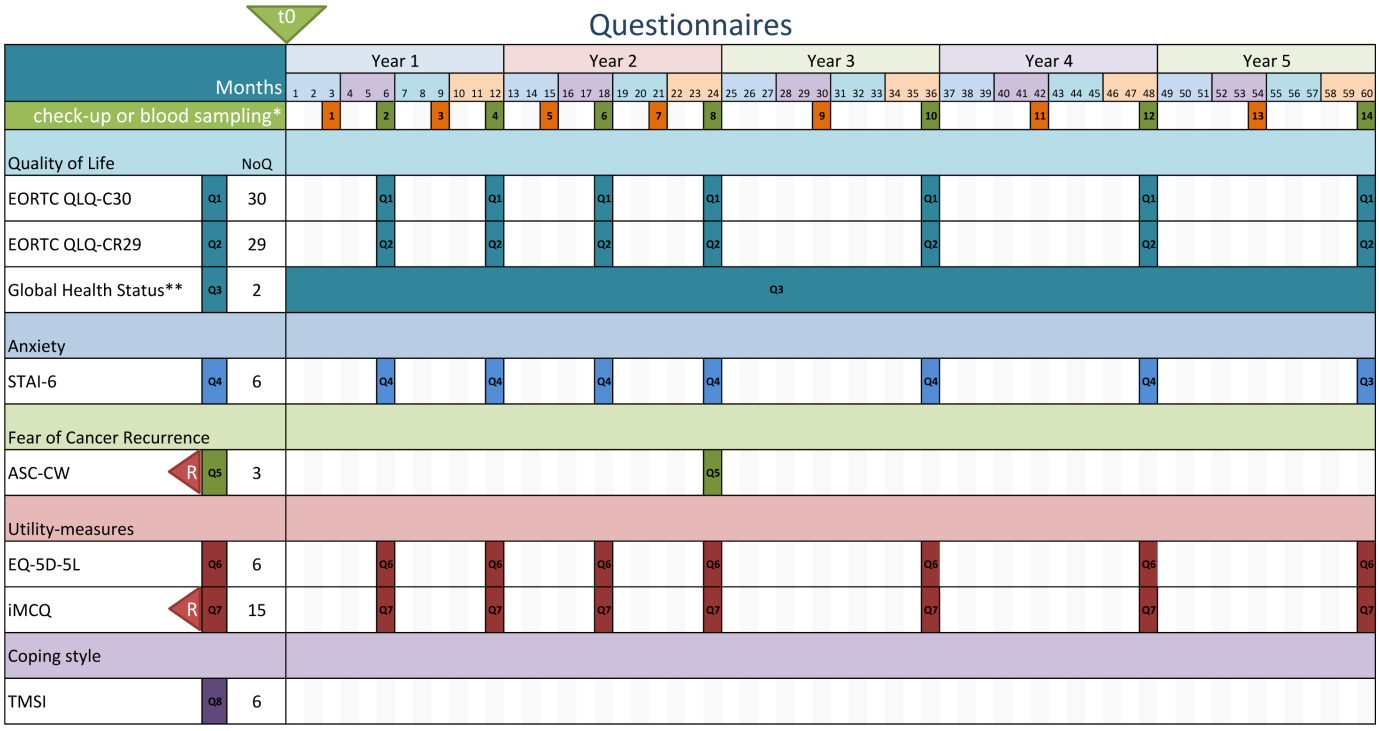

Figure 3 Time points of questionnaires. *Orange = optional blood sampling. Green = standard blood sampling ** the Global Health status is completed every 10 days using a smartphone (or via computer if desired) during the entire duration of the study t0 = Inclusion NoQ = Number of questions R = the ASC-CW and iMCQ are no longer completed in case of disease-recurrence. ASC-CW, Assessment of Survivor Concerns-Cancer Worry subscale; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; EQ-5D-5L, EuroQol-5 Dimension 5-level version; iMCQ, iMTA Medical Consumption Questionnaire; STAI, State-Trait-Anxiety Inventory; TMSI, State-Trait-Anxiety Inventory.

blunting scores are obtained by summing up the relevant items, ranging from 12 to 60.[25] The TMSI is filled in once at baseline.

Sample size calculation

To detect a one-sided statistically significant difference of 5% or more from the prespecified 75% margin with 80% power and a α of 0.025, a minimum of 660 follow-up moments are required. The inclusion period of this study will be 3 years. Based on the last 3 years, a total number of patients eligible for the patient-led follow-up will be more than 200 patients. It is expected that approximately 20% of patients will experience recurrence of disease. Furthermore, an additional 5% of patients is expected to drop out due to other reasons. Therefore, 150 patients are expected to complete the entire 5 years of follow-up, resulting in at least 900 (150×6) optional follow-up moments during the entire study.

Statistical analysis

All main analyses will be performed according to the intention to treat principle using appropriate statistical software, such as the R Project for Statistical Computing (https://www.r-project.org/) and SPSS (SPSS software version 29). However, patients initially included but considered ineligible afterwards based on information that should have been available before inclusion, will be excluded from all analyses.

The primary outcome will be to determine the feasibility of home-based patient-led follow-up. Patient-led follow-up will be considered feasible if less than 75% of all optional follow-up moments are used. This will be tested statistically using a one-proportion Z-test, where the proportion of actually utilised optional follow-up moments (ie, number of additional follow-up moments used/total number of optional follow-up moments) will be compared with the 75% margin. The test will be performed one-sided against an α of 0.025. Implementation of the patient-led aspect of the study follow-up will be considered successful if the actual proportion of utilised follow-up moments is significantly lower than the prespecified 75% margin.

Implementation of at-home blood sampling is considered successful if 25% or more of all scheduled or optional CEA measurements was performed using blood collected at home by the patients themselves. Here, a successful sampling is defined as a sampling of blood by the patient, that reached the clinical laboratory of the hospital via post, and in which a serum CEA level could be determined. Similar to the primary endpoint, a one-proportion Z-test will be used, where the proportion of home-based sampling (ie, number of home-based blood samplings/total number of scheduled or optional blood-samplings performed) will be compared with the 25% margin. The test will be performed one sided, against an

α of 0.025. Implementation of the home-based aspect of the study follow-up will be considered successful if the actual proportion of blood samples successfully collected at home is significantly higher than the prespecified 25% margin.

All patient-reported outcome measures of the study (ie, general and disease-specific HRQoL, anxiety and fear of cancer recurrence) will be tested two-sided against reference values for this specific subpopulation and historic or prospective trial cohorts when available (Prospectief Landelijk Colorectaal Carcinoom Cohort (NCT02070146), ICARE (NTR5580), Distance trial (NL9266)). These will be compared between subgroups within the study population to identify possible relationships between the frequency and setting of postoperative surveillance, patient coping style (assessed by the TMSI), and the respective patient-reported outcome measures. The repeated measurements will be analysed using mixed analysis of variance models, where stratification factors will be taken into account. The single items in the questionnaires will be analysed using (ordinal) logistic regression with random effects.

In addition to comparisons with reference values, and other historic or prospective cohorts when available, we will evaluate the relationships between the frequency and setting of follow-up and the patient-reported outcome measures within the cohort itself. Since patients themselves will be able to determine their own follow-up frequency (ie, more or less frequent) and setting (home based or in-hospital), the effect of this choice on these patient-reported outcome measures can be assessed. This will be done similarly using linear mixed models, corrected for baseline measurements, patient and disease characteristics, and patient coping style (assessed at baseline using the TMSI). Here, the regression coefficients for subgroups of interest within the study (ie, low-frequency choice vs high-frequency choice or home based vs in-hospital) with corresponding 95% CI for that specific patient-reported outcome will be the outcome measures of interest.

In addition to the patient-reported outcome measures collected using questionnaires, we will also assess the diagnostic properties of the (changes in) momentary quality of life assessment (ie, collected every 10 days) to detect cancer recurrence. As this is collected frequently during the study, this can be regarded as a more continuous measurement which may potentially be able to anticipate cancer recurrence and anxiety between scheduled assessments.

Finally, a cost-effectiveness analysis will be performed to evaluate the economic impact of patient-led home-based surveillance in patients with colorectal carcinoma. Cost-effectiveness will model costs in a decision model using probabilities of events and unit costs of interventions.[26] The health effects will be expressed in QALYs. The QALY combines the number of life years with the quality of life measured with the EQ-5D-5L utilities.[27] The cost-effectiveness of patient-led home-based follow-up will be expressed as the incremental costs per QALY gained to allow comparison with historic healthcare interventions.[28]

Case report forms

Data will be collected on digital case report forms (CRF) to document eligibility, safety and efficacy parameters, compliance to treatment schedules and parameters necessary to evaluate the study endpoints. Data to be collected on the CRF are derived from the protocol. All CRF entries must be based on source documents. The CRF and instructions for completing the CRF will be provided in Castor, a cloud-based clinical data management system.

Missing data

Missing data concerning patient-reported outcomes distributed on paper will be considered missing at random. Single missing answers will be imputed using multiple imputation by chained equations. If an entire assessment or entire assessments are missing, no imputation will be performed.

Withdrawal of individual subjects

Subjects can withdraw from the study at any time for any reason if they wish to do so without any consequences and reporting a reason. The investigator can decide to withdraw a subject from the study for urgent medical reasons (death, no compliance of the patient, refusal to continue protocol treatment). Patients may decide to withdraw from completing follow-up questionnaires at any time during the study for any reason.

Ethics and dissemination

Ethical approval was given by the Medical Ethics Review Committee of Erasmus Medical Centre, The Netherlands (2021-0499). Results will be presented in peer-reviewed journals and presented at (inter)national conferences. Patients will be involved in study-related publications.

The sponsor will submit a summary of the progress of the study to the accredited METC annually. Information will be provided on the date of inclusion of the first subject, numbers of subjects included and amendments.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

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