

Supplementary material 1. Questionnaire in English.

Study on perceptions and knowledge about the coronavirus pandemic (COVID-19) among patients with hereditary syndromes predisposing to neoplasms of the digestive system

We are carrying out a study that aims to investigate:

- the perceptions and knowledge of our patients about coronavirus infection
- the impact of this pandemic on their treatment/surveillance protocol
- their current state of health

We contact you as you have signed a consent form in accordance with current national and European legislation on the protection of personal data (Regulation (EU) 2016/679) for the processing of your personal and sensitive data and for the contact for clinical research purposes (IRB TEAD INT 12/18).

We therefore ask you to answer the questions of the following questionnaire by choosing the answer that best represents your opinion or your condition.

I declare that I accept to respond to the questionnaire. I am aware that I can interrupt completing the questionnaire at any time without any obligation on my part to justify the reason. I declare that my consent is an expression of a free decision, not influenced by third parties. I hereby authorize the treatment of my personal data. I hereby authorize the use and anonymous disclosure of the results of the questionnaire in compliance with the current laws on the protection of confidentiality.

I accept

I don't accept

Section-1

Sociodemographic data

S1.1. Patient in the Hereditary Cancer of the Digestive System Registry for:

- Lynch syndrome Familial polyposis Other

S1.2. Sex: Female Male

S1.3. Age: 18-30 31-60 60+

S1.4. Marital status: Single Married Cohabiting Separated Divorced Widowed

S1.5. Children: Yes No

S1.6. Level of education:

- Elementary school Middle school High school diploma University degree

S1.7. Current employment status:

- Retired Employed Unemployed Unemployed and looking for work
 Other _____

Section-2

Perceptions and knowledge of the coronavirus

S2.1. Coronavirus (COVID-19) is scaring you:

- very much
- much
- moderately
- a little
- not at all

S2.2. Do you find the coronavirus (COVID-19) news useful:

- very much
- much
- moderately
- a little
- not at all

S2.3. Do you think the news about coronavirus (COVID-19) is:

- clear and comprehensive
- clear but not comprehensive enough
- unclear
- contradictory

S2.4. What source of information regarding coronavirus (COVID-19) do you think is safe (multiple answers can be selected):

- friends / family / acquaintances
- social media
- media / press
- press conferences / statements / institutional sources

S2.5. What are the symptoms of coronavirus (COVID-19) (multiple answers can be selected):

- cough
- cold
- fever
- shortness of breath
- vomiting
- gastrointestinal problems
- shivering
- headache
- back pain

S2.6. Are you taking special precautions:

- yes
- no

S2.7. If you answered yes to the previous question, what precautions did you take (multiple answers can be selected):

- I stay at home
- I use disinfectants, I wash my hands and follow hygiene rules more carefully
- I use masks and gloves
- I avoid crowded places / I no longer take public transportation
- All of the above
- None of the above

S2.8. If you are working from home, was it:

- your choice
- the decision of the company that employs you
- the decision of the public office that employs you

S2.9. Did the closure of kindergartens and schools cause problems in the management of your daily life?

- yes, I have children and I don't know how to take care of them while working
- yes, I have children and I had to ask for help in managing them while working
- yes, I have children, but I work from home and I can take care of them
- no, I have no children

S2.10. Do you think that products from China are dangerous?

- yes
- no
-

S2.11. Who should you contact if you have flu symptoms in this period?

- the emergency room
- family doctor / attending pediatrician / continuing care physician
- 112 or other numbers provided by the Health Ministry and your Region

S2.12. Is there a treatment for COVID-19?

- yes, and it's an antibiotic
- yes, and it's a vaccine
- no, there is no specific treatment at the moment

Section-3

Impact of the coronavirus emergency on surveillance and cancer treatment

S3.1. Because of your increased risk of cancer due to a genetic predisposition, do you generally feel more fragile than the general population?

- not at all
- a little
- much
- very much

S3.2. Since you became aware of your increased risk of developing a malignancy, do you regularly attend medical checks?

- yes, regularly
- yes, occasionally
- no

S3.3. Generally, does lengthening the time between one medical check and the next cause you anxiety?

- not at all
- a little
- much
- very much

S3.4. Do you think that the COVID-19 (coronavirus) epidemic is more dangerous for you than the general population?

- not at all
- a little
- much
- very much

S3.5. During this period, did you have any planned medical checks that you could not attend due to the COVID-19 health emergency?

- yes
- no

If you answered yes to the previous question:

S3.5.1. Did not being able to attend the planned medical checks because of the COVID-19 emergency cause you anxiety?

- not at all
- a little
- much
- very much

S3.5.2. Have the medical checks that you were unable to attend already been rescheduled?

- yes, all of them
- some of them
- none of them

What you have been diagnosed with is a rare disease that requires more frequent surveillance tests and sometimes different treatments than in the general population. It is therefore essential that the physicians who follow you know these needs and plan the medical checks and any treatments accordingly.

S3.6. Are you aware that within the Unit of Hereditary Tumors of the Digestive System of the IRCCS National Cancer Institute of Milan where you are under surveillance/treatment, there is a registry dedicated to the management (surveillance and treatment) of your condition?

- yes
- no

S3.7. Are you aware that the frequency of the medical checks you regularly undergo, regardless of where, is always established by a team of dedicated professionals?

- yes
- no

S3.8. Do you feel safe knowing that you are being followed by a dedicated team of professionals who, based on your personal and family medical history, assess whether it is appropriate or not to delay an exam due to the COVID-19 emergency?

- not at all
- a little
- much
- very much

Section-4

Health Survey SF12

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

1. In general, would you say your health is:

- excellent
- very good
- good
- fair
- poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- yes, limited a lot
- yes, limited a little
- no, not limited at all

3. Climbing several flights of stairs

- yes, limited a lot
- yes, limited a little
- no, not limited at all

During **the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like

- yes
- no

5. Were limited in the kind of work or other activities

- yes
- no

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like

- yes
- no

7. Didn't do work or other activities as carefully as usual

- yes
- no

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- not at all
- a little bit
- moderately
- quite a bit
- extremely

These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

9. Have you felt calm and peaceful?

- all of the time
- most of the time
- a good bit of the time
- some of the time
- a little of the time
- none of the time

10. Did you have a lot of energy?

- all of the time
- most of the time
- a good bit of the time
- some of the time
- a little of the time
- none of the time

11. Have you felt downhearted and blue?

- all of the time
- most of the time
- a good bit of the time
- some of the time
- a little of the time
- none of the time

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- all of the time
- most of the time
- some of the time
- a little of the time
- none of the time