

SURVEY ON THE EXPERIENCE AND NEEDS OF PATIENTS LIVING WITH OESOPHAGEAL OR GASTRIC CANCER

This survey is being carried out by EuropaColon, a not-for-profit organization established in 2004, dedicated to saving lives from digestive cancers. We are active with over 40 branches across Europe. With your help, we will use the information you provide to help improve conditions and treatments for other patients. As a patient who has experienced treatment of oesophageal or gastric cancer, I am asking you to complete the survey, based on your experience, to help others through their journey.

This is the first survey of its kind and size. Your comments will be used **anonymously** (no one will be able to track your comments) to help us understand the issues and concerns you as an oesophageal or gastric cancer patient face and we will seek to use this information to improve the experience of patients in the future.

We will take your answers to Governments, Policy Makers, Politicians, Industry, Media and others to ask for changes to be made so the treatment of oesophageal and gastric cancer in future to meet your needs. We would also very much like to use your story to raise awareness of oesophageal and gastric cancer, see end of the survey.

We are looking for 1200 patients from 15 countries to complete this survey, together with Doctors and Nurses, we hope to reach this goal in 6 months.

There is no right or wrong answer as you are the expert on your own health. We can send our findings to you if you leave your email address at the end of the survey.

Thank you for taking the time to complete the survey.

Jola Gore Booth
ECO EuropaColon
United against Digestive Cancers

Thank you for deciding to complete the survey to capture the views of patients living with oesophageal or gastric cancer. Take your time to answer all the questions. Once you are done, we would like to ask you to send it to the following address: **EuropaColon, Scotts House, Scotts Lane, Salisbury, SP1 3TR, UK**

Country:

1.0. YOUR ILLNESS

DISCOVERY OF YOUR ILLNESS

1. Why did you initially consult your doctor (tick all that apply)
 - I went for a routine examination
 - I had an emergency hospitalisation
 - I was experiencing symptoms
 - Other

2. What symptoms did you have before you were diagnosed? (tick all that apply)
 - Indigestion and gastric discomfort
 - A bloated feeling after eating
 - Nausea
 - Acid reflux
 - Loss of appetite
 - Blood in the stool
 - Vomiting
 - Weight loss for no known reason
 - Gastric pains
 - Jaundice (yellowing of eyes and skin)
 - Ascites (build-up of fluid in the abdomen)
 - Trouble swallowing
 - Other (please name)
 - No significant symptoms

3. How long did you wait between observing the first symptoms and seeing 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

4. Did you have to wait before seeing your specialist? Yes No

5. When were you first diagnosed with oesophageal or gastric cancer?
Month __ __ Year ____ __
Were you diagnosed with oesophageal cancer? Yes No
Were you diagnosed with gastric cancer Yes No

6. Before your diagnosis of gastric cancer did you receive treatment to eradicate Helicobacter (*Helicobacter pylori*): (*Helicobacter pylori* a kind of germ, which lives in the

sticky mucus that lines the stomach. It is very common and in nearly nine out of 10 people with it, it does not cause any problems) Yes No Don't know

7. How soon after your first consultation were you diagnosed with gastric cancer?

- 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

8. Before being diagnosed with gastric cancer, were you misdiagnosed with another condition (such as irritable bowel syndrome, bloating, jaundice, excessive fatigue, etc.)

Yes No

If **yes**, please tell us what is was: _____

9. Please select the best answer to the statement below (1 very dissatisfied and 5 is very satisfied):

	1	2	3	4	5
"I was satisfied with the time it took for me to receive my cancer diagnosis"					

10. Have any of your first-degree relatives (mother, father, siblings, children) ever had oesophageal or gastric cancer? Yes No I don't know

If yes, which cancer: Gastric cancer Oesophageal cancer

If yes, how many: _____

If yes, what was the age of those relatives when they were diagnosed with oesophageal or gastric cancer:

1.2. YOUR DIAGNOSIS

1. Please select the best answer to the statements below, about the discussion you had your diagnosis appointment (1 means you strongly disagree and 5 means you strongly agree):

When you were diagnosed with cancer...	1	2	3	4	5
Were you told enough about the disease					
Were you told the likely cause of the disease					
Were you told about the investigations to be performed					
Were you told about the likely progression of the disease					
Were you given your stage of the disease (stage 1-4)					
Were you told about possible treatments					
Were you told about the side effects of those treatments					
Were you given the possible outcome of the treatment					

Were you provided family planning counselling or services?					
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2. After you were diagnosed, did you look for further information? Yes No

If yes, where (please mark all that apply)?

- Internet
- Health magazines
- My general practitioner/family doctor
- My pharmacist
- Another health care professional
- Patient organisation
- My family and friends
- Other oesophageal or gastric cancer patients
- Other (please name)

1.3. YOUR TREATMENT

1. Currently you are (more than one answer is possible):
 - Waiting for treatment
 - Completed surgery
 - 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 oesophageal or gastric cancer
 - None of the above (explain)

2. How long did it take between being diagnosed with cancer and starting with 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

*(an MDT is a regular meeting of all professionals involved in assessing cancer treatment where individual cases are discussed by all the relevant clinicians present at the meeting)

4. When making decisions on your treatment plan, what were the most important factors for you (1 being the least important and 5 being the most important)?

	1	2	3	4	5
Stopping the disease from growing					
Shrinking the tumor					
Prolonging my life expectancy					
Stopping the symptoms					
Preserving my quality of life					
Financial difficulties					
Other (please name)					

5. What treatment(s) have you already received to date (mark all that apply)?

- Surgery
- Chemotherapy
- Radiotherapy
- Personalized/targeted medicine (Trastuzumab/Herceptin or Cyramza/ ramucirumab)
- Other medicine (specify if product name is known)
- I am not sure
- I did not receive any treatment

6. Other treatment questions

- Did your doctor or oncologist explain the surgery options? Yes No
- Did your doctor or oncologist explain the risks of surgery? Yes No
- After you were diagnosed, were you given the option of partial or total prophylactic gastrectomy? Yes No
- Did your doctor or oncologist surgeon discuss possible complications with oesophageal or stomach removal? Yes No
- Did your doctor or oncologist discuss living without your oesophagus or stomach and how your diet will be affected? Yes No
- Did you have metastasis in other parts of your body before or after your oesophageal or gastric cancer diagnosis? Yes No
- Indicate where if you know

Chemotherapy

7. Are you still undergoing treatment? Yes No

8. Did you or would you consider stopping the treatment for any of these reasons (1 being the least important and 5 being the most important)?

	1	2	3	4	5
The treatment stopped working for me					
Severity of side effects (i.e. nausea, vomiting, rash, hair-loss, tiredness, etc.)					
Frequency of administration					
Financial restraints					
Feeling tired of the treatment					
Other (please name)					

PAIN

9. At the time of your diagnosis:

- Did you experience cancer related pain? Yes No
- Was it treated successfully? Yes No
- Did this pain continue after diagnosis? Yes No
- Did you talk to your doctor about this pain? Yes No
- Did your doctor ask about any pain you might have? Yes No

10. During your treatment:

- Did you suffer additional pain? Yes No
- Did you raise this with your doctor? Yes No
- Did your doctor ask about any pain you were experiencing? Yes No
- Was this pain treated successfully? Yes No

11. After your treatment: yes/no questions not 1-5 options

- Did you experience the original pain? Yes No
- Did you suffer new pain? Yes No
- Did you raise this with your doctor? Yes No
- Did your doctor ask about new pain you might experience? Yes No

1.4 YOUR CARE

1. Were you given the name and contact details of someone (such as a nurse) you could contact if you had any questions or problems? Yes No
 2. Would such a contact have been useful for you for follow up support? Yes No
 3. Were you offered the chance to enroll on a clinical trial? Yes No
- If yes,** was your treatment via a clinical trial? Yes No

1.5. SUPPORT

1. Who has been your main source of support during your treatment? (1 being less influential source and 5 being the main source)? Please mark all relevant.

	1	2	3	4	5
My partner					
My children					
My parents					
Other family members					
My friends					
Colleagues					
Patient organisation					
Family doctor					
Other patients					
None of the above					

2. Please rate your satisfaction of the medical support you received from your: (please mark all that apply, 1 is least important 5 is most important)?

	1	2	3	4	5
Doctors					
Nurses					
Psychologist					
Social worker					
Other (please name):					

3. In your opinion, which of the following information is important for people with oesophageal or gastric cancer (please mark all that apply, 1 is not important and 5 is very important)?

	1	2	3	4	5
Disease information					
Information about the treatment options					
Information about the side effects of the treatment					
Information about the clinical trials					
Information about diet and nutrition					
Information about the physician/hospitals/health-centers in their country					
Information about the patient support groups and services					
Information about telephone helplines					
Information on how to manage my daily life					

4. What would help patients with oesophageal or gastric cancer in your country that is currently not available (please mark all that apply)?

- Psychologist
- Social worker
- Nutritionist or dietician
- 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
- Other, please specify

5. Please rate the following statements (1 means you strongly disagree and 5 means you strongly agree)

	1	2	3	4	5
You feel that you were given enough information to make informed choices about your treatment by your doctors/nurses					

You were given enough emotional support throughout your treatment by your doctors/nurses					
Your family members were given enough emotional support					
Your children received adequate support and help					
Were you given enough information and support to manage the side effects of your treatment?					
You feel that you were given enough information to make informed choices about your treatment by your doctors/nurses					

2.0. HEALTH LITERACY

Please complete this section - 0 = not relevant, 1 = very bad, 2 = bad, 3 = moderate, 4 = good, 5 = very good

	0	1	2	3	4	5
How well do you understand the instruction leaflets for your medication						
How well do you understand information brochures on health issues						
When you have questions on diseases or complaints, you know where to find information on these issues						
When you want to do something about your health without being sick, you know where to can find information on these issues						
How often were you able to help your family members or a friend if they had questions concerning health issues						
When you have questions concerning health issues, how often were you able to get information and advice from others (family and friends)						
How well are you doing in choosing the advice and offers that fit with you the most						
Regarding information on health on the Internet, are you able to determine which sources are of good and which of poor quality						

3.0. YOUR PROFILE

1. What is your age?
2. Gender: Male Female
3. Are you:
 - Employed
 - Unemployed
 - Retired
 - Unemployed due to a medical condition (i.e. handicapped)
 - Student/intern
 - I have another situation (please name)
4. Do you have other chronic disease?
 - No
 - Yes (please name)

5. How did you find out about the survey?

- Through my doctor (oncologists, gastroenterologists, surgeon, GP, etc.),
- Through my nurse
- Through local patient organization
- Through the internet, social-media
- Other

Do you have other comments you wish us to consider about your experience or your treatment? Please feel free to email them to us: info@europacoln.com

Thank you for taking part in the survey.

- If you would like to receive information on the survey, once published (which we expect in 2019)
- or to share your story with us (this would be very helpful to raise awareness and remove stigma of oesophageal and gastric cancer, also to campaign for more treatment options for oesophageal and gastric cancer). You can of course remain anonymous if you prefer.
- If you would like to participate in local meetings with other patients or carers please respond to info@europacoln.com

This survey has been made possible by support from:



MERCK

Lilly

