SURVEY ON THE UNMET NEEDS FOR PATIENTS LIVING WITH METASTATIC COLORECTAL CANCER (MCRC)

Thank you for deciding to complete the survey on the unmet needs of patients living with metastatic colorectal cancer (mCRC). Take your time to answer all the questions. You can save the survey at any time and continue when you are ready. Alternatively, you can print the survey and complete it on paper. Once you are done, we would like to ask you to send it to the following address:

EuropaColon HQ
Unit 5, Deans Farm
Stratford-sub-Castle
Salisbury, SP1 3YP
UK

1.0. YOUR PROFILE

1. Please fill in your initials:

   — — — —
2. What year you were born?

   — — — —
3. You are:
   - ☐ Male
   - ☐ Female
4. Where do you live (country)?

   _____
5. The place where you live is a:
   - ☐ Rural area (less than 2'000 inhabitants)
   - ☐ Semi-urban area (2'000-50'000 inhabitants)
   - ☐ Urban area (more than 50'000 inhabitants)
   - ☐ Capital city
6. What is your marital status?
   - ☐ Single
   - ☐ Married/living with a partner
   - ☐ Divorced
   - ☐ Widowed

7. What is the highest degree that you have earned? Please circle any qualification you have received.
   - ☐ None
   - ☐ Primary education
   - ☐ Secondary education
   - ☐ College
   - ☐ University education
   - ☐ Post-university education
   - ☐ I don't know
8. Are you:
   - ☐ Employed
   - ☐ Unemployed
   - ☐ Retired
   - ☐ Unemployed due to a medical condition (i.e. handicapped)
   - ☐ Student/intern
   - ☐ I have another situation (please name: _____)
9. Do you have other chronic disease?
   - ☐ No
   - ☐ Yes (please name: _____)
10. Could you please provide us with some information about your lifestyle (please check all that applies)?
   - ☐ I exercise regularly three or more times a week for many years
   - ☐ I exercise occasionally (1-2 per week) during my lifetime
   - ☐ I never exercise
   - ☐ I eat high fiber diet
   - ☐ I eat low fiber diet
   - ☐ My diet is high in fat
   - ☐ My diet is low in fat
   - ☐ I eat red and processed meat more than three times a week
   - ☐ I never eat red and processed meat
   - ☐ I smoke
   - ☐ I drink alcohol 3-4 times per week
   - ☐ I drink alcohol 1-2 times per week
   - ☐ I never drink alcohol
   - ☐ I have a normal weight
   - ☐ I am overweight

11. How did you find out about the survey?
    - ☐ Through my doctor (oncologists, gastroenterologists, surgeon, GP, etc.), (please name them: _____)
    - ☐ Through my nurse (please name them: _____)
    - ☐ Through local patient organization (please name: _____)
    - ☐ Through the internet, social-media (name which: _____)
    - ☐ Other (please name: _____)
12. Please give us the name of the hospital where you are being treated:

    _____

2.0. YOUR ILLNESS

2.1. DISCOVERY OF YOUR ILLNESS

1. Why did you consult your doctor (more than one answer is possible, please mark all that applies)?
    - ☐ I went for a routine examination
    - ☐ I had symptoms non-related to CRC
    - ☐ I had symptoms related to CRC
    - ☐ Because of peer pressure
    - ☐ I was invited to participate in CRC screening program
    - ☐ I wanted to be tested for CRC
    - ☐ I had an emergency hospitalization
2. Prior to your initial diagnosis, did you know what the symptoms of CRC were?
    - ☐ Yes, I was aware of some or all of the symptoms
    - ☐ No, I was not aware
    - ☐ I am not sure
3. What symptoms did you have before you were diagnosed (more than one answer is possible)?
    - ☐ Diarrhea
    - ☐ Constipation
    - ☐ Alternating diarrhea and constipation
    - ☐ Change in bowel habit
    - ☐ Change in appearance of stool
    - ☐ Abdominal (stomach) pain
    - ☐ Felt lump in my stomach
    - ☐ Bloating
    - ☐ Nausea and/or vomiting
    - ☐ Constant urge to go to the toilet
    - ☐ Blood in the stool or dark stool

- ☐ Fatigue/Tiredness/Anemia
- ☐ Breathlessness
- ☐ Fever
- ☐ Night sweats
- ☐ Other (please name: _____)

4. How long did you wait between observing the first symptoms and consulting your physician?
   - ☐ Less than a month
   - ☐ Between 1-3 months
   - ☐ Between 3-6 months
   - ☐ Between 6-12 months
   - ☐ 1 year or more
   - ☐ I cannot remember
5. What describes you best?
   - ☐ I was invited to participate at the CRC screening program and that is how I was diagnosed
   - ☐ I was invited to participate at the CRC screening program but decided not to do so and was diagnosed later, by a chance
   - ☐ Although I am >50 years old I was not invited to participate at colorectal cancer screening program but would if I was invited
   - ☐ Although I am >50 years old I was not invited to participate at colorectal cancer screening program but would not go anyway
   - ☐ I am younger than 50 years
6. When you were screened did you perform a test that aimed to detect small amount of blood in your stool i.e. fecal occult blood test (FOBT) (either guaiac or immunochemical)?
   - ☐ Yes
   - ☐ No
   - ☐ I don't know what this is
7. How quickly did you have a colonoscopy (after the first consultation or positive screening test)?
   - ☐ Up to 2 weeks
   - ☐ Between 2 weeks to a month
   - ☐ Between 1-3 months
   - ☐ Between 3-6 months
   - ☐ Between 6-12 months
   - ☐ More than a year
   - ☐ I cannot remember
   - ☐ I did not have one

8. How soon were you diagnosed with CRC (after the first consultation or positive screening test)?
   - ☐ Up to 2 weeks
   - ☐ Between 2 weeks to a month
   - ☐ Between 1-3 months
   - ☐ Between 3-6 months
   - ☐ Between 6-12 months
   - ☐ More than a year
   - ☐ I am not sure
9. Before being diagnosed with colorectal cancer, were you misdiagnosed with another condition (such as irritable bowel syndrome, hemorrhoids, etc.)
   - ☐ Yes
   - ☐ No
10. When were you initially diagnosed with colorectal cancer?
    Month _ _ Year _ _ _ _
11. Which best describes your situation?
    - ☐ I was initially diagnosed with stage 1, 2 or 3 colorectal cancer, and it progressed to stage 4 (advanced or metastatic disease) colorectal cancer
    - ☐ I was first diagnosed with stage 4 colorectal cancer
    - ☐ I am not sure at which stage I was initially diagnosed but I have stage 4 colorectal cancer now
    - ☐ None of the above
12. If you were initially diagnosed with the disease that was localized in your intestine (colon or rectum), how long did it take from being diagnosed with colorectal cancer until being diagnosed with disease that has spread to another organ (i.e. liver, lungs, lymph nodes)?
    Weeks _ _ Months _ _ Years _ _
13. In your case, how would you rate the process in which the diagnosis was established?
    - ☐ I was very satisfied – the disease was established quickly
    - ☐ Acceptable – I had some consultations and had to wait some time for the examinations and establishing the diagnosis
    - ☐ Not very satisfying – a lot of consultations and a lot of waiting between examinations
    - ☐ Not satisfied at all – too many consultations and waiting too long
14. What doctor(s) or professionals have you visited in the last 12 months exclusively for colorectal cancer (please mark all that apply)?
    - ☐ General practitioner
    - ☐ Gastroenterologist
    - ☐ Oncologist
    - ☐ Surgeon
    - ☐ Radiotherapist

- ☐ Radiologist
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Nurse
- ☐ Dietician
- ☐ Social worker
- ☐ Other (please name: _____)

15. Has anybody in your family ever had colorectal cancer?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know
16. When diagnosed with colorectal cancer, did you advise your immediate family to go for colonoscopy?
    - ☐ Yes
    - ☐ No
    - ☐ I have no immediate family

2.2. YOUR DIAGNOSIS

1. What was your understanding of the disease before the diagnosis?
    - ☐ I was well informed on colorectal cancer
    - ☐ I knew something about colorectal cancer
    - ☐ I knew very little about colorectal cancer
    - ☐ I knew nothing about colorectal cancers
2. While being diagnosed, did you receive clear explanations about:

The nature of the disease	yes ☐	no ☐
The origin of the disease	yes ☐	no ☐
The examinations to be performed	yes ☐	no ☐
The likely progression of the disease	yes ☐	no ☐
Stages of the disease progression	yes ☐	no ☐
Possible treatments	yes ☐	no ☐
Consequences and side effects of treatment	yes ☐	no ☐

3. Following the announcement of the disease, did you seek further information?
    - ☐ Yes
    - ☐ No
4. **If yes**, where (more than one answer is possible, please mark all that applies)?
    - ☐ Internet
    - ☐ Health magazines
    - ☐ My general practitioner/family doctor
    - ☐ My pharmacist

- ☐ Another health care professional
- ☐ Patient organisation
- ☐ My family and friends
- ☐ Other colorectal cancer patients
- ☐ Other (please name: _____)

2.3. YOUR TREATMENT

1. Currently you are:
   - ☐ Waiting for the treatment
   - ☐ Undergoing treatment
   - ☐ Finished with the treatment and now have no evidence of cancer
   - ☐ Finished with the treatment but cancer is still present
   - ☐ I have not undergone treatment for colorectal cancer
   - ☐ None of the above (explain: _____ _____)
2. How long did it take between being diagnosed with colorectal cancer and starting with a cancer treatment?
   - ☐ Up to 2 weeks
   - ☐ Between 2 weeks and a month
   - ☐ Between 1-3 months
   - ☐ Between 3-6 months
   - ☐ Between 6-12 months
   - ☐ More than a year
   - ☐ I cannot remember
3. Was your treatment plan discussed by a multi-disciplinary team (MDT)?
   - ☐ Yes, it was discussed by the multi-disciplinary team (MDT) and a doctor/nurse informed me of the outcome
   - ☐ Yes, it was discussed by the multi-disciplinary team (MDT) but I was not informed of the outcome
   - ☐ No, as far as I am aware, it was not discussed by the multi-disciplinary team (MDT)
   - ☐ I don't know
4. Overall, do you feel that your views were considered when your treatment plan was developed?
   - ☐ Yes
   - ☐ No
   - ☐ I am not sure

5. When making decisions on treatment plan, what are the most important factors for you (rate with 1 being the most important and 5 being the least important)?
   - ☐ Improved prognosis
   - ☐ Preservation of quality of life
   - ☐ Frequency of administration
   - ☐ Financial restraints
   - ☐ Other (please name: _____)
6. Why would you stop taking the treatment (rate with 1 being the most important and 5 being the least important)?
   - ☐ The treatment stopped working for me
   - ☐ Severity of adverse events (i.e. nausea, vomiting, rash, hair-loss, tiredness, etc.)
   - ☐ Frequency of administration
   - ☐ Financial restraints
   - ☐ Feeling tired of the treatment
   - ☐ Other (please name: _____)
7. What treatment for colorectal cancer did you receive (more than one answer is possible, please mark all that apply)?
   - ☐ Surgery
   - ☐ Chemotherapy
   - ☐ Radiotherapy
   - ☐ Personalized/targeted medicine (such as cetuximab, bevacizumab, panitumumab, aflibercept, regorafenib and trifluridine/tipuracil)
   - ☐ Other (such as immunotherapy or clinical trial)
   - ☐ I am not sure
   - ☐ I did not receive any treatment
8. Which chemotherapy drugs did you receive (please mark all that apply)?
   - ☐ 5-FU
   - ☐ Capecitabine
   - ☐ Oxaliplatin
   - ☐ Irinotecan
   - ☐ FOLFOX (combination of 5-FU and oxaliplatin)
   - ☐ FOLFIRI (combination of 5-FU and irinotecan)
   - ☐ XELOX (combination of capecitabine and oxaliplatin)
   - ☐ FOLFOXIRI (combination of 5-FU, oxaliplatin and irinotecan)
   - ☐ Other (please name: _____)
   - ☐ I don’t know
9. Did you complete your chemotherapy treatment?
   - ☐ Yes
   - ☐ No

10. **If no**, why did you stop the chemotherapy treatment (please select all that apply)?
    - ☐ The side effects were too severe
    - ☐ Poor quality of life
    - ☐ The treatment was not working
    - ☐ I was advised by my doctor to stop the treatment
    - ☐ Other (specify: _____)
11. Did you take a molecular test for RAS testing (KRAS, NRAS)?
    - ☐ Yes
    - ☐ No
    - ☐ I don't know
    - ☐ I don't know what this is.
12. **If yes**, do you know the results of the test?
    - ☐ Yes – it determined that I was a candidate for cetuximab/panitumumab
    - ☐ Yes – it determined that I was not a candidate for cetuximab/panitumumab
    - ☐ No, I was not informed of the results
    - ☐ I don't know
13. Did your treatment include any of the following medicines (please mark all that apply)?
    - ☐ Cetuximab
    - ☐ Panitumumab
    - ☐ Bevacizumab
    - ☐ Aflibercept
    - ☐ Regorafenib
    - ☐ Trifluridine/tipiracil
    - ☐ None/I don't know
14. **If none**, do you know why?
    - ☐ These treatments are not available in my country
    - ☐ These treatments are not covered by my health plan
    - ☐ Tests determined I was not a candidate for biologic treatment
    - ☐ I don't know
15. Were you given clear information about the side effects of the treatment?
    - ☐ Yes
    - ☐ No
    - ☐ I am not sure
16. Was the treatment you received the same as explained by your health-care team?
    - ☐ Yes
    - ☐ No
    - ☐ I am not sure

17. Are you still undergoing treatment?
    - ☐ Yes
    - ☐ No
18. **If no**, please explain why?
    - ☐ I was advised by my physician to stop the treatment
    - ☐ The treatment was not working
    - ☐ The side effects of the treatment were too severe
    - ☐ Poor quality of life
    - ☐ Financial constraints
    - ☐ Other (please name: _____)
19. Were you offered the chance of enrolment on a clinical trial?
    - ☐ Yes
    - ☐ No
20. In what type of hospital, you have been treated? Please choose one:
    - ☐ Public hospital
    - ☐ Private hospital
    - ☐ A mixture of both
    - ☐ Other, please specify
    - ☐ I am not sure
21. In general, how would you rate the care received in your hospital?
    - ☐ Poor
    - ☐ Fair
    - ☐ Good
    - ☐ Very good
    - ☐ Excellent

2.4. SUPPORT

1. Who is your main source of support (more than one answer is possible, please mark all that apply)?
    - ☐ My partner (husband/wife)?
    - ☐ My children
    - ☐ My parents
    - ☐ Other family members
    - ☐ My friends
    - ☐ Colleagues
    - ☐ Patient organisation
    - ☐ No one
    - ☐ Other

2. In your case, who is the most important/most valuable point of contact for medical information?
   - ☐ My oncologist
   - ☐ My surgeon
   - ☐ My nurse
   - ☐ Other, please name _____
3. Please grade your degree of satisfaction of the emotional support you have received from your:

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very dissatisfied	Not applicable
Clinicians	☐	☐	☐	☐	☐	
Nurses	☐	☐	☐	☐	☐	
Psychologist	☐	☐	☐	☐	☐	☐
Social worker	☐	☐	☐	☐	☐	☐
Other, please name: _____ _____	☐	☐	☐	☐	☐	☐

4. In your opinion, what would improve your relationship with your health care team (more than one answer is possible, please mark all that apply):
   - ☐ Being considered a valued member of the team.
   - ☐ Sharing the decision making.
   - ☐ Being treating as an individual
   - ☐ Being spoke to in a language I can understand - a less technical approach
   - ☐ Recommendations about how to improve my emotional feelings
   - ☐ Helping me through my ups and downs
   - ☐ More empathy - I am not a number!
5. In your opinion, which of the following information is important for people with metastatic colorectal cancer (please mark all that apply)?
   - ☐ Disease information
   - ☐ Information about the treatment options
   - ☐ Information about the side effects of the treatment
   - ☐ Information about the clinical trials
   - ☐ Information about the physician/hospitals/health-centers in their country
   - ☐ Information about the patient support groups
   - ☐ Information about telephone helplines
   - ☐ Other information (please name: _____)

6. What would help patients with metastatic colorectal cancer in your country that is currently not available (please mark all that apply)?
   - ☐ Psychologist
   - ☐ Social worker
   - ☐ Patient support program (volunteers)
   - ☐ Talking to other patients (Buddy)
   - ☐ Telephone help-line
   - ☐ Internet forum (message board)
   - ☐ Day hospice to meet other patients
   - ☐ Application for my mobile/tablet to help me have all relevant data at one place
7. Please rate the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
You feel that you were given enough information to make informed choices about your treatment	☐	☐	☐	☐	☐
You were given enough emotional support throughout your treatment	☐	☐	☐	☐	☐
Your family members were given enough emotional support	☐	☐	☐	☐	☐
Your children have received adequate support and help	☐	☐	☐	☐	☐

8. Have you been given enough information and support to manage the side effects of your treatment?
   - ☐ Yes
   - ☐ No
   - ☐ I am not sure
9. Who or what, do you feel, has helped you to cope with your treatment? Could you please assign the numbers 1-6 to each of the answers below, 1 being the most important and 6 being the least important.
   - ☐ My friends and family
   - ☐ Patient support group
   - ☐ My clinician
   - ☐ Psychotherapist
   - ☐ My professional life
   - ☐ Other, please name: _____
10. Have you encountered difficulties (i.e. physical, financial or other) during examinations or treatment?
    - ☐ Yes
    - ☐ No

11. **If yes,** which difficulties did you encounter?
    - ☐ You lost your job
    - ☐ You were required to take time off work
    - ☐ You faced work-related stress
    - ☐ You faced discrimination at work based on your illness
    - ☐ Your income was negatively affected
    - ☐ You faced serious financial hardship
    - ☐ You were required to use your savings
    - ☐ You had to borrow money
12. Are you experiencing any of the following ongoing medical side effects of your treatment (select all that applies)?
    - ☐ Bowel dysfunction (i.e. incontinence)
    - ☐ Sexual dysfunction (i.e. erectile dysfunction)
    - ☐ Emotional side effects (i.e. anxiety or depression)
    - ☐ Urology problems (i.e. incontinence or stoma formation)
    - ☐ Peripheral neuropathy (i.e. numbness in your fingertips)
    - ☐ Chemo brain (also known as mild cognitive impairment or cognitive dysfunction)
    - ☐ Other, please specify: _____
    - ☐ I am not sure

3.0. QUALITY OF LIFE OF CANCER PATIENTS (EORTC QLQ-C30)

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

EuropaColon
united against digestive cancers

4.0. EORTC QLQ – C29

During the past week:	Not at All	A Little	Quite a Bit	Very Much
31. Did you urinate frequently during the day?	1	2	3	4
32. Did you urinate frequently during the night?	1	2	3	4
33. Have you had any unintentional release (leakage) of urine?	1	2	3	4
34. Did you have pain when you urinated?	1	2	3	4
35. Did you have abdominal pain?	1	2	3	4
36. Did you have pain in your buttocks/anal area/rectum?	1	2	3	4
37. Did you have a bloated feeling in your abdomen?	1	2	3	4
38. Have you had blood in your stools?	1	2	3	4
39. Have you had mucus in your stools?	1	2	3	4
40. Did you have a dry mouth?	1	2	3	4
41. Have you lost hair as a result of your treatment?	1	2	3	4
42. Have you had problems with your sense of taste?	1	2	3	4
43. Were you worried about your health in the future?	1	2	3	4
44. Have you worried about your weight?	1	2	3	4
45. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
46. Have you been feeling less feminine/masculine as a result of your disease or treatment?	1	2	3	4
47. Have you been dissatisfied with your body?	1	2	3	4
48. Do you have a stoma bag (colostomy/ileostomy) (please circle the correct answer)?	Yes		No	

Answer these questions ONLY IF YOU HAVE A STOMA BAG, if not please continue below:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
49. Have you had unintentional release of gas/flatulence from your stoma bag?	1	2	3	4
50. Have you had leakage of stools from your stoma bag?	1	2	3	4
51. Have you had sore skin around your stoma?	1	2	3	4
52. Did frequent bag changes occur during the day?	1	2	3	4
53. Did frequent bag changes occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your stoma?	1	2	3	4
55. Did you have problems caring for your stoma?	1	2	3	4
Answer these questions ONLY IF YOU DO NOT HAVE A STOMA BAG:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
49. Have you had unintentional release of gas/flatulence from your back passage?	1	2	3	4
50. Have you had leakage of stools from your back passage?	1	2	3	4
51. Have you had sore skin around your anal area?	1	2	3	4
52. Did frequent bowel movements occur during the day?	1	2	3	4
53. Did frequent bowel movements occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your bowel movement?	1	2	3	4

During the past 4 weeks	Not at All	A Little	Quite a Bit	Very Much
For men only: 55. To what extent were you interested in sex?	1	2	3	4
56. Did you have difficulty getting or maintaining an erection?	1	2	3	4
For women only: 55. To what extent were you interested in sex?	1	2	3	4
56. Did you have pain or discomfort during intercourse?	1	2	3	4

Thank you for taking part in the survey. If you would like to receive information on the survey, once published (which we expect in March 2018) or to share your story with us or become a member of a patient organization, please fill in the form below.

Please leave us your details so we can contact you and mark all that applies:

Name: _____

E-mail: _____

☐ I would like to receive the update on the survey, once published

☐ I would like to share my story

☐ I would like to become a member of EuropaColon

☐ I would like to become a member of the local organization

☐ I would like to receive the newsletters from EuropaColon