

Lynch Syndrome Medical Follow-Up Survey

Q1: Demographic Information

- Name
- Date of Birth
- Sex (M/F)
- Mailing Address
- Email Address
- Phone Number
- Health Insurance

PERSONAL CANCER HISTORY

Q2-A: Have you ever been diagnosed with any cancer(s)?

- Yes
- No
- Unsure

Q2-B (IF Q2-A=Yes AND Sex=Male): With what type(s) of cancer have you been diagnosed (please select all that apply)?

- Breast
- Colon/rectum
- Pancreas
- Prostate
- Kidney
- Bladder/ureter
- Other
 - Please provide additional information regarding the type of cancer with which you were diagnosed and at what age:

Q2-C (IF Q2-A=Yes AND Sex=Female): With what type(s) of cancer have you been diagnosed (please select all that apply)?

- Breast
- Colon/Rectum
- Uterus/Endometrium
- Ovarian/Fallopian Tube/Primary Peritoneal
- Pancreas
- Kidney
- Bladder/ureter
- Other
 - Please provide additional information regarding the type of cancer with which you were diagnosed and at what age:

Q2-D: At what age(s) were you diagnosed with Q2-B/Q2-C cancer(s)?

COLON CANCER RISK MANAGEMENT HISTORY

Q3: Have you had your entire colon surgically removed (known as a complete colectomy)?

- Yes
 - No
 - Unsure
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Q4: When was your last colonoscopy (where a doctor uses a long, flexible camera to check your colon [intestines])?

- Within the last year
- 1-2 years ago
- 2-5 years ago
- >5 years ago
- Never

CANCER RISK MANAGEMENT HISTORY

Q5-A (IF Sex=Male): Have you received any of the following surgeries or cancer screenings (please select all that apply):

- Stomach and small intestine cancer screening (Endoscopy or EGD - a thin, flexible tube with a tiny video camera on the end is passed down the throat)
 - When do you undergo your most recent stomach and small intestine screening?
 - Within the last 5 years
 - More than 5 years ago
 - Kidney/ureter cancer screening (urinalysis)
 - When did you undergo your most recent kidney/ureter cancer screening?
 - Within the last year
 - More than one year ago
 - Pancreatic cancer screening (CT/MRI/Endoscopy or blood tests including liver function tests or CA19-9/CEA)
 - When did you undergo your most recent pancreatic cancer screening?
 - Within the last year
 - More than one year ago
 - Brain cancer screening (neurologic exam by your doctor during your annual physical)
 - When did you undergo your most recent brain cancer screening?
 - Within the last year
 - More than one year ago
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Q5-B (IF Sex=Female): Have you received any of the following surgeries or cancer screenings (please select all that apply):

- Hysterectomy (uterus was surgically removed)
 - What was your age when you had your hysterectomy?
- BOTH ovaries were surgically removed
 - What was your age when you had both ovaries/your second ovary removed?
- Uterine cancer screening (ultrasound and biopsies)
 - When did you undergo your most recent uterine cancer screening?
 - Within the last year
 - More than one year ago
- Ovarian cancer screening (ultrasound and CA-125 blood test)
 - When did you undergo your most recent ovarian cancer screening?
 - Within the last year
 - More than one year ago
- Stomach and small intestine cancer screening (Endoscopy or EGD - a thin, flexible tube with a tiny video camera on the end is passed down the throat)
 - When do you undergo your most recent stomach and small intestine screening?
 - Within the last 5 years
 - More than 5 years ago
- Kidney/ureter cancer screening (urinalysis)
 - When did you undergo your most recent kidney/ureter cancer screening?
 - Within the last year
 - More than one year ago
- Pancreatic cancer screening (CT/MRI/Endoscopy or blood tests including liver function tests or CA19-9/CEA)
 - When did you undergo your most recent pancreatic cancer screening?
 - Within the last year
 - More than one year ago
- Brain cancer screening (neurologic exam by your doctor during your annual physical)
 - When did you undergo your most recent brain cancer screening?
 - Within the last year
 - More than one year ago

HEALTHY LIFESTYLE RESOURCES

Q6: Since you had genetic counseling, have you made any of the following lifestyle changes (please select all that apply)?

- Lost weight
- Made healthier changes to your diet
- Exercised more
- Quit smoking
- None of these

Relatives can have up to a 50% risk, or 1 in 2 chance, of also having the same mutation that was found in you. This would also increase their risk for cancer. It is strongly recommended that your family members undergo genetic testing to clarify their own cancer risks.

Q7-A: Have any of your family members had or scheduled genetic testing?

- Yes
 - No
 - Unsure
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Q7-B (IF Q7-A=Yes): How many of your family members have had or have scheduled genetic testing?

Q7-C (IF Q7-A=Yes): If you are comfortable, please provide the names of your family members that have been tested:

Survivorship programs can help patients with Lynch syndrome (with or without a cancer diagnosis) get connected to resources like exercise classes, social workers, dietitians, peer support groups, etc. Services are open to all patients and are free of charge.

Q8: Have you been referred to or met with survivorship services?

- Yes
 - No
 - Unsure
 - I do not wish to meet with survivorship services
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Q9: A Genetic Patient Navigator (GPN) is a healthcare provider who will be able to assist you with any issues you may face in obtaining care. Would you like the Genetic Patient Navigator (GPN) to assist you with any of the following (please select all that apply)?

- Schedule appointments or services
- Place referrals for doctors
- Coordinate survivorship services
- Help get family members tested
- Smoking cessation resources
- Healthy lifestyle resources
- Other
 - Since you selected "Other", please specify